HELEN CHILDS, BSc Hons., PG Cert.

PSYCHOLOGISTS' RESPONSES TO MEDICATION CONCERNS

Section A: What are the experiences of taking psychotropic medication in service users from minoritised ethnic backgrounds with psychosis-related diagnoses? A systematic review and thematic synthesis

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Summary of The Major Research Project

Section A: Presented here, is a systematic review of the literature detailing the experiences of taking psychotropic medication in service users from minoritised ethnic backgrounds with psychosis-related diagnoses. Eleven qualitative studies are discussed and critically appraised. The review synthesises findings under six main categories; medication helping versus negative effects; coercion; "They're quite happy to just hand out pills"; surrender versus disengaging; the need for cultural understandings alongside medication; and family support for versus opposition to medication. The review provides some initial evidence which suggests negative experiences of medication (predominant in the papers), although not specific to ethnicity per se, are more likely to be compounded if service users are a member of a minoritised ethnic group. Future research would benefit focusing on the voices of service users from minoritised ethnicities looking directly at this issue and investigating how clinicians might respond to service users who wish to challenge their current treatment.

Section B: Presented here, is a study exploring psychologists' experience of responses to concerns about the medication of service users given a psychosis-related diagnoses. Guided by a critical realist grounded theory methodology, the constructed model identified 43 sub-categories organised within six main categories: Observing Coercion; 'Walking the Tight Rope'; 'Listen' or 'Shut Down'; Service Users 'Stuck in the Middle'; Teams, People and Relationships; Economic Climate and Societal Discourses. Findings highlight some of the dilemmas participants experienced regarding medication and is important in its acknowledgement of how difficult it can be to negotiate these dilemmas. The results indicate the need to improve shared decision making with service users, to offer increased support in the withdrawal of medication, and to help teams feel able to take more positive risks in relation to prescribing.

CONTENTS

Major Research Project: Section A

What are the experiences of taking psychotropic medication in service users from minoritised ethnic backgrounds with psychosis-related diagnoses? A systematic review and thematic synthesis

Word Count: 7900 (8035)

Abstract

Introduction: There is a growing body of evidence regarding the potential harmful effects of ‘antipsychotics’, which are the recommended primary treatment for psychosis-related diagnoses in Western countries. Research shows members of minoritised ethnic groups in the UK and USA are more likely than White people to be diagnosed with a psychosis-related diagnosis and be prescribed medication alone, often at higher doses. One theory suggests this is due to the racialisation of psychosis-related diagnoses in psychology and psychiatry. This review aimed to explore the experiences of service users from minoritised ethnicities of taking medication for psychosis-related diagnoses.

Methodology: A search of four relevant electronic databases identified 11 qualitative studies for inclusion in a narrative review.

Literature review: The results of the studies were synthesised and presented under six main categories; medication helping versus negative effects; coercion; “They’re quite happy to just hand out pills”; surrender versus disengaging; the need for cultural understandings alongside medication; and family support for versus opposition to medication.

Clinical and research implications: The review provides some initial evidence which suggests negative experiences of medication (predominant in the papers), although not specific to ethnicity per se, are more likely to be compounded if service users are a member of a minoritised ethnic group. Implications include the need to mitigate power imbalances between clinicians and service users and increase awareness of clinician bias. Future research would benefit focusing on the voices of service users from minoritised ethnicities looking directly at this issue and investigating how clinicians might respond to service users who wish to challenge their current treatment.

Keywords: Race, Ethnicity, Minoritised, Psychosis, Medication, Antipsychotic, Qualitative

What are the experiences of taking psychotropic medication in service users from minoritised ethnic backgrounds with psychosis-related diagnoses? A systematic review and thematic synthesis

Understanding terminology around ‘race’, ethnicity, and ‘minoritised’ status

The term ‘race’ in the context of this review is considered a social construct categorising individuals largely based on physical traits, such as skin colour. Fernando (2010; 2017) describes the term as rooted in historical and prejudicial beliefs about imagined genetic differences, which served to legitimise White European/ American domination over others. Ethnicity is a broader term than ‘race’ and usually refers to long standing shared cultural traditions, language, national origin, and religion (Bulmer, 2016). Although ‘race’ and ethnicity are distinct constructs, they are often used interchangeably in the literature.

The term ‘minoritised ethnic’ is adopted when referring to individuals who are not White. This term was chosen instead of BME (Black and minority ethnic) or BAME (Black, Asian and minority ethnic) due to the latter terms criticised grouping of diverse ethnicities, suggesting different communities can be seen as a collective whole (e.g. HM Government, 2021). Furthermore, the term ‘minority’ is considered misleading as it suggests people are oppressed because they are few, not because they are non-White. It is felt ‘minoritised ethnic’ better reflects the realities of social processes of power and domination by White institutions and interpersonal prejudices. However, in the interest of accurately interpreting the literature the reader will at times come across alternative terminology.

Understanding Psychosis

Psychosis is a term commonly used in society for experiences that attract diagnoses such as schizophrenia, schizoaffective disorder, and bipolar disorder. The British

Psychological Society’s (BPS) description of experiences commonly thought of as psychosis included combinations of ‘hearing voices speaking when there is no one there’, ‘holding strong beliefs that others around you do not share’, ‘difficulties with thinking and concentrating’ and ‘appearing inexpressive, withdrawn, listless, apathetic or unmotivated’ (Cooke, 2017, p. 10 - 11). The Diagnostic and Statistical Manual for Mental Disorders 5th edition (DSM-V) (American Psychiatric Association, 2013) divides these experiences into ‘positive’ and ‘negative symptoms’.

Prevalence of Psychosis in minoritised ethnic groups

The higher prevalence of psychosis-related diagnoses amongst minoritised ethnic groups has been well documented (Keating, 2016). African-Americans were found to be 3.3 times more likely than White Americans to be diagnosed and treated for schizophrenia (Breshnahan et al., 2007). In the UK, higher rates of diagnosis have been noted particularly among those of African and Caribbean origin, with Black-Africans nine times more likely than White British people to receive a diagnosis (Halvorsrud et al., 2018). Other minoritised ethnic groups also had higher rates of diagnosis, but to a smaller extent (Coid et al., 2008; Fearon et al., 2006). Similar higher rates have been found in ten other countries, largely in northern Europe (Read et al., 2013; Veiling, 2013). Fernando (2017) suggests these higher rates of diagnosis may be due to unrecognised institutional racism, including stereotype-related perceived dangerousness. This is supported by the suggestion that rates in the West Indies are lower than for White people (Fernando et al., 2014).

Models and Treatment Approaches

Antipsychotics

Since their introduction in 1950s, ‘antipsychotics’ have been the recommended primary treatment for psychosis (National Institute of Clinical Excellence [NICE], 2014). These were initially called major tranquillisers but later marketed as targeting ‘schizophrenia’ (Moncrieff, 2013). This treatment approach has been generated from dominant biological theories which conceptualise psychosis as a medical illness resulting primarily from brain pathology (e.g. American Psychiatric Association, 2018). The dopamine theory of schizophrenia and psychosis is the most central to the idea that ‘antipsychotics’ exert a disease-centred action. The theory states that the group of nerve cells which communicate using dopamine, a chemical neurotransmitter, are over-active (Van Rossum, 1966). However, a review by Kendler and Schaffner (2011) suggested subsequent research has not upheld this hypothesis.

The evidence for the use of ‘antipsychotics’ in treatment is mixed. A number of studies support their effectiveness in treating acute psychotic symptoms short-term and reducing risk of ‘relapse’ (e.g. Bola et al., 2012; Leucht et al., 2017; Mackin & Thomas, 2011). However, concerns have been raised related to long-term use. A number of adverse effects such as diabetes, grey-matter volume decrease, cognitive slowing and lethargy have been reported (e.g. De Hert et al., 2012; Moncrieff, 2013; Rummel-Kludge et al., 2010). Despite recommendations for shared treatment decision making, studies report service users feel coerced into taking medication and disempowered (Bjornestad et al., 2020; Thompson et al., 2020; Morant et al., 2016). This may explain why around 40-74% stop taking their medication (Lacro et al., 2002; Lieberman et al., 2005).

Psycho-Social Approaches

Early Trauma and Adversity

Alternative psychosocial approaches have gained in popularity over recent years. A widely acknowledged hypothesis is that adverse childhood life experiences and trauma plays a causal role in psychosis (e.g. Larkin & Read, 2008; Read et al., 2005, 2009, 2014; Varese et al., 2012). Studies have found a relationship between the degree of childhood adversity and the probability of psychosis (e.g. Spauwen et al., 2006; Scott et al., 2007; Read et al., 2014). Research has shown childhood trauma can affect developing brains and their structure and function. This has led to the development of the Traumagenic Neurodevelopmental Model of psychosis (Read et al., 2014). Such neurodevelopmental changes can result in the heightened sensitivity to stress found in people diagnosed with psychosis. This is supported by evidence that differences in the brains of individuals diagnosed with schizophrenia, such as the overactivity of dopamine (which are often cited to support the biological hypothesis), is a common finding in traumatised children (e.g. Holtzman et al., 2013; Teicher et al., 2012).

Social-Economic Disadvantage and Deprivation

Additionally, there is strong evidence that poverty and discrimination are causative factors of psychosis. Research has shown a correlation between low socio-economic status and psychosis (McKenzie, 2002). Diagnosis of a psychotic disorder is strongly correlated with living in urban environments in developed Western countries (Newbury et al., 2016). Those who experienced discrimination were found to be three times more likely to have psychosis-related experiences compared to those who had not experienced discrimination (Janssen et al., 2003). The 2011 census in the UK found minoritised ethnic groups are more likely to be exposed to considerably higher levels of poverty, unemployment, racial harassment and poorer health (Office for National Statistics, 2012). It is therefore argued that the higher rates of psychosis are explicable by the socioeconomic factors affecting these communities (e.g. McKenzie et al., 2002).

One response to evidence linking poverty with psychosis is the social drift theory. This argues psychosis affects everyone equally, but people become poor because of their illness (Read et al., 2013). Studies testing this theory, however, found no evidence of such 'social drift' (Wheaton, 1978). One factor making research in this area difficult is the role of diagnosis-related stigma and discrimination, which in themselves may affect life chances (Corrigan et al., 2014). This raises the issue of intersecting disadvantage due to exclusion related to both mental health diagnosis and ethnicity (Phelan & Link, 2015).

Cognitive-behavioural Explanations

Psychological approaches have been put forward to explain processes which link adversity and subsequent psychosis. For example, the cognitive model (Garety et al., 2001) suggested the way people interpret psychotic phenomena accounts for distress and disability, rather than the psychotic experiences themselves. Such interpretation is maintained by thinking biases, dysfunctional schemas, and adverse social environments. Cognitive behavioural therapy (CBT) for psychosis, a specialist CBT approach, is recommended as an adjunctive treatment to 'antipsychotics' (NICE, 2014). However, initial evidence suggests it can be effective without psychiatric medication being needed (e.g. Morrison et al., 2012; 2014)

Critical Approach to Psychosis as a 'Racialised' Diagnosis

Critics of the above explanations argue they are constructed on the basis of White knowledge and Eurocentric sources alone (Fernando, 2017). The increased risk of a diagnosis of psychosis amongst minoritised ethnicities is debated to be more complex than exposure to childhood trauma, social disadvantage, and discrimination. It is claimed to be more to do with historically-rooted racialisation of schizophrenia and diagnoses in psychiatry and psychology

(Fernando, 2012; 2017). The term ‘racialised’ refers to the ascription of ‘racial meaning to a previously racially unclassified relationship, social practice, or group’ (Omi & Winant, 1986, p. 111). The term ‘racism’ is defined as ‘a way of thinking that places superior White people in a position of power over racially inferior peoples of various other races’ (Fernando, 2017, p. 12). Fernando (2017) describes how psychology and psychiatry developed when ideas concerning the biological superiority of White people were commonly accepted and are consequently rooted in racist theories. For example, ‘Drapetomania’ was the name of a mental illness given to Black people for absconding from slavery in an earlier version of the DSM (Fernando, 2017). Metzl (2010, p. xxi) explored how embedded racism resulted in schizophrenia becoming a ‘Black disease’. He describes how fear of Black militancy in 1960s civil rights in the USA led to revisions in the diagnoses of schizophrenia which included ‘masculine belligerence’. This was then disproportionately given to African-American men, which Metzl (2010) argues was essentially used for social control.

More covert, less easily recognised, and usually not consciously intended forms of racism, ‘institutional racism’, are argued to continue to exist in mental health services in Western countries. This is said to ‘permeate diagnosis, risk assessment, service planning and so on’ (Fernando, 2012, p. 120). Institutional racism is defined as ‘the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin’ (McPherson, 1999, p. 8) Studies which appear to demonstrate the outcomes of institutional racism have found there is a higher likelihood of minoritised ethnic group members being compulsorily detained, to arrive via the criminal justice system, and be physically restrained and secluded (Halvorsrud et al. 2018; Keating et al., 2002). There is evidence Black patients are more likely to be prescribed ‘antipsychotic’ medication and less likely to be offered psychotherapy (Das-Munshi et al. 2018). ‘Antipsychotics’ are also more likely to be prescribed at higher doses and be a depot medication, a long acting ‘antipsychotic’ medication given by intramuscular injection (Das-Munshi et al. 2018; Moncrieff, 2009). Furthermore, outcomes of treatment are poorer, with evidence suggesting longer stays in acute care, more re-admissions, and more outpatient follow-ups (Nazroo et al., 2020). The Sainsbury Centre for Mental Health (Keating et al., 2002, p. 8) suggested higher drop-outs rates and non-compliance with treatment amongst Black African and Caribbean ethnic groups can be attributed to ‘cultural ignorance’ of service providers, with this leading to adverse experiences of mental health services resulting in a reluctance to use them.

Calls for Culturally Adapted Approaches to address Inequalities

Numerous policy interventions and recommendations have recognised the need to address the inequalities in service provision. NICE guidelines (2014) recommend culturally adapting treatment approaches for psychosis. The Department of Health (DoH; 2003) produced the Inside Outside report which acknowledged the role of institutionalised racism in maintaining the current inequalities. The Delivering Race Equality Action Plan (DoH, 2005) highlighted disparities within the mental health system and identified areas to address over the following five years.

Despite these calls, a recent review of the use of the Mental Health Act (HM Government, 2020) has found there has been little change. The use of the MHA has continued to rise, with particularly Black or Black British people having higher detention rates and more community treatment orders (CTO) compared to White British people. A CTO is a legal requirement to receive treatment in the community which commonly involves medication, and if individuals do not follow the conditions of their CTO they can be taken to hospital and detained. The review names ‘structural or institutional racism in both health services and wider society’ (HM Government, 2020, p. 14) as possible causes of the inequality.

Rationale

The above literature highlights persistent disparities in the diagnosis and treatment of psychosis in relation to minoritised ethnic groups. The growing body of knowledge regarding the potential harm of ‘antipsychotic’ medication combined with its greater use in minoritised ethnic groups is of concern. In light of the current policies addressing these inequalities, it was surprising a discussion of ‘race’ and ethnicity was absent in two recent qualitative reviews of ‘antipsychotic’ medication experiences (Bjornestad et al., 2020; Thompson et al., 2020). The omission of ‘race’ and ethnicity on a topic which disproportionately affects those belonging to minoritised ethnic groups could be argued to be an example of how (probably unintentional) institutional racism exists at present within research. This review therefore aimed to specifically seek out research on the experiences of people belonging to minoritised ethnicities. The following question was to be addressed:

What are the experiences of service users from minoritised ethnic backgrounds of taking medication for psychosis-related diagnoses?

Methodology

Literature Search

A systematic review of the literature was carried out to answer the above review question in January 2021. An electronic search of PsychInfo, Medline, ASSIA and Web of Science databases was conducted using the search terms seen in Table 1.

Table 1

Terms Used in Electronic Search of Databases

Search Terms
"Black" OR "Asian" OR "mixed" OR "African" OR "Caribbean" OR "African-American" OR "African-Caribbean" OR "Latin*" OR "Pakistani*" OR "Indian" OR "Bangladeshi*" OR "Chinese" OR "Hispanic*" OR "Arab" OR "minorit*" OR "ethnic*" OR “race*” OR “racial*” OR "racial perspective*" OR "ethnically diverse" OR “culture*”
AND
"experience*" OR "qualitative" OR "view*" OR "perspective*" OR "insight*" OR "perception*" OR "engagement" OR "personal account*" OR "understanding*" OR "opinion*" OR “interpretative” OR “interpretive” OR “hermeneutic”
AND
"mental health service*" OR "mental health" OR "psychosis" OR "schizophrenia" OR "schizoaffective" OR "schizo*" OR "bipolar" OR “severe mental illness*” OR "psychiatric medication*" OR "neuroleptic*" OR "atypical antipsychotic*" OR "antipsychotic*" OR "anti-psychotic*" OR "major tranquil*" OR "psychotropic*" OR "depot injection*" OR “depot medication*” OR "psychiatric medication*" OR "coercion" OR "coercive" OR "mental illness" OR "inpatient"

Eligibility Criteria

The applied inclusion and exclusion criteria can be seen in Table 2.

Table 2

Eligibility Criteria Applied to Studies

Inclusion and Exclusion Criteria

Inclusion Criteria:

- Studies included qualitative methodology
- Studies explored specifically the experiences of members of minoritised ethnic groups.
- Studies included either a majority of participants (more than 50%) with psychosis related diagnoses (e.g. schizophrenia, bipolar, schizoaffective) or had less than 50% of participants with a psychosis-related diagnoses but had sufficient information about medication that is normally prescribed to people with psychosis-related diagnosis
- Participants comment about their experience of medication
- Studies took place in a Western country
- Studies written in English
- Studies from peer reviewed journals

Exclusion Criteria:

- Studies which did not meet the inclusion criteria
- Studies which explored experiences of participants in whom their psychosis was associated with organic brain diseases such as dementia

The search yielded 1,695 papers after duplicates were removed. Titles were screened against the eligibility criteria and discarded if these were not met. A total of 134 abstracts were read, which resulted in a full text review of 42 articles. A manual search of reference lists of related papers identified for full text review were also searched. A final 11 papers were identified as appropriate for this review and are summarised in Table 3. See Figure 1. for a flow chart of progression of this literature search.

Figure 1

Flowchart Demonstrating Selection of Papers

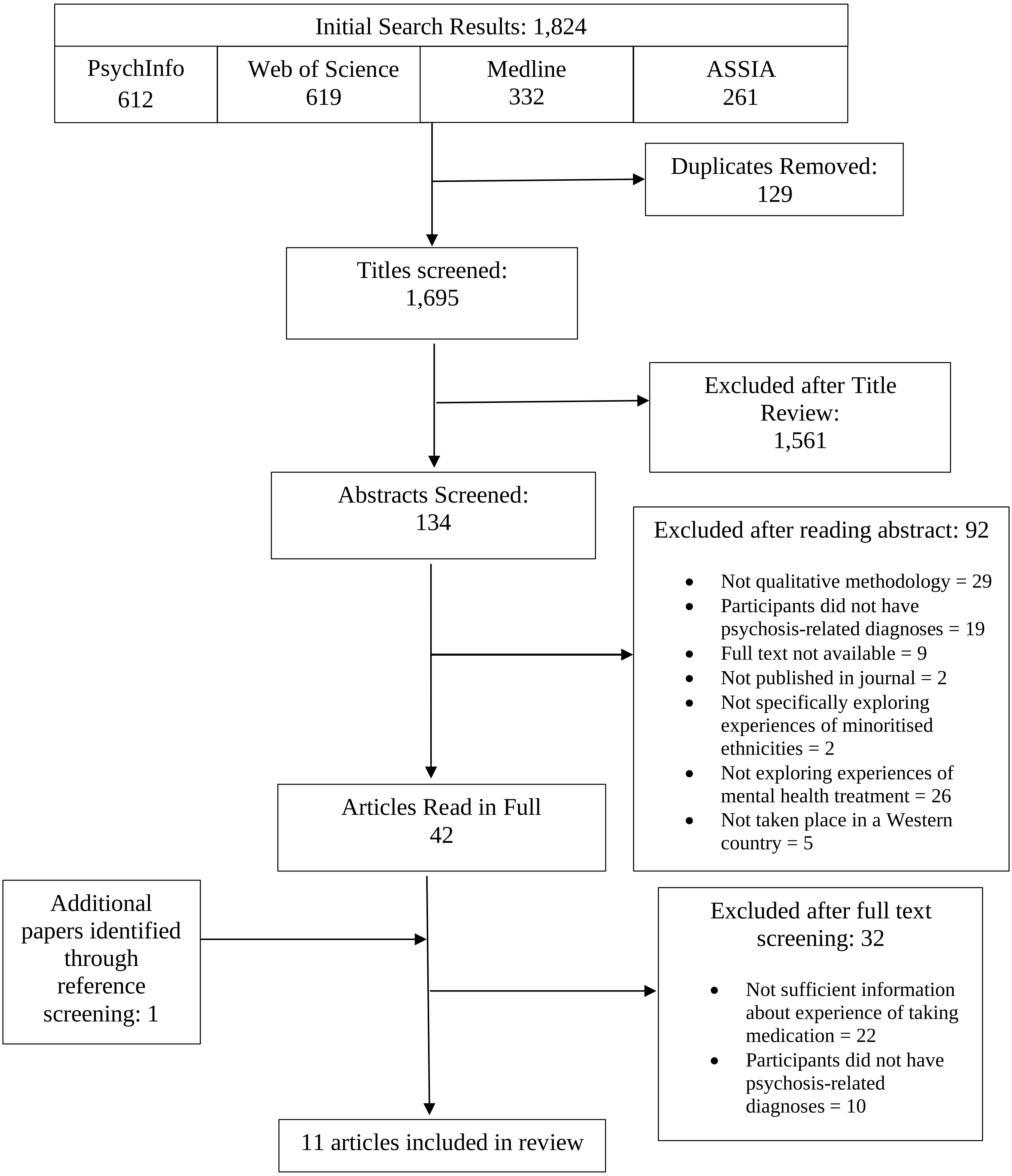

Table 3

Overview of Selected Studies

Study, location	Title	Setting	Aim	Sample size, characteristics, diagnoses	Analytic approach	Findings/Main themes
1.Greenwood et al. (2000)	Asian in-patient and carer views of mental health care. Asian views of mental health care.	UK, Acute wards in large inner city psychiatric hospital	To gain an understanding of Asian individuals' experiences of mental illness and treatment	14 'Asian', all participants identified 'Indian subcontinent' as country of origin (this includes countries such as India, Pakistan, Sri Lanka) (no details of specific ethnicities) 10 Muslim, 1 Sikh, 1 Buddhist, 1 Christian 9 first generation, 5 second generation 8 M, 6 F 24-66 years (mean 39.4) 8 schizophrenia or psychosis, 3 depression, 1 substance misuse, 1 personality disorder, 1 'other'	In-depth/open-ended interviews using grounded theory approach	-Culturally specific explanations necessitating want of non-western treatments to be used as complimentary to Western medication treatment -Experiences of concerns not being listened to (language difficulties and lack of interpreters onsite highlighted as barrier to concerns being heard) -Experiences of medication as helpful
2.Secker & Harding (2002)	African and African Caribbean users' perceptions of inpatient services.	UK, African and Caribbean mental health resource centre	To explore the inpatient experiences of a sample of African and African Caribbean people	26 (Characteristics only available for 24) 18 African-Caribbean, 6 'African heritage' 16 M, 10 F 16 schizophrenia (no comment of other diagnoses) as of African heritage.	Semi-structured interviews using content analysis	-Reliance on medication alone and lack of talking therapies -Lack of control and power over treatment decisions -Lack of information provided on difficulties and treatment -Adverse effects -Forced administration of medication which was attributed to racism by some participants -Racial stereotypes made by staff affecting decisions to prescribe medication
3.Bowl (2007)	Responding to ethnic diversity: black service users' views of mental health services in the UK.	UK, African-Caribbean mental health resource centre, local psychiatric hospital, and a residential facility for African-Caribbean men	To investigate African-Caribbean mental health service users' views of existing services within one local area and how these services might be improved	13 African-Caribbean 9 M, 4 W Ages 21 – 60 10 schizophrenia, 2 bipolar	Focus groups and semi-structured interviews using Thematic analysis	-Knowing how long they were going to be on medication important in preparing for recovery -Lack of information provided about medication
4.Chakraborty, McKenzie & King (2009)	Discrimination, ethnicity and psychosis—a qualitative study	UK, London psychiatric hospital	To look at two groups of patients diagnosed with psychosis, Black Caribbean and White British, and present a qualitative comparison of the individual's experience of unfair	20 10 Black Caribbean 5 M, 5 F 27 – 59 years (mean 43.7) 10 White British 5 M, 5 F 26 – 47 years (mean 39.3)	Open-ended ethnographic interviews, type of analysis not specified	-Forceful administration of depot medication attributed to racism -Experiences of not being offered alternative therapy to medication due to 'race' -Lack of control and power over treatment decisions -Black Caribbean participants expressed similar experiences of unfair treatment as White participants, however Black Caribbean participants were more likely to attribute these experiences to racism than to anything else

			treatment and its perceived cause	All diagnosed with psychotic disorders		
5.Weich et al. (2012)	Experiences of acute mental health care in an ethnically diverse inner city: qualitative interview study	UK, Home Treatment Teams	To explore service users' and carers' accounts of recent episodes of severe mental illness and of the care received in a multi-cultural inner city, examining factors impacting on these experiences, including whether experiences were mediated by ethnicity	40 16 South Asian (3 Indian, 2 Bangladeshi, 11 Pakistani) 8 Black (3 Black British, 3 Black Caribbean, 3 mixed, 1 Black African) 16 White (14 White British, 1 White other, 1 White Irish) 22 M, 18 F Ages not specified All with diagnosis of psychotic disorder, predominantly schizophrenia	In-depth interviews, analysis not specified	-Religious healing/prayer used in parallel to medication for Muslim service users (no alternative explanatory frameworks used by other ethnic groups) -Ethnic disparities in the amount of control over medication treatment within inpatient care, not care in Home Treatment Teams The following themes applied to all ethnicities: -Adverse effects -Lack of information about medication -Concerns not being heard by professionals -Desire to cope without medication -No ethnic differences found in medication adherence
6.Mfoafo-M'Carthy (2014)	Community treatment orders and the experiences of ethnic minority individuals diagnosed with serious mental illness in the Canadian mental health system.	Canada	To explore in detail the encounters of individuals of ethnic minority background who had experienced CTOs	24 14 Black Canadians, African Canadians and Caribbean Canadians, 1 'West Asians', 6 'South Asians', 2 'East Asians' 1 'Middle East' Gender not specified 18-59 years 16 schizophrenia, 1 schizoaffective disorder, 5 bipolar disorder, 2 depression	In-depth semi-structured interviews using IPA	-Medication compliance being an integral part of the CTO process -Being coerced into accepting CTO as this was contingent on being discharged from hospital -CTO helping medication compliance and having positive outcomes -Feeling powerless due to informal threat of rehospitalisation if you do not comply with treatment -Adverse effects -A small number of participants perceived treatment of CTO to be racist -Majority did not feel experience of treatment was impacted by their ethnicity -Focus on medication and lack of offer of talking therapy
7.Myers & Ziv (2016)	"No One Ever Even Asked Me that Before": Autobiographical Power, Social Defeat, and Recovery among African Americans with Lived Experiences of Psychosis	USA, high-poverty urban area, peer mental health clinic	To understand how primarily African American male service users at a newly opened peer mental health clinic talked about trying to take charge of their own lives and seek recovery from a psychotic disorder, and the phenomenological, social and situational features of that effort	65 (observed at the clinic) 20 (interviewed) More than 50% African American (no further details specified) Ages 18 – 60 82% M, 18% F More than 90% had diagnosis of psychotic disorder	Field notes, observations and semi-structured interviews using ethnographic method	-Loss of power and social defeat -Not agreeing with the biomedical explanation but still being expected to take medication – no one engaging with participants' alternative explanations -Descriptions of upsetting experiences of being forced to take depot injections against their will -Adverse effects -Receiving a quick diagnosis and prescription of medication -Cycling in and out of hospital -Surrendering to medication -Socially adverse lives in which they already feel defeated, which is then exacerbated by a mental health system which makes service users feel even more powerless
8.Wagstaff et al. (2018)	Experiences of mental health services for	UK, Assertive outreach teams	To examine the experiences of men with a diagnosis of	7 'Black' (no further details provided)	Semi-structured interviews using IPA	-All that mental health services offer is medication -Lack of understanding of the purpose of medication

	‘Black’ men with schizophrenia and a history of disengagement: a qualitative study		schizophrenia, who described their ethnic identity as ‘Black’ and had a history of disengagement from mental health services.	7 M 31 – 64 years (mean age 49) Schizophrenia (all described as substance users)		-Anger at the lack of control over prescription and ingestion of medication which was perceived to contribute to disengagement from services -Strong animosity for depot medication -Adverse effects -Some recognition of the benefits of oral medication
9.Tang (2019)	The double hazard in recovery journey: The experiences of UK Chinese users of mental health services	UK, Chinese community centres across three large cities	To contribute to the discussion of recovery-oriented service with a study on the experience of Chinese people using UK mental health services	22. Chinese 13 F, 9 M Most common age range 31 – 40 9 psychosis related diagnoses (including schizophrenia, schizo-affective disorder). Others diagnosed include stress/anxiety, mixed anxiety/depression, depression and ‘unknown’. Although <50% diagnosed with psychosis, sufficient information was provided on medication for psychosis-related diagnoses	In-depth interviews suing Thematic analysis	-Lack of talking therapies, medication offered as only treatment -Religious healing used alongside medication -Medication experienced as beneficial -Adverse effects of medication -Lack of information provided on medication -Concerns not being heard by professionals -Medication non-compliance -Support from family to take medication
10.Tuffour, Simpson & Reynolds (2019)	Mental illness and recovery: an interpretative phenomenological analysis of the experiences of Black African service users in England	UK, Community mental health teams and inpatient facilities	To explore Black African service users’ experiences of recovery from mental illness and to understand how they conceptualise recovery.	12 Black African (first or second generation) 9 F, 3 M 19 – 57 years (Mean age 33.3) Schizophrenia and paranoid schizophrenia	Semi-structured interviews using Interpretative Phenomenological Approach (IPA)	-Finding the medication helpful -Adverse effects of medication -Reluctance to take medication following influence from family -Being coerced into taking medication -Resigned acceptance of medication
11.Lawrence et al. (2021)	Ethnicity and power in the mental health system: experiences of White British and Black Caribbean people with psychosis	UK, recruited from AESOP-10[1] cohort (Morgan et al. 2017) which recruited from mental health services in London and Nottingham supporting first-episode psychosis	To investigate the long-term experience of living with psychosis and navigating mental health service within different ethnic groups	35 17 Black Caribbean, 15 White British, 3 non White-British 17 M, 18 F 21 – 50 years Schizophrenia	Semi-structured interview using thematic narrative analysis	The following themes occurred across ethnicities: - Lack of information provided on medication - Being coerced into taking medication - Adverse effects - Concerns about medication not being heard - Resigned acceptance of medication Specific experiences of Black Caribbean participants compared to White participants - Greater feelings of powerlessness - Less control over treatment decisions - Families having less influence over treatment decisions -

Note. [1]AESOP is an acronym for the ‘Aetiology and Ethnicity of Schizophrenia and Other Psychoses’. AESOP-10 is a ten year follow up study of 557 individuals with a first-episode of psychosis (Morgan et al. 2017).

Review

Structure and Methodology of Review

The following review attempts to critique and synthesise the selected papers. A brief overview of their key characteristics is first provided. Study quality is then assessed using the Critical Appraisal Skills Programme (CASP) qualitative assessment tool (Critical Appraisal Skills Programme, 2018) which is widely used in qualitative synthesis (Appendix A). All papers were considered to be of sufficient quality to be included in the review. Table 4 shows main strengths and weaknesses of each paper and Appendix B table contains numerical ratings of each study assessed using the CASP.

A thematic synthesis (Thomas & Harden, 2008) follows a discussion of the quality of the papers. This is an established method based on thematic analysis principles (Braun & Clarke, 2006) and is recommended for integrating qualitative studies on mental health topics (Lachal et al., 2017). Data were extracted from the results and discussion sections of the included papers which described or analysed participant experiences of medication. The analysis took place in three stages; line-by-line coding of the extracted data; the development of descriptive themes; and the generation of interpretative theme clusters (Thomas & Harden, 2008). To enhance the validity of the synthesis, themes and sub-themes were collated into tables and discussed with the researcher and lead supervisor. Interpretative theme clusters were jointly developed with both researchers. Appendix C include example quotations supporting the development of the themes.

Overview of Selected Papers

Of the 11 studies included, nine took place in the UK, one in the USA and one in Canada. Participants were recruited from a variety of settings, including inpatient facilities, community mental health services, local community centres, and a peer run mental health clinic. A range of minoritised ethnic groups were described across the papers. These included Black Caribbean (*n* = 61), Black African (*n* = 19), Black British (*n* = 3), 'mixed' ethnicity (*n* = 3), African-American (*n* = <10), Black Canadian, African Canadian and Caribbean Canadian (*n* = 14), 'Black' (*n* = 7), Indian (*n* = 3), Bangladeshi (*n* = 2), Pakistani (*n* = 11), Chinese (*n* = 22) , 'West Asian' (*n* = 1), 'South Asian' (*n* = 6), 'East Asian' (*n* = 2), 'Middle East' (*n* = 1), and 'Asian' who identified 'Indian subcontinent' as country of origin (*n* = 14). Three papers compared experiences to White participants (Chakraborty et al., 2009; Lawrence et al., 2021; Weich et al., 2012).

Six studies were restricted to people with a psychosis-related diagnosis (Bowl, 2007; Chakraborty et al., 2009; Lawrence et al., 2021; Tuffour et al., 2019; Wagstaff et al., 2018; Weich et al., 2012), the other five papers included diagnoses such as depression, anxiety and personality disorder. All data were collected via individual face to face interviews, and two papers additionally used focus groups (Bowl, 2007) and ethnographic field notes (Myers & Ziv, 2016).

None of the studies specifically aimed to explore the experiences of medication for psychosis-related diagnoses. However, the experience of medication was discussed in the context of receiving mental health treatment across a number of different settings. Four studies specifically explored the experience of inpatient settings (Greenwood et al., 2000; Secker & Harding, 2002), community treatment orders (Mfoafo-M'Carthy, 2014) and acute mental health care (Weich et al., 2012). The other seven studies explored experiences of mental health care more broadly, which included participant reports of receiving medication in the community and within hospital/inpatient facilities.

Table 4

Main Strengths and Weaknesses of Papers

Study	Main Strengths	Main Weaknesses
1.Greenwood et al. (2000)	• Justified choice of research design • Clear recruitment strategy • Discussion of why some participants chose not to take part • Discussion of data saturation • Critical examination of role as researcher and potential bias • Details of gaining informed of consent from participants • Partial handling of effects study on participants during the study • Clear data analysis using recognised qualitative method • Clearly discussed findings and consideration of its contribution to the literature	• No comment on whether ethics approval had been sought • No discussion of how effects of the study were handled on the participants after study • Credibility of findings not discussed • Participants described as 'Asian' with no disaggregation of ethnicities
2.Secker & Harding (2002)	• Clear recruitment strategy • Discussion of data saturation • Details of explanation of confidentiality to participants • Clear data analysis using recognised qualitative method • Clearly discussed findings and consideration of its contribution to the literature	• No justification for choice of qualitative design • No comment critically examining role as researcher therefore unable to account for potential bias • No comment on whether ethics approval had been sought • No discussion of how effects of the study were handled on the participants during and after study • Credibility of findings not discussed •
3.Bowl (2007)	• Clear recruitment strategy • Discussion of why some participants chose not to take part • Use of both focus groups and interviews • Details of informed consent, confidentiality and ethics approval • Critical examination of role as researcher and potential bias • Clear data analysis using recognised qualitative method • Credibility of findings discussed • Clearly discussed findings and consideration of its contribution to the literature • Increased depth of understanding through focusing on experiences of Black Caribbean service users	• No justification for choice of qualitative design • Data was collected through note taking meaning some data was possibly lost • Saturation of data not discussed • No discussion of how effects of the study were handled on the participants during and after study • Limited details provided on data analysis

4.Chakraborty, McKenzie & King (2009)	• Clear recruitment strategy • Discussion of why some participants chose not to take part • Critical examination of role as researcher and potential bias • Details of ethics approval • Clear data analysis using recognised qualitative method • Clearly discussed findings and consideration of its contribution to the literature • Increased depth of understanding through focusing on experiences of Black Caribbean service users • Inclusion of White participants allowing direct comparisons to be made	• Type of qualitative design not specified • Saturation of data not discussed • No comment on informed consent or confidentiality • No discussion of how effects of the study were handled on the participants after study • Credibility of findings not discussed
5.Weich et al. (2012)	• Justified use of qualitative design • Clear recruitment strategy • Discussion of why some participants chose not to take part • Discussion of data saturation • Details of informed consent, confidentiality and ethics approval • Clear data analysis using recognised qualitative method • Credibility of findings discussed • Clearly discussed findings and consideration of its contribution to the literature • Recruited participants from a range of minoritised ethnic groups allowing for cross-ethnic comparisons	• Type of qualitative design not specified • No comment critically examining role as researcher therefore unable to account for potential bias • No discussion of how effects of the study were handled on the participants during and after study • Only recruited small numbers of participants from different ethnic groups meaning participants unlikely to be representative
6.Mfoafo-M'Carthy (2014)	• Justified choice of research design • Clear recruitment strategy • Details of informed consent, confidentiality and ethics approval • Critical examination of role as researcher and potential bias • Clear data analysis using recognised qualitative method • Credibility of findings discussed • Clearly discussed findings and consideration of its contribution to the literature	• No discussion of why some participants chose not to take part • Saturation of data not discussed • No discussion of how effects of the study were handled on the participants during and after study • Exclusion of participants who could not speak English meaning participants were not a fair representation of the minoritised ethnic communities in Toronto.
7.Myers & Ziv (2016)	• Justified choice of research design • Clear recruitment strategy • Clearly described data collection • Data collected through both interviews and ethnographic field notes • Critical examination of role as researcher and potential bias • Details of informed consent • Credibility of findings discussed • Clearly discussed findings and consideration of its contribution to the literature	• No discussion of why some participants chose not to take part • Saturation of data not discussed • No comment critically examining role as researcher therefore unable to account for potential bias • No comment on whether ethics approval had been sought • No discussion of how effects of the study were handled on the participants during and after study • Data analysis only partially described

		• Information on the ethnicities of all participants not provided
8.Wagstaff et al. (2018)	• Justified choice of research design • Clear recruitment strategy • Discussion of why some participants chose not to take part • Brief critical examination of role as researcher and potential bias • Clear data analysis using recognised qualitative method • Credibility of findings discussed • Clearly discussed findings and consideration of its contribution to the literature	• Saturation of data not discussed • No details of discussion of informed consent or confidentiality • No discussion of how effects of the study were handled on the participants during and after study • Participants' ethnicity described as 'Black' with no specification of whether they identified as being of African or Caribbean heritage
9.Tang (2019)	• Justified choice of research design • Clear recruitment strategy • Discussion of data saturation • Details of informed consent and confidentiality • Clear data analysis using recognised qualitative method • Clearly discussed findings and consideration of its contribution to the literature • Increased depth of understanding through focusing on experiences of Chinese service users	• No discussion of why some participants chose not to take part • No comment critically examining role as researcher therefore unable to account for potential bias • No comment on whether ethics approval had been sought • No discussion of how effects of the study were handled on the participants after study • Credibility of findings not discussed
10.Tuffour, Simpson & Reynolds (2019)	• Clear recruitment strategy • Critical examination of role as researcher and potential bias • Details of informed consent and ethics approval • Clear data analysis using recognised qualitative method	• No discussion of why some participants chose not to take part • Saturation of data not discussed • No discussion of how effects of the study were handled on the participants during and after study • Credibility of findings not discussed
11.Lawrence et al. (2021)	• Critical examination of role as researcher and potential bias • Details of informed consent, confidentiality and ethics approval • Clear data analysis using recognised qualitative method • Credibility of findings discussed through using more than one analyst • Inclusion of White participants allowing direct comparisons	• No discussion of why some participants chose not to take part • Saturation of data not discussed • No discussion of how effects of the study were handled on the participants during and after study

Assessment of Methodological Quality

Research Aim and Design

All papers clearly stated the aims of their research which were appropriate for qualitative methods. The aims of two papers focused on service user experiences of discrimination (Chakraborty et al., 2009) and disengagement (Wagstaff et al., 2018) in mental health services. Discussions of medication use within the context of these aims possibly meant participants were more likely to have reported negative experiences. This possibly created bias in the overall review findings towards negative responses of medication.

A qualitative approach was deemed appropriate given the studies aimed to gain an in-depth understanding of individuals' experiences. The majority of papers named the qualitative method chosen to address their aims. This included thematic analysis (Bowl, 2007; Lawrence et al., 2021; Tang, 2019), IPA (Mfoafo-M'Carthy, 2014; Tuffour et al., 2019; Wagstaff et al., 2018), ethnography (Myers & Ziv, 2016), grounded theory (Greenwood et al., 2000) and content analysis (Secker & Harding, 2002). However, for two papers (Chakraborty et al., 2009; Weich et al., 2012) the type of qualitative method used was not made clear.

Seven papers (Bowl, 2007; Greenwood et al., 2000; Lawrence et al., 2021; Mfoafo-M'Carthy, 2014; Myers & Ziv, 2016; Secker & Harding, 2002; Tuffour et al., 2019; Tang, 2019; Wagstaff et al., 2018) justified their choice of qualitative method. However, four papers (Chakraborty et al., 2009; Bowl, 2007; Secker & Harding, 2002; Weich et al., 2012) did not discuss this.

Recruitment Strategy

All studies explained how participants were selected. The sample sizes varied. However, they were all considered appropriate for qualitative research. Most papers described using purposive sampling. In five studies (Lawrence et al., 2021; Mfoafo-M'Carthy, 2014; Myers & Ziv, 2016; Tuffour et al., 2019; Tang, 2019) the researchers did not discuss why some people chose not to take part. Without this information, it is not possible to determine whether a selection bias existed.

The studies varied in their recruitment of people from minoritised ethnicities. Five studies (Bowl, 2007; Chakraborty et al., 2009; Lawrence et al., 2021, Tang, 2019; Tuffour et al., 2019) recruited service users from one minoritised ethnic background. These included people of Black Caribbean (Bowl, 2007; Chakraborty et al., 2009; Lawrence et al., 2021), Black African (Tuffour et al., 2019), and Chinese (Tang, 2019) heritage. Findings from these five papers possibly have an increased depth of understanding of the experiences of medication within these groups. It also may have enabled researchers to look closer at within group variations. Only two papers (Chakraborty et al., 2009; Lawrence et al.,2021), which both focused on the experiences of Black Caribbean men and women, compared experiences to White participants. Making direct comparisons to the dominant culture meant these two papers could draw firmer conclusions on whether certain experiences of medication were likely to be a result of the ethnicity of participants.

A further four papers (Myers & Ziv, 2016; Secker & Harding, 2002; Wagstaff et al. 2018), had a slightly broader inclusion of minoritised ethnic groups. Secker and Harding (2002) recruited people of both African and African-Caribbean heritage. Wagstaff (2018) recruited Black service users in the UK but did not specify whether participants identified being of African or Caribbean heritage. Myers and Ziv (2016) stated over half their participants identified as African-American, indicating there were participants of other ethnicities they did not provide information on. Greenwood et al. (2000) recruited 'Asian' participants who all identified the 'Indian subcontinent' as their country of origin. Grouping together the experiences of individuals in these papers is possibly problematic since there are likely significant cultural differences within these groups.

Weich et al. (2012) and Mfoafo-M'Carthy (2014) interviewed participants from a range of minoritised ethnicities. This increased the breadth of findings and allowed for cross-ethnic comparisons. However, such comparisons should be interpreted tentatively since both papers recruited small numbers of participants which were not equally spread across ethnic groups. In Weich et al. (2012), Black service users were underrepresented, particularly people of Black African heritage. Similarly, Mfoafo-M'Carthy (2014) included only a small number of 'West Asians', 'East Asians' and 'Middle East' participants. Additionally, Mfoafo-M'Carthy (2014) excluded participants who could not speak English, meaning participants were not a fair representation of the minoritised ethnic communities in Toronto.

Ethical Issues

All papers, except two (Chakraborty et al., 2009; Wagstaff et al., 2018) provided sufficient detail on gaining informed consent and explaining confidentiality. Four papers (Greenwood et al., 2000; Myers & Ziv, 2016; Secker & Harding, 2002; Tang, 2019) did not provide details of ethical approval.

All studies involved participants sharing experiences of mental health treatment, which for some participants was being received at the time of interviews. Given the sensitivity of this topic it is a concern most papers did not discuss the handling of the effects of the study. Greenwood et al. (2000) discussed choosing to interview participants who were near discharge. Chakraborty et al. (2009) commented briefly on limiting interviews to an hour due to the topic being 'potentially inflammatory' (p. 26). However, it would have been helpful to see if participants needed support after the study.

Data Collection

All papers collected data via semi-structured interviews. Two studies (Bowl, 2007; Myers & Ziv, 2016) used additional data collection methods through focus groups (Bowl, 2007) and ethnographic field notes (Myers & Ziv, 2016). The use of more than one form of data collection strengthened these paper’s findings. However, the form of data used by Bowl (2007) possibly counteracted this strength; notes were taken instead of audio recording and transcribing interviews meaning they ‘lost some of the direct verbatim feel of participants' (Bowl, 2007 p. 204). Only three papers (Greenwood et al., 2000; Tang, 2019; Weich et al., 2012) discussed how data collection stopped once saturation had been reached. This strengthens the findings of these studies because they are less likely to have missed important strands of experience in the targeted groups.

Four studies (Myers & Ziv, 2016; Secker & Harding, 2002; Tang, 2019; Weich et al., 2012) failed to critically examine their relationship with participants. This is problematic as the ethnicity of the researcher, and any perceived power differential, may have affected how openly participants discussed experiences, particularly if researchers were White (Rhodes, 1994). It is therefore difficult to be confident bias did not affect findings.

Data Analysis, Quality Assurance, and Findings

Bowl (2007) and Myers and Ziv (2016) provided limited descriptions of their analysis process. The other nine papers clearly described how categories and themes were derived from the data. All papers presented sufficient data to support their findings. Six studies (Bowl, 2007; Lawrence et al., 2021; Mfoafo-M’Carthy, 2014; Myers & Ziv, 2016; Wagstaff et al., 2018; Weich et al., 2012) discussed the credibility of their findings, mainly through using more than one analyst. Without quality assurance methods carried out, the findings from the five other studies are weakened (Chakraborty et al., 2009; Greenwood et al., 2000;

Secker & Harding, 2002; Tang, 2019; Tuffour et al., 2019). All papers explicitly reported their findings in relation to their research question.

Synthesis of Literature

Findings relating to the experiences of taking psychotropic medication in service users from minoritised ethnic backgrounds, with psychosis-related diagnoses, are discussed in terms of six resulting categories (see Table 5).

Table 5

Thematic Categories

Themes	Total number of Papers
1.Medication Helping versus Negative Effects	11
2.Coercion	11
a) Lack of Information Provided on Medication	8
b) Lack Autonomy and Power	10
c) Forcible administration	5
3.“They’re quite happy to just hand out pills”	6
4.Surrender versus Disengaging	5
5.The Need for Cultural Understandings Alongside Medication	3
6.Family Support versus Opposition to Medication	5

Medication Helping versus Negative Effects

Most papers pointed to both positive and negative effects of medication. Some participants from six studies (Greenwood et al., 2000; Lawrence et al., 2021; Mfoafo-M’Carthy, 2014; Tang, 2019; Tuffour et al., 2019; Wagstaff et al., 2018), and across a range of ethnicities, reported benefits of taking prescribed medication for psychosis-related diagnoses. These included reductions in auditory hallucinations and improved daily living

(Tuffour et al, 2019; Greenwood et al., 2000). Additionally, medication had a positive impact on the sense of self for a few participants through helping develop a ‘positive identity’ (Wagstaff et al., 2018, p. 164) and inspiring ‘optimism’ (Tuffour et al., 2019, p. 110). For some participants the benefits of medication came after finding the optimal dosage with professionals (Lawrence et al., 2021). A number of participants on a CTO reported that this increased their medication compliance which ‘stabilized their condition’, improved self-esteem, and enabled reintegration into the community. However, it is unclear whether these positive effects were a result of the medication or increased contact with professionals who made participants feel validated and respected (Mfoafo-M’Carthy, 2014).

In contrast to these benefits, the majority of studies included significantly more data on the negative effects of medication (Lawrence et al., 2021; Myers & Ziv, 2016; Secker & Harding, 2002; Tang, 2019; Tuffour et al., 2019; Wagstaff et al., 2018, Weich et al., 2012). These appeared to occur across all ethnicities, including White participants (Chakraborty et al., 2009; Lawrence et al,. 2021; Weich et al., 2012). Across studies, a number of participants struggled with sedative effects and blunted thinking and feelings (Lawrence et al., 2021; Myers & Ziv, 2016; Tang, 2019; Tuffour et al., 2019; Wagstaff et al., 2018). Participants described feeling like a ‘zombie, a ‘vegetable’ (Larwence et al., 2021, p. 4) and ‘wolly headed’ (Tang, 2019, p. 274). During ethnographic fieldwork, authors observed ‘vibrant’ African American men change to ‘drooling and nodding off’ (Myers & Ziv, 2016, p. 399). Participants in Tuffour et al.’s (2019) study reported additional negative effects of weight gain, speech difficulties and a loss of interest. One Black African female was particularly concerned about medication causing infertility, which the authors commented would possibly have negative social and cultural consequences. A study of Chinese service users found medication brought an ‘unwanted reminder of patienthood’ (Tang, 2019, p. 275).

Coercion

Lack of Information Provided on Medication

Six of the 11 papers (Bowl, 2007; Lawrence et al., 2021; Secker et al., 2002; Tang, 2019; Wagstaff et al., 2018; Weich et al., 2012) described a lack of information being provided on their medication. Participants, across ethnicities, therefore experienced taking medication without fully understanding the rationale. Bowl's (2007) study of the experiences of African Caribbean men and women found a lack of clarity on the length of use of medication, which was found to be important information to help participants prepare for recovery.

Failing to impart adequate information created frustration with professionals (Weich et al., 2012). Individuals felt 'tricked' and unable to make an informed decision (Tang et al., 2019, p. 275). Consequently, information about medication was researched independently by some participants (Lawrence et al., 2021; Secker & Harding, 2002), although one Black Caribbean female participant stated professionals 'don't want that' (Lawrence et al., 2021, p. 4).

Lack of Autonomy and Power

Many participants across all studies, except for Bowl (2007), described little to no choice over their treatment. Diagnoses and prescriptions occurred 'in very little time' (Myers & Ziv, 2016, p. 400) and concerns voiced about the dosage of medications, and their adverse effects, were disregarded and in some cases not believed by professionals (Greenwood, 2000; Lawrence et al., 2021; Myers & Ziv, 2016; Secker & Harding, 2002; Tang, 2019; Tuffour et al., 2012; Wagstaff et al., 2018; Weich et al., 2012).

This lack of autonomy over treatment decisions engendered a strong sense of powerlessness within many participants in all ten studies. One Black male participant described the attitude of services as ‘Take a tablet and just say nothing.’ (Wagstaff et al., 2018, p. 161). In another study, an inpatient African-Caribbean participant described having to wait six months for a tribunal in order to challenge their treatment (Secker & Harding, 2002). Two studies (Myers & Ziv, 2016; Tang, 2019) found professionals imposing a biomedical explanation, and persistently rejecting participant narratives which did not align with this, also instigated feelings of powerlessness.

For individuals subject to CTOs, power and autonomy appeared to be restricted further. The CTO created an informal threat of rehospitalisation and possible arrest, leaving many participants ‘crippled with fear’ of having their freedom taken away (Mfoafo-M’Carthy, 2014, p. 7). Additionally, authors commented how many participants were coerced into accepting the conditions of their CTO, as this was their only way of being discharged from hospital.

A lack of autonomy and power appeared to be a general experience of medication that was not attributed to ethnicity alone. However, seven papers (Chakraborty et al., 2009; Greenwood et al., 2000; Lawrence et al., 2021; Myers & Ziv, 2016; Secker & Harding, 2002; Tang, 2019; Weich et al., 2012) found being a member of a minoritised ethnic group compounded this experience. Lacking the capability to speak English, with an absence of suitable interpreters, limited the ability of Asian inpatient (Greenwood et al., 2000) and Chinese service users’ (Tang, 2019) involvement in treatment decisions. Lawrence et al. (2021) found Black Caribbean participants, when compared to White participants, had notably less control over treatment decisions and more pronounced feelings of powerlessness: in this study, only White participants reported successfully negotiating a reduced dosage of medication through arguing it was necessary for their work. Lawrence et al. (2021) considered this to occur due to unconscious biases amongst staff and less access to personal and social resources to help Black Caribbean participants navigate service interactions.

Additionally, some participants in Secker and Harding's (2002) study reported racial stereotyping by professionals who '…just look at you and think, oh you're Black you've got mental health problems and give you tablets and that's it…' (p. 164). Across three studies (Lawrence et al., 2021; Myers & Ziv, 2016; Tang, 2019), a number of service users from minoritised ethnicities were already feeling powerless as a result of being in disadvantaged social and economic positions. The imposition of medication and diagnosis was found to exacerbate these existing feelings (Lawrence et al., 2021; Myers & Ziv, 2016; Tang, 2019).

However, the picture on unequal treatment was not always clear. Weich et al. (2012) briefly commented that ethnic disparities were found in the amount of control over medication treatment, but only within inpatient care and not in the community. The study included a range of different ethnicities and it is not clear which participants this occurred for. Similarly, the majority of participants from a range of minoritised ethnic groups receiving medication in the community, through CTOs, did not feel their experience of treatment was impacted by their ethnicity (Mfofao-M'Carthy, 2014).

Forcible Administration

Across five papers, participants recalled distressing experiences of being forcibly administered depot medication against their will (Chakraborty et al., 2009; Myers & Ziv, 2016; Tuffour et al., 2019; Secker & Harding, 2002; Wagstaff et al., 2018). All participants in these papers were of either African or Caribbean origin. In two studies (Chakraborty et al. 2009; Secker & Harding, 2002) participants described multiple staff 'grabbing' (Chakraborty et al. 2009, p. 24) and 'dragging' (Secker & Harding, 2002, p.165) them into a room where they were held down and injected. Another participant's arms became 'locked in the air above him' after being injected against his will, which the authors commented was a 'gesture reminiscent of surrender' (Myers & Ziv, 2016, p.402). Similarly, authors of another paper described a participant as ‘an obedient hostage’ who complied with the depot injection to ‘secure her freedom’ (Tuffour et al, 2019, p.111). The animosity participants felt towards the depot medication was also associated with the administration being experienced as degrading (Wagstaff et al., 2018, p.161).

In two papers (Chakraborty et al., 2009; Secker & Harding, 2002), participants felt the forcible depot administration was related to their skin colour. One participant described the nurses having a ‘racist motive’ and wanting to ‘make people suffer’ (Secker & Harding, 2002, p.165). Another participant felt staff stereotyped her as a ‘Black Madwoman’ (Chakrabroty et al,. 2009, p.24) and assumed she was not going to listen and therefore needed to hold her down.

“They’re quite happy to just hand out pills”

The overreliance on medication as a treatment for psychosis-related diagnoses was discussed in six papers (Chakraborty et al., 2009; Mfoafo-M’Carthy, 2014; Secker & Harding, 2002; Tang, 2019; Wagstaff et al., 2018; Weich et al., 2012). A number of participants commented on how they wanted access to talking therapies but were either not offered or were refused this treatment and given medication alone. These participants viewed medication as not the only ingredient to recovery. Exclusive focus on medication alone was therefore in conflict with some participants’ social explanations of their difficulties. Consequently, some participants felt not enough time was spent helping them understand their difficulties or learn ways of coping:

> “Instead of people trying to sort out my mind […] people just thought it would be easier to pump me with psychotic prescriptions’ (Secker & Harding, 2000, p. 163).

In two studies (Chakraborty et al., 2009; Mfoafo-M’Carthy, 2014), two participants believed not being offered talking therapies was related to their ‘race’. An African-Caribbean male described how other patients were receiving counselling, and he was not, which he was 'A 100% positive it was my colour … I just know'. (Chakraborty et al., 2009, p.23).

Surrender versus Disengaging

The lack of autonomy and power over treatment, as discussed above, meant a number of participants across five studies (Lawrence et al., 2021; Mfoafo-M'Carthy, 2014; Myers & Ziv, 2016; Secker & Harding, 2002; Tuffour et al., 2019) felt they had no choice but to 'surrender' (Myers & Ziv, 2016, p.406) to a medication regime. For a number of participants this involved a resigned acceptance of the adverse effects of medication, which for some was felt as a 'necessary evil' (Weich et al., 2012, p.122) in order to live life as fully as possible (Lawrence et al., 2021; Tuffour et al., 2019; Weich et al., 2012). Some participants felt they only had to surrender if they were 'legally compelled' (Wagstaff et al., 2018, p.161) to or if they were in hospital (Mfoafo-M'Carthy, 2014; Tuffour et al., 2019; Wagstaff et al., 2018).

A number of participants across six studies (Lawrence et al., 2021; Myers & Ziv, 2016; Tang, 2019; Tuffour et al., 2019; Wagstaff et al., 2018; Weich et al., 2012) chose to not comply with medication. This was seen as a way of exerting control over their lives and/or to escape adverse effects of medication (Lawrence et al., 2021; Myers & Ziv, 2016; Tang, 2019; Tuffour et al., 2019; Wagstaff et al., 2018; Weich et al., 2012). Some participants reported choosing to reduce or stop medication independent of professional support (Lawrence et al., 2021; Tang, 2019; Wagstaff et al., 2018). For one female Black African participant, the prospect of forced medication resulted in her threatening to leave the UK: 'I would go back to my country which is Zimbabwe … why do I have to suffer in this country?' (Tuffour et al., 2019, p.111).

Unfortunately, disengaging in medication treatment meant some participants 'cycled in and out of hospital' (Lawrence et al., 2021; Myers & Ziv, 2016, p.400). This diminished participants' sense of agency and some individuals who had rejected taking medication over time reluctantly agreed to the treatment (Chakraborty et al., 2009; Lawrence et al., 2021; Myers & Ziv, 2016; Wagstaff et al. 2018). This feeling is captured by an African-American male participant who had been in and out of hospital the previous decade: 'So I take the medicine and I go. I am compliant. I am mentally ill.' (Myers & Ziv, 2016, p.401). These experiences were found across a range of ethnicities. Weich et al.'s (2012) study which included participants from a range of ethnicities, including White British participants, concluded there were no ethnic differences in medication adherence (Weich et al., 2012).

The Need for Cultural Understandings Alongside Medication

Non-Western religious and spiritual treatments were used alongside medication by some participants across three studies (Greenwood et al., 2000; Tang, 2019; Weich et al., 2012). This occurred when participants held culturally specific explanations of their difficulties which necessitated religious and spiritual healing. This took the form of consulting with religious leaders and prayer. For all these participants, non-Western approaches were seen as complementary to medication and not as an alternative. For one Pakistani female participant, her and her family praying meant 'a lot of things got better', but she believed 'medication first' helped her (Weich et al., 2012, p.122).

The need for cultural understandings alongside medication was not reported across all ethnicities. Weich et al. (2012) highlighted that alternative help was sought only by some Muslim participants and not by any African Caribbean, Black African or Caribbean, or White British participants (the authors did not clarify the ethnicities of all the Muslim participants). The two other studies focused on the experiences of Chinese participants (Tang, 2019) and Asian inpatient service users, whose predominant religion was Muslim (Greenwood et al., 2000). However, alternative understandings may have been overlooked in many of the papers since these were not a main focus.

Family Support versus Opposition to Medication

The influence of family on medication treatment was discussed across five studies (Lawrence et al., 2021; Myers & Ziv, 2016; Secker & Harding, 2002; Tang, 2019; Tuffour et al., 2019). In two papers, which explored the experiences of Chinese participants (Tang, 2019) and African-American men (Myers & Ziv, 2016), two participant's families were in favour of medication. The families were described to 'empower' (Tang, 2019, p.276) and to 'convince' (Myers & Ziv, 2016, p.405) participants to take medication.

In contrast, one Black-African male participant reported a reluctance to take medication due to his family's negative beliefs about them (Tuffour et al., 2019). In another study of African and African-Caribbean inpatient participants, the father of one individual, who was unhappy with their medication, 'tried but failed' (Secker & Harding, 2002, p.163) to influence their son's treatment decision. Lawrence et al. (2021) similarly found family members attempted to challenge treatment decisions. Their findings found families of Black Caribbean participants had less success in influencing treatment decisions compared to families of White British participants. As with other studies reporting differences between the experiences of different ethnic groups, these are qualitative and likely subject to sampling bias, and therefore suggest a need to investigate with larger and perhaps more representative samples or in a wider range of contexts.

Discussion

The review set out to explore experiences of service users from minoritised ethnicities taking medication for psychosis-related diagnoses. The 11 qualitative study results were synthesised and presented under six main categories; medication helping versus negative effects; coercion; “They’re quite happy to just hand out pills”; surrender versus disengaging; the need for cultural understandings alongside medication; and family support versus opposition to medication.

Setting the Findings into the Context of Broader Literature

Reports of positive medication effects appeared most apparent for participants who received additional professional support with whom they had built a good rapport (Mfoafo-M’Carthy, 2016). This is in line with previous research finding positive clinical outcomes to be associated with supportive and respectful therapeutic alliances (Dixon et al., 2016).

More data, however, was reported on negative effects of medication, usually in the same papers. These were characterised by sedation, blunted thinking and feeling, weight gain, and loss of interest. Both negative and positive effects appeared to be a general experience of medication, not specific to ‘race’ and ethnicity, and echoed findings of previous qualitative reviews (Bjornestad et al., 2020; Thompson et al., 2020).

Consistently reported in nearly all papers were experiences of being coerced into taking medication. These findings imply NICE (2014) guidelines, which state the choice of ‘antipsychotic’ medication should be made by the service user and healthcare professional together, are not commonly adhered to. The lack of information provided on medication, experienced across ethnic groups, echoes findings from the National Clinical Audit of Psychosis (Royal College of Psychiatrists, 2018) which found less than a third of patients were given accessible information.

Coercive treatment was also characterised for many as a lack of autonomy and a feeling of powerlessness. This is in line with findings from previous reviews of users of ‘antipsychotics’ that have not focused on ethnicity (Bjornestad et al., 2020; Thompson et al., 2020). This current review, however, shed light on how ‘race’ and ethnicity can compound these experiences. Two studies found participants who were not White were less able to influence medication decisions and negotiate dosage reductions. Whilst these were relatively small and qualitative studies, they are consistent with previous research which found Black service users are more likely to be given higher doses of medication (Das-Munshi et al. 2018). The finding of forcible administration of depot medication was also unique to this review. This possibly indicates a higher prevalence of depot injections occurring for participants in the studies selected for this paper, particularly people of African and Caribbean heritage. This would support Das-Munshi et al.’s (2018) findings of there being a higher prevalence of depot injections amongst Black service users. A few studies were also consistent with higher rates of diagnoses and medication being given due to racial stereotyping (Fernando, 2017; Keating, 2016).

Despite guidelines recommending medication is offered as part of a comprehensive treatment package (NICE, 2014), including, for example, psychotherapy, the majority of studies described medication being used as an exclusive treatment, to the extent that alternative and culturally based understandings seemed to be side-lined. This could be viewed as an indication of mental health services remaining Eurocentric in nature and focused on distress as an ‘illness’. Furthermore, a small amount of data supported findings that people of Black African and Caribbean heritage are less likely to be offered psychotherapy and more likely to be offered medication, consistent with previous quantitative studies (Das-Munshi et al. 2018).

For some participants, the lack of autonomy and power over treatment decisions meant they, in effect, surrendered to taking medication. Others chose not to comply with treatment in an attempt to regain control and avoid adverse effects. This is in line with previous studies which found people with psychosis, who had been previously hospitalised against their will, reported lower levels of medication adherence once in the community (Jaeger et al., 2013). Differences across ethnicities were not apparent in relation to this theme.

Unique to this review was the experience of needing cultural understandings alongside medication. Although this was a lesser discussed topic, the importance of faith and prayer alongside medication was notable. A spiritual framework appeared to co-exist with the medical model. This is in keeping with previous studies which reported using multiple explanations and approaches, such as biomedical and spiritual, can assist recovery in complex mental health conditions (Haliburton, 2009; Lewis, 2014).

Family was also considered an important influence on the experience of medication for some participants across ethnic groups. Previous research found minoritised ethnic groups with a collectivist orientation value services which consider their family members (Khalathil et al., 2011). For some, family members supported the biomedical model and encouraged participants to access medication. For others, there was familial pressure to avoid medication. There was some description of family members advocating for changes in treatment on behalf of participants. A small amount of evidence suggesting the ‘race’ and ethnicity of families impacted how much power they had to influence family member’s treatment. However, as with other reported disparities, it is difficult to be sure these were not artefacts of the studies small and possibly biased samples.

Limitations

The scope of this review was limited by the literature search finding only a small number of papers exploring experiences of service users from minoritised ethnicities with psychoses-related diagnoses, none of which focused specifically on the experience of medication. Of the papers included, a number did not disaggregate some of the ethnicities of their participants. This has resulted in some experiences being grouped into a homogenous category, consequently underplaying social contexts and diverse cultural experiences of medication treatment. The quality of the included papers was generally high in relation to their stated aims, but the studies were diverse in their aims and analyses. Furthermore, the review was carried out by only one researcher, and although checked by a supervising researcher, this singularity increases the possibility of bias which should be held in mind. Finally, the included studies covered a 21-year time span. This brings into questions the generalizability of findings from earlier studies.

Clinical Implications

Services would benefit from mitigating the large power imbalances existing between clinicians and service users, for example by making more advocates available who come from minority ethnic groups, as is due to be piloted by the government (HM Government, 2021). Service personnel should be particularly alert to their role in perpetuating existing feelings of disempowerment in many service users from minoritised ethnic backgrounds. Clinicians should therefore ensure they are providing a more autonomous role in the treatment decision making process and ensure service users are aware of their right for advocacy.

There needs to be clearer accessible information on medication and service users should be offered multiple treatment options, not medication alone (NICE, 2014). As part of this, there should be more training and engagement into alternative explanatory frameworks with an increased recognition of non-western cultural experiences (Paez et al., 2009).

The findings highlight how common it is for service users to experience adverse effects of medication. Services should ensure they are regularly reviewing medication and listening carefully to concerns. This can help ensure service users have a sense of power over their treatment which could help prevent disengagement.

Finally, interwoven through some descriptions of medication treatment were experiences of overt and covert racism. This is consistent with Fernando's (2017) claim, although none of the papers specifically examined racism. Nonetheless, services could benefit from ongoing engagement with community groups and/or advocates from different groups to increase awareness of how bias affects diagnosis, risk assessment and treatment decisions.

Future Research

Given the lack of focus on medication, as such, in the papers identified, future research on the experiences of medication for psychosis-related diagnoses would benefit from focusing on voices of service users from minoritised ethnicities to look directly at this issue. Exploring experiences of specific ethnicities may allow for more within group comparisons and avoid grouping experiences into homogenous categories. Including White participants for comparison may help highlight the ethnic disparities in mental health care.

More research addressing how clinicians might respond to service users who wish to challenge their current treatment would also be beneficial. This could apply to service users from both minoritised ethnic and White backgrounds, but there appears to be a shortage of independent mental health advocates drawn from minoritised ethnic groups (Newbigging et al., 2015).

Conclusion

The review investigated the experiences of service users from minoritised ethnic backgrounds taking medication for psychosis-related diagnoses. While some benefits of medication were reported, more commonly medication was associated with adverse effects. Participants reported having little to no control over treatment decisions, with alternative options not commonly offered. Many participants felt they had no choice but to take a passive stance in accepting medication or to disengage with treatment. Being given depot medication was experienced as especially distressing, particularly for service users of African and Caribbean heritage. The importance of having a cultural explanatory framework, alongside the biomedical model, was important for some service users, as was the involvement and opinions of family members. The review provides some initial evidence which suggest that negative experiences of medication, although not specific to ethnicity per se, are more likely to be compounded if service users are a member of a minoritised ethnic group. Future research would benefit from focusing on the voices of service users from minoritised ethnicities to look directly at this issue and exploring how clinicians might respond to service users who wish to challenge their current treatment.

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Major Research Project: Section B

'Walking the tight rope': a qualitative study looking at clinical psychologists' responses to concerns about service users' medication

Word Count: 7940 (8345)

Abstract

Objectives: The objective of this research was to explore psychologists' experience of concerns about the medication of service users with a psychosis-related diagnoses, their experiences of responding to these concerns, and what are the perceived outcomes of these responses.

Design: This study utilised a qualitative, interview-based design, guided by a critical realist grounded theory.

Methods: Twelve clinical psychologists working with individuals given a psychosis-related diagnoses, across a range of service settings, participated in semi-structured interviews.

Results: The constructed model identifies 43 sub-categories organised within six main categories: Observing Coercion; 'Walking the Tight Rope'; 'Listen' or 'Shut Down'; Service Users 'Stuck in the Middle'; Teams, People and Relationships; Economic Climate and Societal Discourses.

Conclusions: The study highlights some dilemmas participants experienced regarding medication and is important in its acknowledgement of how difficult it can be to negotiate these dilemmas, as represented by the category 'Walking the Tight Rope'. Furthermore, the results indicate the need to improve shared decision making with service users, to offer increased support in the withdrawal of medication, and to help teams feel able to take more positive risks in relation to prescribing.

Keywords: Psychologists, Psychosis, Medication, Antipsychotics, Grounded Theory

‘Walking the tight rope’: a qualitative study looking at clinical psychologists’ responses to concerns about service users’ medication

Introduction

‘Antipsychotics’, or ‘neuroleptics’, are the recommended primary treatment for psychosis-related diagnoses, such as schizophrenia, schizoaffective disorder, and bipolar disorder (National Institute of Clinical Excellence [NICE], 2014). They were introduced in the 1950s and referred to as major tranquilizers before later marketed to treat ‘schizophrenia’ (Moncrieff, 2013). This treatment approach is generated from dominant biological theories conceptualising psychosis as a medical illness resulting from an underlying brain abnormality (e.g. American Psychiatric Association, 2018). ‘Antipsychotics’ are suggested to exert a disease-centred action which corrects such abnormality. Moncrief (2013) pointed to the absence of evidence supporting this ‘disease-centred model’ and proposed an alternative ‘drug-centred model’. This suggests ‘antipsychotics’ can modify normal brain processes causing alterations to emotions and behaviour in a similar way to other mind-altering substances, such as alcohol.

Alternative understandings of a ‘disease model’ also emphasise the causal role childhood trauma can play in the development of psychosis. The Traumagenic Neurodevelopmental Model of psychosis (Read et al., 2014) proposed how childhood trauma can affect the structure and function of developing brains which can result in the heightened sensitivity to stress found in people diagnosed with psychosis. Bloomfield et al. (2021) stated how important it is to recognise the role of childhood trauma and pointed to findings of people who have had such experiences tended to do less well on ‘antipsychotics’ but were often prescribed more of them.

Many service users have found ‘antipsychotics’ beneficial and evidence has supported their use treating acute psychotic distress short-term (e.g. Leucht et al., 2017; Mackin & Thomas, 2011). It is widely recognised, however, ‘antipsychotics’ can also be problematic. They are powerful drugs which can produce wide ranging adverse physical and psychological effects (Morant et al., 2016). Common negative effects include emotional blunting, weight gain, diabetes, sedation, sexual dysfunction, and brain volume reduction (e.g. De Hert et al., 2011; Moncrieff, 2013; Rummel-Kludge et al., 2010). Reviews of service users’ experiences found drug effects disrupted a sense of self and impacted social functioning and achievement of life goals (Bjornestad et al., 2020; Thompson et al., 2020).

Concerns have been raised about the overreliance on ‘antipsychotics’. This includes issues with polypharmacy (being prescribed more than one psychotropic medication at one time) and doses being rapidly increased in order to quickly stabilise and discharge service users from acute services (Cooper et al., 2019; Roberts et al., 2018). Additionally, existing research suggests clinician concerns about risk and ‘relapse’ causes a reluctance to reduce or discontinue medication. Stability through maintenance treatment is often favoured over reducing ‘antipsychotics’, even if this means not tackling potential over-medication (Cooper et al., 2019; Happell et al., 2014; Quirk et al., 2012; Simmons et al., 2017). Wider concern of overmedication has been raised by the All Party Parliamentary Group for Prescribed Drug Dependence (2021) who state they are addressing the growing problem of increasing numbers of medication prescriptions, including ‘antipsychotics’. To help address this issue, guidance aiming to enable therapists to have conversations with clients taking or withdrawing from prescribed psychiatric medication has recently been published (Rizq et al., 2020).

Morant et al. (2016) argued being involved in treatment decisions is crucial. However, despite NICE (2014) guidelines stating ‘antipsychotic’ medication decisions should be made by service user and healthcare professional together, shared decision making (SDM) is seemingly not routinely used or effective, as discussed next. The National Clinical Audit of Psychosis (Royal College of Psychiatrists, 2018) found just 35% of service users were recorded being involved in medication decisions. Qualitative studies have highlighted how service users commonly feel coerced into taking medication (Bjornestad et al., 2020; Morant et al., 2018; Thompson et al., 2020). Evidence suggests some psychiatrists adopt a paternalistic stance and use a range of strategies, including relaying statistics about risk of ‘relapse’, to persuade people to stay on ‘antipsychotics’ (Cooper et al., 2019). Critics of the SDM model argue how it has been imported from physical to mental health care and fails to acknowledge unequal power dynamics of mental health consultations (Morant et al., 2016). Furthermore, Mikesell et al. (2016) argued SDM is not possible due to service users being frequently perceived as not competent to make decisions.

The issues above cannot be ignored by the clinical psychology profession. Morant et al. (2016) argued medication decisions are complex and should not just include the prescriber and service user, but all parties involved in their care. Clinical psychologists (psychologists) may be meeting service users more regularly than prescribing psychiatrists, which might provide opportunities to explore ‘problems of medication’ (Morant et al., 2016, p. 1008). Furthermore, one can surmise that adverse medication effects, such as sedation, could impact therapeutic work (Miller, 2004).

This inevitably may present clinicians with dilemmas viewed as possibly belonging in the ethics territory. An existing theory which could help us understand how a psychologist might respond in these situations is the Theory of Interpersonal Behaviour (TIB; Triandis, 1980). TIB suggests perceived consequences, emotions, social normative beliefs, and personal normative beliefs affect one’s intention to perform a stated action. Once an intention is created, past experience and facilitating conditions can constrain or support the translation of intention into behaviour. In a review of factors influencing healthcare professionals’ intentions and behaviours based on social cognitive theories, TIB best predicted intentions to behave in a certain way when faced with clinical practice, compliance with guidelines, documentation, and acceptance of technology (Godin et al., 2008). More recently, TIB effectively predicted medical students' decisions in an ethical dilemma involving hierarchy, patient autonomy, and conflict with self-interest (Li et al., 2020). Students' feelings of guilt and perceived facilitating resources, namely their trust in senior physician's decisions and supervision, most significantly predicted decision making. Li et al. (2020), however, did not specify how much variance was explained, making it unclear as to how much it helps us understand people's decision-making. Furthermore, the ethical dilemma was specific to medical students and based on a vignette rather than participant's actual experience.

TIB may prove helpful in a more general sense, but Cooke, Smythe and Anscombe's (2019) grounded theory model may prove more relevant to the current study. This looked at psychologists' responses to dilemmas arising in a mental healthcare context in relation to their concerns about the dominance of the medical model. Three main responses were identified: conflict, compromise and collusion, with collusion representing an insidious sense of acting against one's own values. This model suggests some possible hypotheses that could be tested in relation to how a psychologist would respond to concerns over medication. However, it does not refer to the specific area of medication and was developed on a small sample, which authors acknowledged may have been biased towards people with a specific view. This study aimed to provide a preliminary investigation of how psychologists respond when they think medication might be problematic.

Rationale

The above literature highlights the growing body of knowledge regarding the distressing potential harm 'antipsychotic' medication can cause. The additional evidence of service users not being adequately involved in treatment decisions combined with some professionals' reluctance to reduce or discontinue 'antipsychotics' is of concern. Psychologists are possibly meeting some service users more frequently than prescribing psychiatrists and therefore might have more opportunities to become aware of medication being problematic. This inevitably might cause dilemmas for psychologists in knowing how to respond. The study sought to build a grounded theory about how psychologists respond when they become concerned about medication. In order to guide theory-building, the following specific questions were posed in relation to a sample of psychologists who have ever felt concern about a service user's medication:

a. In what ways do participants describe becoming aware that medication may be problematic?

b. When they have concerns about their client's medication how do they respond to these concerns?
c. What outcomes do participants describe following on from those concerns and from their responses?
d. What factors do participants feel enable or inhibit them in discussing medication with their clients and with their team?

Method

Design

A qualitative study using an abbreviated (see Data Analysis) grounded theory (GT) methodology was used. GT consists of systematically collecting and analysing qualitative data to construct theories about social processes which are 'grounded' in real life experiences (Charmaz, 2006). GT was chosen as an appropriate method as it could encourage an understanding of how, why and when psychologists might find it harder or easier to have a sense of agency in situations where they feel concerned about medication, from their own perspective. It also enabled subjective experience to be placed in a social context (Willig, 2008).

Given my critical realist stance, whereby I view an observable reality exists, but knowledge is fallible and subject to bias, this study chose to adopt Strauss and Corbin's (2008) GT approach, in abbreviated form (see Data Analysis).

Participants

Twelve UK clinical psychologists took part. Table 1 provides characteristics of the interviewees.

Table 1

Participant Characteristics

Participant	Work Setting	Band/Leadership role	Time in Current Setting (years)	Time Qualified (years)	Belong to Psychosis SIG (Y/N)	Full time (F/T) or Part-Time (P/T)
P1	Primary Care Team for Psychosis	8a	1.5	3	No	F/T
P2	Community Mental Health Team/Rehab Team	8a	3	9	Yes	P/T

P3	Early Intervention for Psychosis	Principal psychologist and clinical lead	7	14	Yes	F/T
P4	Early Intervention for Psychosis	Principal psychologist	7	8	No	F/T
P5	Early Intervention for Psychosis	7	1.5	2	No	F/T
P6	Community Mental Health Team	Not stated	1	3	No	F/T
P7	Inpatient Low Secure Forensic Service	7	1	1	No	F/T
P8	Community Mental Health Team	Head of psychological therapies and clinical lead	15	15	No	F/T
P9	Inpatient Adult Acute and Psychiatric Intensive Care Unit	8b principal clinical psychologist	12	14	No	P/T
P10	Children and Adolescent Team (Psychosis Pathway)	Lead psychologist for EIP under 18s	8	8	Yes	P/T
P11	Inpatient Older Adult	Not stated	2	2	No	P/T
P12	Home Treatment Team	7	1	1	No	F/T

Procedure

Recruitment

Individuals were eligible if they were qualified clinical psychologists working with service users considered at risk of developing, or had been diagnosed with, a psychosis-related diagnosis for a minimum of one year and had experienced a concern about a service user's medication within the last twelve months. No specification was made about the type of concern. The study was advertised across a number of locations to enable visibility of the research (Table 2).

An opportunistic sampling method was initially employed. A snowballing approach was then adopted whereby a number of participants circulated study details following their interviews. Recruitment through these different pathways meant participants were drawn throughout the UK across a number of different settings ranging in years of clinical practice.

Table 2

Recruitment Locations

Recruitment Location	Marketing Medium
The British Psychological Society (BPS) Twitter and Facebook platforms	Study details with link[1] distributed on social media platforms (Appendix D)
BPS Psychosis & Complex Mental Health Faculty mailing list	Study details with link (Appendix E) distributed via email by teaching colleague at Salomons Institute for Applied Psychology
Distribution of study via connections of research supervisors and trainee clinical psychologist colleagues	Study details with link sent via email (Appendix E)

Note. Link[1] refers to the URL which redirected participants to the online screening questionnaire

In the emails circulated there was a link to an initial screening questionnaire hosted by Qualtrics. This included questions such as length of time since qualification and current work setting (Appendix F). These were asked with the possibility of theoretical sampling (Strauss & Corbin, 1998) in mind. For example, emerging hypotheses sought to explore whether psychologists who were working with service users with higher risk presentations (for example in forensic inpatient settings) felt less able to respond to medication concerns. As the initial screening questionnaire respondents did not include individuals who were working in inpatient settings, links with existing colleagues were used to make people with that experience aware of the study and invite them to complete the screening questionnaire. Recipients were asked to leave a contact email if they were willing to be interviewed. All those who completed the screening questionnaire were made aware they may not be invited to take part and were asked whether they would like a summary of the study emailed to them in case they were not contacted. In the end only two people were not contacted, both of whom were sent summaries of the study as requested. Participants selected for an interview were emailed an information sheet (Appendix G) and consent form (Appendix H) in advance of their interview. All participants provided consent via electronic signatures (hand-written and electronically inserted). An end of study summary report was emailed to each participant who took part (Appendix I).

Data Collection

One-to-one interviews were conducted via computer voice calling software or telephone. The interviewer checked participants were clear about the purpose of the study and had a chance to ask questions before the interview.

Interviews followed a semi-structured schedule (Appendix J) which was developed following a literature review, discussions with study supervisors, and a consultation with a service user from Salomons advisory group of experts by experience. It was piloted with the supporting supervisor who is a clinical psychologist with experience in working with individuals with psychosis-related diagnoses. The pilot interview elicited rich data meaning the schedule was not substantially amended. Questions aimed to generate data related to the research questions (Corbin & Strauss, 2008). Modifications occurred over the course of interviews to assist with the elaboration of emerging hypotheses (Corbin & Strauss, 2008).

All participants were debriefed and invited to receive summaries of the results. All interviews were audio recorded using a digital recorder and transcribed verbatim. Interviews lasted between 44 to 84 minutes.

Data Analysis

Data were analysed following an abbreviated version of Corbin and Strauss' (2008) approach, using the software package Atlas.ti.

After every interview hypothesising and memo-writing were carried out to ensure there was a degree of analysis contemporaneous with data collection, as well as reflexivity (Appendix K). Emerging hypotheses were discussed during meetings with research supervisors throughout data collection. During these meetings suggestions for areas of enquiry to be focused on in subsequent interviews were discussed. For example, exploring whether participants felt protected characteristics, such as 'race' and ethnicity, impacted their own and team responses to concerns. The process of analysis involved open coding, constant comparison, use of the coding paradigm, and theoretical integration (Table 3). Unlike the full version of GT, initial open coding began after the twelfth (final) interview.

Table 3

Process of Data Analysis

Stage	Description
Open coding	This involved 'breaking data apart' (Corbin & Strauss, 2015, p.239) and proceeded line-by-line for the first five interviews (Appendix L) which prompted close examination of the data.
Constant comparison	This was the main technique employed to compare the broken-down data for similarities and differences. Data found to be conceptually similar were grouped together early on under higher-level descriptive concepts.
Coding paradigm	The use of the coding paradigm helped analyse the data for context and further group codes into conditions, actions, emotions, and consequences (Corbin and Strauss, 2008).
Theoretical integration	Theoretical integration (Corbin & Strauss, 2008) involved reviewing and sorting through memos and diagrams and outlining what was seen as the overarching theoretical scheme.

Note. In practice, analysis involved a moving back and forth between stages.

Further memos (Appendix M) were written throughout coding along with diagramming of each participant's experience (Appendix N). No new categories or inconsistencies emerged during the coding of the final two interviews. Each category appeared well defined and developed in terms of properties and dimensions and included variation. Theoretical sufficiency (Dey, 1999) was therefore considered to be achieved. Respondent validation was received by three participants who all fed back that the theory captured their experiences well (Appendix O) and only suggested minor additions to two categories.

Quality Assurance Methods

Several processes were carried out to maximise the quality of the research (Yardley, 2000). A bracketing interview was completed with a peer prior to data collection. This deepened awareness of my potential biases, such as being critical of the medical model and having personal and professional experiences of seeing psychotropic medication being offered alone, apparently without exploration of underlying difficulties or discussions of possible adverse effects. Additionally, it helped me be aware that some participants might see benefits to medication and to not ignore this. Memo-writing and consultations with research supervisors, where emerging codes and theories were discussed, further helped me stay alert to possibilities of privileging viewpoints which corresponded with my own. A section of coding was also cross-checked by the lead research supervisor. Within the critical realist framework, it is acknowledged it is always inevitable prior assumptions will have played some role into the analysis. The reader is therefore invited to take the above into account when evaluating the study's findings.

Ethical Considerations

The plan of the study was granted approval by the Salomons Institute for Applied Psychology ethics panel (Appendix P). Confidentiality and its limits were stated in the information sheet and reiterated prior to the interview. It was anticipated some aspects of the interview might touch on difficult experiences of working with people in distress or of finding it difficult to voice concerns about their treatment. Contact details for where to seek support were provided at the end of the screening questionnaire (Appendix Q). The interviewer was alert to the possibility of distress throughout the interview. All participants were asked at the end (once the recorder was off) whether they were left with any difficult feelings or had any questions. Participants responded positively to the interview with most commenting on finding it helpful to have space to reflect on their experiences.

Confidentiality of the collected data was protected by encrypting and storing interview audio data, anonymised verbatim transcripts, and participant details on a password protected computer. Once the audio data were transcribed the recordings were erased. Disguising identifying data from the interviews was discussed with several participants and transcripts were amended accordingly.

Results

The final GT model is presented in Figure 1. It comprises of six main categories (Table 2). **Observing coercion** captures the way participants described becoming concerned about medication. '**Walking the tight rope'** illustrates the balancing act in negotiating their responses to these concerns. How teams and doctors respond to concerns raised are illustrated within '**listen' or 'shut down'**. This is followed by different service user outcomes described within **service users 'stuck in the middle'**. The outer circles illustrate the many contextual factors found to impact concerns held and how they may be responded to. The information below will describe each category in detail.

Table 2

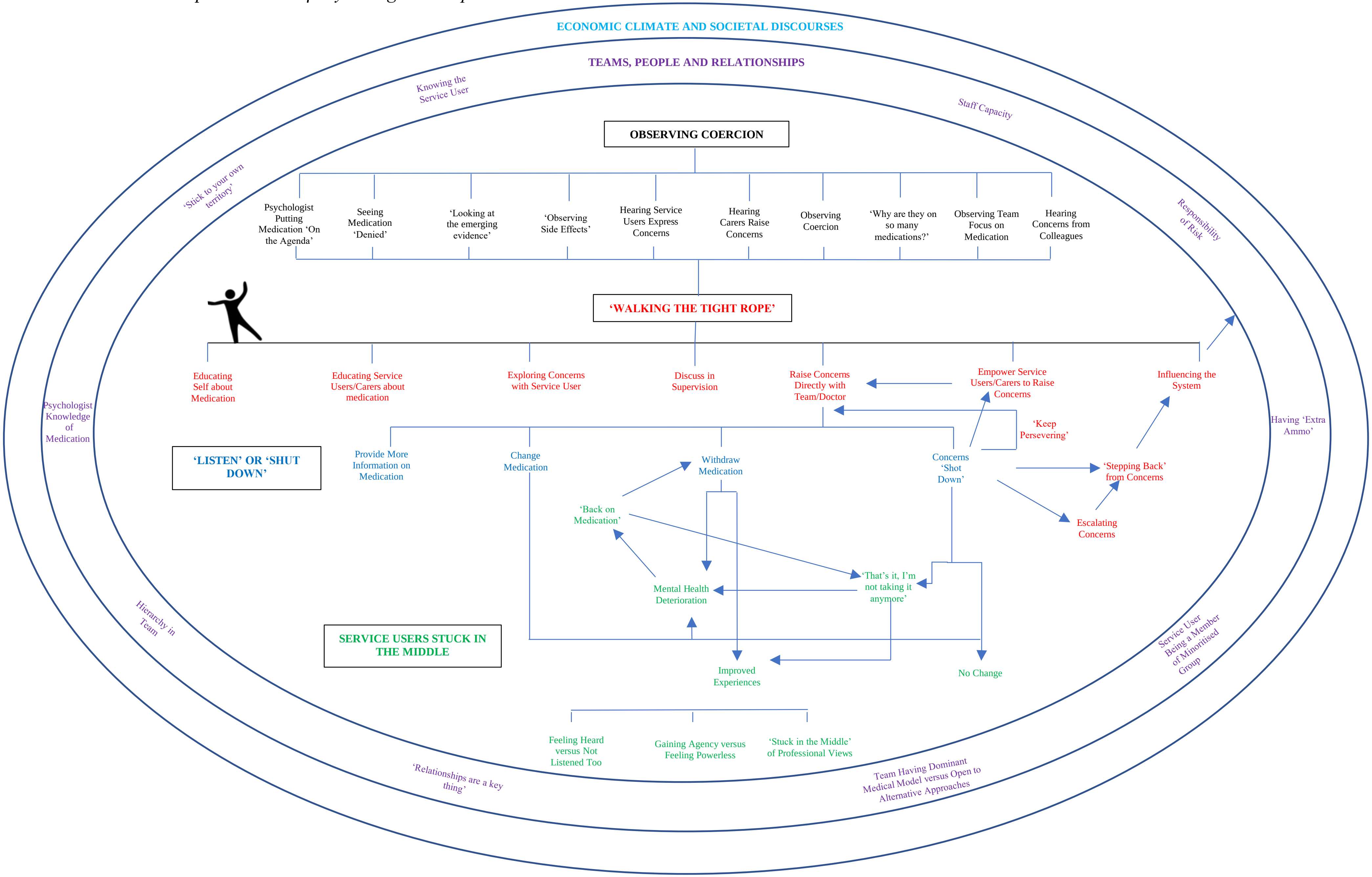
Category and Sub-Category Names

Category	Sub-category
A: Observing Coercion	1. Psychologist Putting Medication 'On the Agenda' 2. Seeing Medication 'Denied' 3. 'Observing Side Effects' 4. Hearing Service Users Express Concerns 5. Hearing Carers Raise Concerns 6. Observing Coercion 7. 'Why are they on so many medications?' 8. Observing Team Focus on Medication 9. Hearing Concerns from Colleagues
B: 'Walking the Tight Rope'	1. Educating Self about Medication 2. Educating Service Users/Carers about medication 3. Exploring Concerns with Service Uses 4. Discuss in Supervision 5. Raise Concerns Directly with Team/Doctor 6. Empower Service Users/Carers to Raise Concerns 7. 'Keep Persevering'

	8. Escalating Concerns 9. ‘Stepping Back’ from concerns 10. Influencing the System 11. Not Wanting to be Divisive 12. Difficult to Maintain a Critical Perspective
C: ‘Listen’ or ‘Shut Down’	1. Provide More Information on Medication 2. Change Medication 3. Withdraw Medication 4. Concern’s ‘Shot Down’
D: Service Users ‘Stuck in the Middle’	1. Improved Experiences 2. No Change 3. ‘That’s it, I’m not taking it anymore’ 4. Mental Health Deterioration 5. ‘Back on Medication’ 6. Feeling ‘Heard’ versus ‘Not Listened Too’ 7. Gaining Agency versus Feeling Powerless 8. ‘Stuck in the Middle’ of Professional Views
E: Teams, People and Relationships	1. Staff Capacity 2. Responsibility of Risk 3. Having ‘Extra Ammo’ 4. Service User Being Member of Minoritised Group 5. Team Having Dominant Medical Model versus Open to Alternative Approaches 6. ‘Relationships are a Key Thing’ 7. Hierarchy in Team 8. Psychologist Knowledge of Medication 9. ‘Stick to Your Own Territory’ 10. Knowing the Service User
F: Economic Climate and Societal Discourses	

Figure 1

A Visual Representation of Psychologists' Responses to Concerns about Service Users' Medication



Category A: Observing Coercion

This category captures the different ways participants described becoming concerned about medication.

Observing Coercion (both category and one of the subcategory names)

All participants described experiences of **observing service users be coerced** into taking medication. For most participants this involved service users not being given enough information about medication, leaving them unable to make an informed decision. Adverse effects of medication were described as either ‘not being talked about’ (P5), ‘minimised’ (P3), or ‘dressed up’ (P3) in inaccessible language.

Many participants expressed concern over the expectation of service users to take medication for a long time and being told a reduction would ‘be dangerous’ (P3). Participant 5 described how this left ‘people feeling like they’re not allowed to come off it [medication]’.

Community treatment orders (CTOs) were perceived to be particularly coercive. Participants expressed concern over whether it is possible to gain informed consent when service users are told ‘…you don’t have to take it [medication] but if you don’t take it we’re gonna section you’ (P10). A few participants shared their worries about the use of depot medication as part of the CTO agreement, especially after witnessing how ‘invasive’ (P7) it was. Some participants worried about hearing teams describe service users as lacking insight when they challenged medication decisions:

> ‘People are labelled as kind of troublemakers […] if anyone disagrees with their medication regime, for example […] You know that the person lacks insight and almost like we must increase their medication until they succumb to come to realise that they really, they really are unwell.’ (P4)

Some participants, mostly working in inpatient settings, expressed concern over medication being used to control ‘aggressive and challenging behaviour’ (P9) through sedating participants, and described medication as a ‘chemical restraint’ (P7) and a ‘modern-day use of the straight jacket’ (P12).

‘Why are they on so many medications?’

A few participants described becoming concerned over the frequency of **service users being on more than one psychotropic medication**. Participant 9 described observing their team’s decision to ‘put another antipsychotic into the system’ until they were ‘rattling with more pills’. Participant 2 expressed concern about the lack of research on the effects of combining different medications and the possible dangers of this.

Observing Service Focus on Medication

Numerous participants felt concerned that their **teams and/or doctors focused on medication** being the most important, and often only, treatment for psychosis. Participants described frequently hearing doctors and teams discuss psychosis within an illness paradigm: psychosis was referred to as a ‘brain disease’ (P4) and being caused by a ‘chemical imbalance’ (P2,4 and 8). This felt problematic as it was incongruent with participant’s formulation of psychosis being caused by adverse life events.

> ‘…there’s a kind of tacit implication, that the idea that they’ve got an illness, like they’ve got schizophrenia, therefore there’s a chemical imbalance which needs to be corrected and that’s what the problem is […] rather than they’ve had some awful things happened and it’s messed with the head a bit.’ (P8)

A number expressed psychology felt like an ‘add on’ (P12) and if it was offered it was only an adjunctive to medication. Some participants described how there was a perception if one medication did not work, then a service user needed to keep being ‘tried on all others until they’ve been through absolutely every single one’ (P4).

Putting Medication ‘on the Agenda’

Some participants became concerned through **putting medication ‘on the agenda’** (P4) and proactively asking service users about their experience, particularly if they had a role of care coordinator.

> ‘You open up opportunities for them to tell you if they have got any concerns. And again, I often think that is stuff care co-ordinators and psychiatrists don’t have time for, to speak to clients about. Whereas psychologists we maybe do have a bit more time so we can address it.’ (P1)

‘Looking at all the emerging evidence’

A few participants described becoming concerned about medication from reading research about the effect of ‘antipsychotics’:

> ‘…looking at all the *emerging* evidence I think I have become only fairly recently, more and more acutely aware of [...] the level of harm this [antipsychotics] is causing.’ (P2)

‘Observing Side Effects’

Participants became concerned about medication after directly ‘**observing side effects’** (P2). Service users were reported to be seen ‘bumping into walls’ (P6), ‘slowing their words’ (P7) and acting like ‘zombies’ (P9). A number of participants believed this was due to medication doses being too high. This was particularly prominent in inpatient settings. Other adverse effects noticed were ‘dribbling’ (P2, 9), ‘glazed eyes and staring’ (P7), ‘restlessness’ (P5, 9), ‘weight gain’ (P2, 3, 4, 8, 10) and ‘facial grimaces’ (P2). Participants also reported noticing ‘difficulty accessing emotions’ (P2) during individual therapy sessions:

> ‘It’s just very difficult to get the necessary emotional engagement and emotional tone in the room because people are taking tablets which make them apathetic and numb their emotions.’ (P3)

Hearing Service Users Express Concerns

Several participants described becoming concerned about medication after **hearing service users express concerns** to them. Service users were said to express distress about the adverse effects discussed above, and report additional effects such as ‘constipation’ (P9), ‘erectile dysfunction’ (P4), and ‘breast tissue’ growth (P4, P10). Many participants were concerned about the impact adverse effects had on service users’ daily functioning which could consequently affect their mood.

> ‘So, I'm thinking about a client who is on a dose of an antipsychotic that is affecting their concentration and making them sleep a lot during the day, which gets in the way of them working full time, which is really important to them. And this, of course, lead to dissatisfaction and, you know, just general unhappiness.’ (P6)

Some service users were also described to raise with participants how they felt they did not need medication but felt unable to challenge this themselves.

Hearing Carers Raising Concerns

Most participants described how ‘carers definitely do have a role of raising concerns’ (P4). Commonly carers were described to raise concerns about adverse effects described above. Equally, participants described carers expressing concerns about service users ‘not taking enough medication’ (P5) or worries about ‘non-compliance’ (P10).

Seeing Medication ‘Denied’

Many participants described seeing the benefits of ‘antipsychotic’ medication, largely when used short-term to help ‘slow down thoughts and feelings’ (P6) for people who are very distressed. Some participants raised that services, however, ‘think too much in diagnostic groups’ (P4) when making medication decisions. Participant 4 described how this can result in some service users being denied medication:

> ‘I find it quite difficult when, if we've got somebody who's distressed, who might benefit from a short-term medication strategy, that effectively seems to be denied to some people. And yet other people it seems to be sort of forced upon, whether they want to or not.’ (P4)

Participants felt medication decisions needed to be made on a more individual basis rather than be dictated by a diagnosis and a specific treatment pathway.

Hearing Concerns from Colleagues

Some participants became aware medication was problematic after hearing concerns from colleagues. These commonly occurred during team meetings. Participant 7 described hearing concerns during:

> ‘Informal conversations with the nursing team erm who might share their own concerns that kind of match with mine.’ (P7)

Category B: ‘Walking the Tight Rope’

This category illustrates the difficult balancing act participants described when negotiating how to respond to their concerns.

Exploring concerns with the service user enabled some participants to gather more information. Participant 6 described after a client raised feeling tired from their medication they first ‘asked a couple of questions […] like when they started to notice it [tiredness], how it affects them, other potential explanations etc’.

A number of participants would try to **educate themselves about medication.**

> ‘I know I don't know loads about it [medication], but I do read quite a bit and have yeah, I've learned enough about it I think, to kind of have some idea about what effects different things have on people.’ (P5)

Some participants felt able to **educate service users and carers about medication**. Participant 3 described showing one service user a study on how ‘risperidone had quite a significant impact on people’s weight’ after information on this adverse effect had been requested.

A few participants described how concerns would be ‘**discussed with my supervisor**’ (P1). Participant 10 said their supervisor’s ‘ideas helps to relieve me of something if I feel stuck’.

Empowering service users and carers to raise concerns with the doctors was also a common response described by most participants. Participants described choosing this response instead of raising concerns themselves because: i) they wanted to ‘build them [service users] up and tell them about their rights’ (P12) so they feel they have the power to negotiate their own treatment decisions; ii) they felt service users had a ‘bit more chance’ (P2) at achieving a better outcome; iii) they felt they would be raising concerns too frequently and would come ‘across as quite anti-medication’ (P5); iv) they were unable to be present for the meeting where concerns could be discussed.

Most participants described **raising concerns directly with the team and doctors** and advocating on the service user’s behalf**.** Participant 1 found ‘adopting a position of naivety and curiosity’ helpful (P1). Participant 5 described strategically using diagnostic language:

> ‘You almost have to start using the language of diagnosis […] So you’re arguing for a different diagnosis against the psychosis, to have a different medication considered.’ (P5)

Some participants described how they would **‘keep persevering’** (P1) with raising concerns if they were not responded to.

> ‘So yeh, I just think it’s perseverance, consistently delivering the same message, but being open-minded.’ (P1)

Some others ended up ‘**stepping back’** (P6) **from their concerns** if they felt they were not getting anywhere.

> ‘We're not understanding, we're not seeing both sides. I'm going to park it.’ (P6)

Participants 2 and 10 described examples of how they ‘**escalated’** (P10) **concerns** to someone more senior in their service.

> ‘So I kind of escalated and there was an overall kind of review.’ (P10)

A number of participants responded to their concerns through **influencing the system:** they described teaching and educating teams about alternative explanatory frameworks as well as taking part in research.

> ‘And I think we probably have a role, as psychologists, to discuss all the different bits of evidence and you know we do know about research and things. I once did a talk for psychiatrists about the hearing voices approach and brought a service user.’ (P5)

Many participants felt they had acquired knowledge about medication and were able to share an important perspective. However, most participants expressed concern about sharing their view because they **did not want to be divisive** in their team or ‘step on the toes of medics’ (P11). Participants described previous experiences of teams not responding well to either themselves or a colleague who had acted assertively which made them feel wary of this approach. Not responding, however, to some felt ‘abusive’ (P7) towards service users. Participant 3 believed raising adverse effects of drug treatments was ‘not just a responsibility but potentially an ethical duty’.

> ‘On the one hand I want to maintain and develop those relationships with my colleagues […] But at the same time I can’t just be trying to maintain those relationships and staying on their good side. Ultimately, I’ve got clients who are suffering.’ (P3)

Furthermore, a number of participants described finding it **difficult to maintain a critical perspective**. This appeared more apparent for participants who described training on a ‘critical course’ (P12) and ‘endorsed’ (P12) critical psychology values. There was a sense these participants were losing their critical identity to a medically dominated system. A couple of participants expressed concern that they were going to end up/had ended up being ‘part of the problem’:

> ‘It’s unlikely that I, for me to go through a day at work without someone saying something that I find distressing about drugs and diagnosis and treatment for disorders. So, if I try to engage with it all then I just become very exhausted. But maybe I worry that I have adapted so much, that now I’ve become part of the problem.’ (P8)

Category C: ‘Listen’ or ‘Shut Down’

This category illustrates the range of different responses by the team and/or doctor to concerns raised.

Participants described a range of different responses by the team and/or doctor. For some, teams were described to be receptive and listen to concerns. A couple of participants described how teams met with service users to **provide further information about medication**:

> ‘We arranged for a meeting with the pharmacist to come in, to actually spend some time talking to him about the different medications.’ (P9)

If there were concerns about medication being too high or there being adverse effects, the team might agree to **change service users to a different medication:**

> ‘They change the medication to something else. Like for instance, they change erm something aripiprazole to clozapine, let’s say. Which is a medication from which practically nobody has a way out.’ (P2)

Participants described that less frequently teams and doctors agreed to reduce doses and, in some cases, **withdraw a service user from medication**. Withdrawal was perceived by some participants to happen too slow or ‘too quick’ (P2).

> ‘I think the psychiatrists in our team will often talk about ‘right so okay let’s work towards reducing it’, but that is always *very* slow.’ (P10)

Most participants described experiences of **concerns being ‘shot down’** (P11) by teams and/or doctors who felt either unwilling or unable to make any changes.

> ‘…they’ll literally say ‘no I’m not doing that’ without actually responding to what seem like legitimate concerns..’(P9)

Category D: Service Users Stuck in the Middle

This category illustrates the different outcomes for service users and how responses from teams can affect how they feel.

A few participants described how some service users saw an **improvement in their experiences.**

> ‘When their tablets get reduced all of a sudden a lightbulb comes up and they can think again.’ (P3)

For other service users, however, there was **no change** and they continued to experience the same difficulties.

> ‘It seems like they’ve done something, but really the other medication is not much better than the *previous* medication.’ (P2)

Participants described a number of service users who had their concerns dismissed could result in them withdrawing ‘outside of the knowledge of their mental health professional’ (P4). Service users who withdrew from medication, with or without professional support, were described to often experience a **mental health deterioration** where some ended up ‘back in hospital’ (P10) and **‘back on medication’** (P6)**.** Participants felt that service users often saw the deterioration of mental health ‘as a bit of a lesson’ (P4) that they should not try withdrawing again. Some participants suggested that deterioration was due to the withdrawal effects of the medication. Service users were described by some participants to have repeated unsuccessful withdrawals.

> ‘A lot of people get frustrated and go right **that’s it I'm not taking it anymore**. They stop it abruptly, or come off too quickly, get a little withdrawal effects then end up going back on it.’ (P3)

How service users were described to feel in these situations varied and often depended on service responses. Service users were described to either **feel ‘heard’** (P1,6) **versus ‘not listened to’** (P6). Participant 10 described how for one service user not being listened to by professionals ‘totally ruined his relationship with CAMHS’.

Service users also appeared to have experiences of either **gaining agency versus feeling ‘powerless’** (P7, P11). Participant 3 said their client became ‘less deferent’ and ‘more active’ during conversations with the psychiatrist after they had provided them with information about the effects of their medication. However, it appeared service users more commonly felt decisions were ‘non-negotiable’ (P4, P6, P10). ‘Controlling’ (P6) responses by teams appeared to result in ‘stripping people of their agency’ (P6) and making service users feel ‘powerless’(P7, P11) and untrustworthy.

> ‘He was probably left with a sense of people don’t in any way trust him, that we don’t trust him to take his medication, that we don’t trust him to stay well.’ (P10)

Some participants described service users feeling ‘**stuck in the middle’** (P4) **of professional views**.

> ‘And so, even now when they see their psychiatrist, on the one hand they are trying to appease the psychiatrist, on the one hand they are trying to appease the voices, and on the one hand they are trying to appease say myself…’ (P3)

Category E: Teams, People and Relationships

Knowing the service user and having a therapeutic relationship with them was perceived by numerous participants as an important factor which enabled them to raise concerns.

> ‘The things that make it easier would be if I got erm a kind of working relationship-therapeutic relationship with the service user.’(P7)

Staff Capacity affected both the participants and their team members’ ability to have space to think and respond to concerns.

> ‘I think if there were more staff on the ward, nursing staff, they wouldn't be burnt out so quickly, which means they would probably be able to hold some of these concerns in mind much more tentatively…’(P7)

The **responsibility of risk** was raised by all participants as a significant factor impacting teams’ and doctors’ abilities to respond to concerns about medication.

> ‘…if anything were to go wrong[…]it’s the responsible clinician that will be stood up in the coroner’s court with the very clever lawyers paid lots of money to try to make them look stupid and you know, their careers, livelihoods could be on the line if they get things wrong.’ (P9)

There was a higher responsibility of risk when service users had a history of violence to others or themselves. Some teams and psychiatrists appeared more ‘risk adverse’ (P4, 9) compared to other teams which were more able to hold uncertainty and take ‘positive risks’ (P6). Most teams described appeared to prioritise short-term risk over the risks of taking ‘antipsychotic’ medication long-term.

Some participants talked about how it felt easier to raise concerns when they had ‘psychologically minded colleagues in other professions’ (P1), or had other colleagues or carers sharing the same concerns as them:

> ‘Yeah, but when the carer does have concerns it’s much easier to raise concerns as there’s some **extra ammo**.’ (P5)

Nearly all participants talked about how **‘relationships are the key thing’** (P8) which helps them feel more comfortable raising concerns.

The openness of psychiatrists to discuss medication affected the ability of participants to raise concerns and the outcomes of discussions. For some participants, psychiatrists were ‘approachable to think about challenges’ (P9) related to medication. However, many described experiences of psychiatrists being ‘defensive’ (P9) and ‘dictatorial’ (P10) when being challenged about medication decisions. These participants felt stuck in what they could do to get a better response.

> ‘I guess there was probably something quite condescending in the response that I got, like, just don't go there, **stick to your own territory**.’ (P11)

A few participants described how in some teams the **‘medical model is particularly dominant’** (P1) which meant there was an increased ‘focus on treatment being about medication’ (P5). This made it difficult to challenge medication decisions. However, other teams appeared more **open to alternative treatment approaches:**

> ‘I don't think we're the most medication heavy team either, and there is a consideration of other ways of working.’ (P6)

Most participants described how a medical ‘**hierarchy’ in a team**, ‘where psychologists and their opinions sit below the psychiatrist’ (P1), made it harder to raise concerns about medication. Inpatient settings were described as more ‘hierarchical’ (P4) than community services. Having more junior psychologists appeared to exacerbate this hierarchy, although it appeared to still exist even when participants were more qualified. Participant 3 believed an ‘open dialogue approach’ can address hierarchy. However, they experienced psychiatrists as resistant to this approach:

> ‘Being very much influenced by open dialogue I-I kind of see a much more flattened hierarchy […] and everyone’s opinion is equally valid […] But of course, lots of psychiatrists see it as a threat.’

A few participants felt the **service user being a member of a minoritised group** influenced participants’ and teams’ responses to concerns. Some participants were aware of the research regarding the disparities in the treatment of Black service users with psychosis-related diagnoses. This awareness made Participant 12 more likely to offer psychology. Participant 12 also reported observing ‘more depots and things like that with Black service users’. Participant 10 observed it being harder for service users and carers from minoritised ethnicities ‘to express any sort of disagreement’ to ‘all these White professionals making decisions’. Additionally, being from a ‘deprived background’ and having a ‘learning disability’ made it harder to challenge medication decisions as teams were more likely to question the service user’s ‘competence and capacity’ (P10).

Finally, participant **knowledge of medication** impacted how confident some participants felt to explore and raise concerns with service users and their teams.

> ‘And I think knowledge is what gives me the confidence to challenge in team situations.’ (P1)

Category F: Economic Climate and Societal Discourses

A number of participants discussed the wider impact of the economic climate which has resulted in ‘cuts in the NHS’ (P2). This had resulted in psycho-social interventions ‘disappearing’ (P2) and an increased focus on the biomedical model and medication as treatment. Some participants raised the issue of there being ‘no beds available’ (P2, 12) in hospitals. Participant 12 described therefore there is an increased pressure in teams to quickly stabilise service users:

> ‘…so we’re gonna put you on X amount of dose to like sedate you enough that you’re safe enough to be in the community. Whereas, if we had X amount of time and X amount of beds […] I don’t think psychiatrists, or our system, would give antipsychotics at the rate that they do.’

A few participants talked about how people who hear voices are stereotyped as ‘dangerous’ (P7) and ‘unpredictable’ (P12). This was ‘perpetuated by the media’ (P7) and described to cause public anxiety. Serious incident investigations were described as ‘punitive’ (P6) and created anxiety in the system which can lead to more coercive behaviour to service users by staff. The ‘pharmaceutical industry’ (P2, 8) was described to be ‘worth a lot of money’ and hold a great deal of power over the narrative that ‘medication is the thing that people need’ (P8). Participant 6 described how ‘our role’ in mental health settings ‘almost becomes less about the client and more about the public and the public reassurance, and medication and antipsychotics seem to do that.’

Discussion

The model produced is broadly consistent with Triandis' (1980) Theory of Interpersonal Behaviour (TIB). For example, the TIB process of perceived consequences affecting intention to perform an action is reflected within the sub-category 'Not wanting to be divisive', which found many participants' view of negatively impacting working relationships prevented them from being more challenging of medication decisions.

There are, however, dimensions which are absent in TIB, such as the power dynamics and hierarchies seen as limiting the extent to which participants could make changes. This finding is supported by previous research which found team leaders in CMHTs, who are likely to be psychiatrists, could facilitate or actively block the implementation of a recovery focused approach (Leamy et al., 2015).

Another element of the current model not in TIB (at least as viewed from a psychologist decision-making perspective) is the impact of the responsibility of short-term (as opposed to longer-term) risk and pressure of being a responsible clinician. This supports existing research which found concerns about risk and 'relapse' caused psychiatrists to be reluctant to reduce or discontinue medication (e.g. Cooper et al., 2019). The New Ways of Working for Everyone Report (National Institute for Mental Health in England, 2007) attempted to address the issue of psychiatrists holding clinical responsibility by recommending services implement distributed leadership, whereby responsibility and clinical decisions are shared amongst the team and not a single individual. However, the findings of the present study may reflect that psychiatrists continue to have legal responsibility which may have a powerful counter-effect to any attempt at making decisions truly shared.

As alluded to above, this study also shed light on how most teams and doctors prioritised managing short-term risk and lacked consideration of the risk of taking medication long-term, or the potential reward of not doing so. The tendency of humans to discount the value of future rewards relative to ones immediately available has been reflected in previous research (Berns et al., 2007). Cuing individuals to imagine the future has been shown to shift preferences towards delayed rewards (e.g. Schacter et al., 2017). Increased thinking in teams around the benefits of a service user not being on medication long-term may be beneficial.

Cooke et al.'s (2019) model of how psychologists managed dilemmas in a mental healthcare context has multiple similarities to this study. Both theories emphasise the benefits of having good working relationships and 'extra ammo', or 'allies' as referred to by Cooke et al. (2019), when challenging ideas. Cooke et al.'s (2019) three responses of conflict, compromise and collusion also appear to be reflected within the current model's 'Walking the tight rope'. 'Walking the tight rope', however, appears to be more dynamic and helps visualise the inner struggle about how to negotiate medication concerns. It also captured additional responses, such as empowering service users and carers.

An additional novel dimension was the number of different ways participants described under the category 'Observing coercion'. The findings cohere with other research suggesting service users are frequently being coerced into taking medication, being prescribed a combination of psychotropics, and being perceived to lack the competency to make treatment decisions (e.g. Thompson et al., 2020, Roberts et al., 2018 Mikesell et al., 2016).

Another notable concern observed by participants was the discrepancy between psychiatry and psychology's formulation of psychosis. This is discussed in an interview with Lucy Johnstone (Aftab & Johnstone, 2020) who emphasised the issue that:

> '…there is a crucial difference between what the DCP [Division of Clinical Psychology] Guidelines define as "'psychiatric formulation' as opposed to 'psychological formulation.'" The first might look something like "schizophrenia

> triggered by life stresses and bereavement," whereas the second might be summarized as "hearing hostile voices as a result of childhood sexual abuse."'

Johnstone (Aftab & Johnstone, 2020) further reflected how this discrepancy can be confusing for service users. This is consistent with the current study's findings of service users feeling 'stuck in the middle' of professional views.

Another service user outcome described by several participants included the deterioration of mental health following the withdrawal of medication. The suggestion this is due to withdrawal effects is supported by the literature: research has found the discontinuation of 'antipsychotics' can cause a range of severe and long-lasting adverse effects (Moncrieff, 2019). Moncrieff (2019) further echoes the current study's findings that withdrawal effects are often viewed by clinicians as the return of a symptom which can result in service users taking medication long-term.

'Economic climate and societal discourses' was an additional dimension unique to the produced model. The idea that mental health services manage public anxiety about psychosis is consistent with Vassilev and Pilgrim's (2007) assertion that social control is at the centre of the actions of mental health organisations and of the staff who work within them. The influence of pharmaceutical companies has been previously explored. For example, Mosher, Gosden and Beder (2013) presented evidence of drug companies' perpetuating narratives of 'schizophrenia' as a brain disease and promoting hyperbole about the dangerous intentions of untreated 'schizophrenia'.

Limitations

The study's sample size was relatively small. However, there was diversity in service settings, locations in the UK, and seniority. It is possible participants who chose to participate were more inclined to be critical of medication as a treatment for mental health difficulties.

However, an attempt was made to keep the wording of the study open to any concern about medication, and a few responses did concern denial of/too little medication. Snowball sampling can also mean people sharing similar views or concerns may have come forward, rather than individuals who had widely differing views from those already in the study.

As discussed in the methodology, prior assumptions will have played a role into the analysis. However, quality assurance methods were carried out to minimise and make transparent some potential biases (see methodology). The diary entry from 07.09.20 (Appendix I), for example, notes how I managed to ‘stick with’ a participant’s concern about service users not being on enough medication despite wanting to ‘move away… due to my assumption of medication is not helpful’.

Given the findings of the review by Childs (unpublished), which found being a member of a minoritised ethnicity can compound negative experiences of taking medication for psychosis-related diagnoses, it was surprising institutional racism and disparities in treatment did not come up more in participant responses. While the impact of ‘race’ and ethnicity was not the focus of this study, had specific questions enquiring about the influence been asked sooner in interviews participants might have commented on this more. However, the limited responses might have been due to the fact the majority of participants were White.

Ideally, further demographic information of participants’ ethnicity, age and gender would have been formally collected in order to have enhanced the situating of the sample. However, full information was collected about the professional role and service context of each of the participants.

Clinical Implications

This study highlights some dilemmas psychologists have about medication and is therefore important in its acknowledgement of how difficult it can be to negotiate these dilemmas, as represented by ‘Walking the tight rope’. This reinforces the need for the recent BPS guidelines ‘Enabling conversations with clients taking or withdrawing from prescribed psychiatric drugs’ (Rizq et al., 2020) available for psychological practitioners. Whilst some people have argued that prescription rights would be helpful, the aforementioned guidelines illustrate ways of having such conversations without needing such rights. The experience of the interviews as being beneficial to have a space to reflect indicates psychologists might benefit from having more dedicated spaces to think about medication concerns.

The category ‘observing coercion’ indicates the need for clearer information to be shared with service users about medication and its adverse effects to ensure service users have a fully informed choice. The findings also suggest there should be increased support for the withdrawal of medication.

To address hierarchies and power dynamics more services might benefit from training staff in an Open Dialogue approach (Seikkula, 2003) to help ensure the opinions of colleagues, service users, and key individuals in their social network are considered. Since findings indicate some psychiatrists can block service changes, close evaluation of the implementation of the approach may be necessary.

Organisations would benefit from exploring ways to make serious incident investigations feel less threatening. This might enable teams to take more positive risks with clients, rather than feel pressurised to prioritise short-term risk management over client choice. As alluded to earlier, cuing individuals to imagine the future may also shift preferences towards delayed rewards (e.g. Schacter et al., 2017), for example of keeping medication to a minimum and reducing as early as possible.

In line with previous research (Das-Munshi et al., 2018; Lawrence et al., 2021), the findings of the sub-category ‘service user being a member of a minoritised group’ included participant reports of Black service users being given more depots and experiencing increased difficulty challenging medication decisions compared to White service users. In light of this, teams might benefit from more training in cultural awareness and sensitivity, and in anti-racist practice. More widely available help for families from minoritised ethnic backgrounds to appeal treatment decisions would also seem advantageous.

Future Research

Given the similarities between the present findings and Cooke et al. (2019) and the small and potentially biased samples in both studies, there is a need for further research to test some of the theoretical principles in both models on larger and more diverse samples, perhaps operationalising some key concepts to determine more clearly when psychologists feel able to move to more open and successful challenging of medication decisions, and who they may find as allies. Research should also be directed at prescriber decision-making to determine the type of training that may enable them to take more positive risks in relation to prescribing, for example by bringing future pay-offs to mind (avoiding the risk of longer-term harm and shortened life) as well as competing short-term risks versus benefits of medication, such as the effect on people's ability to work towards valued goals such as those in the vocational sphere.

Conclusions

The study examined psychologists' responses to concerns about the medication of service users with psychosis-related diagnoses. The constructed model illustrated the way participants became concerned about medication, such as through observing coercion. Responses to concerns were identified, such as raising concerns directly with teams/doctors and empowering service users and carers to raise concerns. Participants' overall impression of negotiating how to respond felt like 'Walking the tight rope'; a balancing act between

taking a risk and gaining a benefit for the service user. Teams and/or doctors were experienced as either unwilling to make changes, or agreeing to swap, reduce, or withdraw medication. Consequently, service users’ experiences were described as either improving, not changing, or deteriorating. Participants felt this contributed to service users feeling either listened to or not heard, gaining agency or feeling powerless, and feeling stuck in the middle of professional views. Some contextual factors described as impacting concerns and how they were responded to were responsibility of risk, team hierarchy, the service user being a member of a minoritised group, and the economic climate. The results foreground the difficulty psychologists may experience when negotiating medication dilemmas. They also suggest the importance of ensuring treatment decisions are shared, that service users are supported to withdraw from medication, and that teams feel more able to take more positive risks in relation to prescribing.

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Section C: Appendices of Supporting Material

Appendix A: Critical Appraisal Skills Programme Qualitative Checklist

1. Was there a clear statement of the aims of the research?

2. Is a qualitative methodology appropriate?

3. Was the research design appropriate to address the aims of the research?

4. Was the recruitment strategy appropriate to the aims of the research?

5. Was the data collected in a way that addressed the research issue?

6. Has the relationship between researcher and participants been adequately considered?

7. Have ethical issues been taken into consideration?

8. Was the data analysis sufficiently rigorous?

9. Is there a clear statement of findings?

10. How valuable is the research?

Appendix B: Papers scored by CASP Quality Assessment Tool

	Greenwood et al. (2000)	Secker & Harding (2002)	Bowl (2007)	Chakraborty et al. (2009)	Weich et al. (2012)	Mfoafo-M'Carthy (2014)	Myers & Ziv (2016)	Wagstaff et al. (2018)	Tang (2019)	Tuffour et al. (2019)	Lawrence et al. (2021)
1.Was there a clear statement of the aims of the research? Consider; what was the goal of the research, why it was thought important, its relevance	2	2	2	2	2	2	2	2	2	2	2
2. Is a qualitative methodology appropriate? Consider; if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants, Is qualitative research the right methodology for addressing the research goal	2	2	2	2	2	2	2	2	2	2	2
3. Was the research design appropriate to address the aims of the research? Consider if the researcher has justified the research design	2	1	1	1	1	2	2	2	2	2	2
4. Was the recruitment strategy appropriate to the aims of the research? Consider: if the researcher has explained how the participants were selected, if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study, if there are any discussions around recruitment (e.g. why some people chose not to take part)	2	2	2	2	2	1	1	2	1	2	2
5. Was the data collected in a way that addressed the research issue? Consider; if the setting for the data collection was justified, if it is clear how data were collected, if the researcher has justified the methods chosen, if the researcher has made the methods explicit, if methods were modified during the study. If so, has the researcher explained how and why, if the form of data is clear, if the researcher has discussed saturation of data	2	1	1	2	2	2	1	1	2	1	1
6.Has the relationship between researcher and participants been adequately considered? Consider; if the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location, how the	2	0	2	2	0	2	0	1	0	2	2

researcher responded to events during the study and whether they considered the implications of any changes in the research design											
7. Have ethical issues been taken into consideration?	1	1	1	1	1	1	1	1	1	1	1
Consider, if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained, if the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study), if approval has been sought from the ethics committee											
8.Was the data analysis sufficiently rigorous?	2	2	1	2	1	1	1	2	2	2	2
Consider; if there is an in-depth description of the analysis process if thematic analysis is used, whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process, if sufficient data are presented to support the findings, to what extent contradictory data are taken into account, whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation											
9.Is there a clear statement of findings?	1	1	2	1	2	2	2	2	1	1	2
Consider; whether the findings are explicit, if there is adequate discussion of the evidence both for and against the researcher's arguments if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst), if the findings are discussed in relation to the original research question											
10. How valuable is the research?	2	2	2	1	2	2	2	1	1	2	2
Consider; if the researcher discusses the contribution the study makes to existing knowledge or understanding, if they identify new areas where research is necessary, if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used											
Total score:	18	14	16	16	15	17	14	16	14	17	18

Note. The following scoring was applied; 2 = yes, 1 = somewhat, 0 = no/can't tell

Appendix C: Example Quotations Evidencing Theme Development

Below are some example quotations supporting the theme development.

Themes	Example Quotes
1.Medication Helping versus Negative Effects	‘Those who found medication helpful considered it useful in maintaining daily life (Rosie, female, 31) …(Tang, 2019) ‘In addition to medication compliance and the improved ability to get along with others, some of the participants discussed the importance of the treatment associated with the CTO: the CTO stabilized their condition.’ (Mfoafo-M’Carthy, 2014) ‘He experienced its iatrogenic effects as disabling: Kevin: Taking it makes you feel like … becoming another person. You feel like time flies very slowly… I cannot concentrate. I felt like I was ‘woolly headed’, deprived of all kinds of emotion.’ (Tang, 2019) ‘There was a wealth of material from both service users and carers, across all ethnic groups, about the side effects of medication. At best medication was cited as a necessary evil, at worst the cause of considerable additional problems.’ (Weich et al. 2012) ‘On other days, the same man might be on such high doses of antipsychotic medications that we watched him fight to keep his eyes from rolling back in his head.’ (Myers & Ziv, 2016)
2.Coercion	
i)Lack of Information Provided on Medication	‘Many complained that information has been rarely forthcoming. ‘I didn’t know what I was taking, they didn’t explain to me what was wrong with me, then they had meetings, but they didn’t have meetings with me involved in there, so I didn’t really understand why I was there. But the medication, I don’t know, I don’t know what it was for.’ (Lawrence et al., 2021) ‘However, as with other issues related to their care, the participants either did not understand the purpose of medication or appreciate its role from the professional’s perspective.’ (Wagstaff et al., 2018) ‘….nor did participants feel that they were told enough about either their medication.’ (Bowl, 2007)

	‘Martin went to his GP for severe headache and was prescribed anti-psychotics without explanation. He was angry and reported feeling ‘tricked’ into starting a course of psychiatric medication without being given proper information to make an informed decision.’ (Tang, 2019)
	‘A failure to appear to listen to these concerns and to impart adequate information contributed to service users’ and carers’ frustration with professionals.’ (Weich et al., 2012)
ii)Lack Autonomy and Power	‘Participants often felt powerless, forced to take medication against their will and unable to make their concerns heard.’ (Lawrence et al., 2021).
	‘Rebel felt he was not listened to when he tried to influence the dose of depot medication he was receiving. This subsequently impacted on his experience of taking the medication: I used to communicate to them to say that I wouldn’t like that, in other words, ‘Don’t give it me’. But they insist … participants felt that they had little choice in the process of being treated by mental health services.’ (Lawrence et al., 2021)
	‘One consequence of this was the resounding sense among many of the black Caribbean participants that medication and their diagnosis were imposed on them, the latter often incongruent with their own social model of their condition (see below), confirming negative expectations and exacerbating feelings of powerlessness.’ (Lawrence et al., 2021)
	‘Some participants reported that they were being coerced into taking medication.’ (Tuffour et al., 2019)
	‘James was told that he needed to take medications for the rest of his life, regardless of how he felt about them or how they made him feel.’ (Myers & Ziv, 2016)
	‘Sometimes I do (sic) (take medication for the sake of) my son, because they told me, if I don’t take the medication, Children’s Aid might take my son, you know, I might lose my son.’ (Mfoafo-M’Carhty, 2014)
	‘Some participants experienced their processes of prescription and finding the right medication as a deprivation of agency.’ (Tang, 2019)

iv)Forcible administration	‘There is particular animosity reserved for depot medication and this animosity is not only from the experience of being under the influence of the medication but also the physical process by which the injections are administered: Josh: ‘Sticking the needle and dropping my trousers and looking at my arsehole and all that’.’ (Wagstaff et al., 2018) ‘For example, Jane reported that getting a depot injection on the ward is something she has ‘to go along’ with: Sometimes when you’re here and you don’t want the injection you feel as if you just have got to go along. (Jane) Jane’s account suggests that she feels trapped into taking her medication. The impression is that she feels trapped on the ward, and that she must act as an obedient hostage by complying with her depot injection, something she fundamentally disdains, to secure her freedom.’ (Tuffour et al., 2019) ‘I know it sounds a bit, uh, it sounds a bit kind of not right but I think it was that racist motive that they wanted to make people suffer, some of the nurses, and they used to come along and drag you from the dinner table, about six of them, just pick you up and drag you. . . hands and everything, you know, your hands and arms would be all over in the air, and they’d be dragging you down the corridor and then take you into a room and hold you down and inject you.’ (Secker & Harding, 2002) ‘Jade related unfair medical treatment to her skin colour: Jade: ‘…and I said “No, I’m not moving. I’m quite comfortable here” and the next minute there’s three of them grabbing me, [they] took me to the room and gave me an injection… So I was obviously some danger to them.’ AC: ‘Why do you think that they did that?’ Jade: ‘I think that they just thought: “She’s not gonna do what we say, so we’re gonna hold her down”, judging me by my skin-colour. I think it must definitely come into it. ‘Cos on TV it’s always “black mad-man” or “black madwoman” kills passer-by… I think they’ve got this basic form that they judge people by and it’s not right.’ (Chakraborty et al., 2009)
3.“They’re quite happy to just hand out pills”	‘More specifically, they reported that they were not offered talk therapy or counselling while on the CTO, which they would have preferred to seeing a psychiatrist and/or taking medication.’ (Mfoafo-M’Carthy, 2014) ‘Variously, the participants reported that all mental health services offer is medication.’ (Wagstaff et al., 2018)

	‘In most cases, the problems described revolved around a lack of access to ‘talking treatments’ coupled with a reliance on medication alone. For example: I asked to see a psychologist and they point blank refused to let me see a psychologist at any time at all.’ (Secker & Harding, 2002) ‘Medication was the first and often the only treatment offered when they first engaged with mental health services. Some expressed the wish to have more options presented and available to them (e.g., talking therapy).’ (Tang, 2019)
4.Surrender versus Disengaging	‘There is nothing I can do about the side-effects. I think all medications have got side-effects. There is nothing I can do. (Asana) There is an indication of resignation and pragmatism in the comment above. It appears that Asana has given up and there is nothing she can do to stop the side effects that come with her medication.’ (Tuffour et al., 2019) ‘Mark also speaks of surrender: Surrendering to “the routine” that made him miserable. He felt isolated and weak and had trouble seeing a way forward.’ (Myers & Ziv, 2016) ‘Josh said when he was asked if he had ever disengaged, ... well it’s not my choice you know. I ain’t got a choice because I got, if the mental health people come with me or come to give me medication, I take it, you know what I mean? But deep down I really don’t want it.’ (Wagstaff et al., 2018) ‘Almost all participants described episodes of reducing or stopping their medication in the community …This decision was typically taken independently of community mental health teams and presented as a rare opportunity for individuals to exert control over their illness. Val (BC) expressly stated that she took this decision herself as she felt that her doctor would dismiss her concerns. Frequently, however, this led to a worsening of symptoms and repeat hospital admissions, thereby having the perverse effect of diminishing individuals’ sense of agency. A handful of participants described their despair at being subject to a seeming unending cycle of psychotic episodes, medication, non-compliance and compulsory admissions.’ (Lawrence et al., 2021) ‘The doctor can only force me when I am in the hospital, but when I go home no one will force me to take the medication.’ (Tuffour et al., 2019)

5.The Need for Cultural Understandings Alongside Medication	‘Some Muslim service users consulted a Mowlana (a respected Muslim religious leader) or other healers in parallel with medical treatments (whereas no White British, African Caribbean, Black African or Caribbean participants spoke of seeking alternative help).’ (Weich et al., 2012) ‘Then I started to pray as well…it did help as well; medication and prayer—both things together. Obviously with us praying a lot things got better but I thought it would never, never have helped. Medication yes—both things but I like to say medication first.’ (Weich et al., 2012) ‘Where culturally specific explanations were given, treatment necessitated religious healing either alone or in conjunction with medication. Only two people mentioned black magic. It was clear that these participants preferred to apply both Western and Eastern models.’ (Greenwood et al., 2000) ‘Some patients still used traditional or religious healing but these were not discussed with staff. ‘I’d like to have both treatments - before I felt that the holy man only was great, now I see that he is not God. No, the medication and the holy man would be quicker.’’ (Greenwood et al., 2000) ‘She reported that two important turning points of her recovery were finding the right medication and finding Christianity, which helped her to clear her feeling of ‘disturbance by ghosts’. Two different explanatory frameworks based on a biomedical/scientific model and a spiritual model co-exist in Nui-xin’s narrative. (Tang, 2019)
6.Family Support versus Opposition to Medication	‘Enabling factors such as support from family members or the Chinese community centre staff were found to empower users to make decisions about taking medication.’ (Tang, 2019) ‘Kofi also described his initial reluctance in taking medications because of his own and his brother’s preconceived fears: Initially I found it very difficult taking medication because I think everyone has certain ideas about antidepressants and anti-psychotic medication. I just assumed that it will make me crazier or get hooked ... . Initially I was completely against it because my brother was quite negative and told me not to take them.’ (Tuffour et al., 2019)

	‘James’s family wanted him to take his medications regardless of whether they made him overweight, groggy, or stiff.’ (Weich et al., 2012)

Appendix D: Study information shared by BPS via Twitter and Facebook social media platforms

Message sent via Twitter:
Inviting clinical psychologists to take part in a study exploring concerns they have experienced about the medication of service user/s. Click link for more information
https://cccusocialsciences.az1.qualtrics.com/jfe/form/SV_elf4lrIjj7XR2Hr

Message sent via Facebook:
*******Inviting clinical psychologists to take part in a study exploring concerns they have experienced about the medication of service user/s.********

My name is Helen Childs and I am a trainee clinical psychologist at Canterbury Christ Church University. I'd like to invite you to take part in my study. It aims to explore how clinical psychologists respond when they experience concerns about the effect of a service user's medication.

The purpose is to build a model of these responses which we hope may increase the awareness of possible concerns.

I am inviting clinical psychologists who have worked with service users who are considered at risk of developing or have been diagnosed with a psychotic disorder (schizophrenia/psychosis/schizoaffective disorder) for a minimum of one year and have at some point experienced concerns about a service user's medication.

If you are interested in taking part, please click the link below and answer the very brief online screening questionnaire. This will ask some short questions about your work and what setting you currently work in. This questionnaire will be anonymous. At the end of the questionnaire, you can leave an email to be contacted on if you would be happy to be contacted to take part in a skype interview where you will be able to talk in-depth about your experience of concerns about service users' medication.

Many Thanks,
Helen Childs

Link: https://cccusocialsciences.az1.qualtrics.com/jfe/form/SV_elf4lrIjj7XR2Hr

Appendix E: Details of study circulated via email

**Inviting clinical psychologists to take part in a study exploring concerns they have experienced about the medication of service user/s.*******

My name is Helen Childs and I am a trainee clinical psychologist at Canterbury Christ Church University. I'd like to invite you to take part in my study. It aims to explore how clinical psychologists respond when they experience concerns about the effect of a service user's medication.

The purpose is to build a model of these responses which we hope may increase the awareness of possible concerns and lead to increased support for psychologists in their efforts to address these situations.

I am inviting clinical psychologists who have worked with service users who are considered at risk of developing or have been diagnosed with a psychotic disorder (schizophrenia/psychosis/schizoaffective disorder) for a minimum of one year and have at some point experienced concerns about a service user's medication.

If you are interested in taking part, please click the link below and answer the very brief online screening questionnaire. This will ask some short questions about your work and what setting you currently work in. This questionnaire will be anonymous. At the end of the questionnaire, you can leave an email to be contacted on if you would be happy to be contacted to take part in a skype interview where you will be able to talk in-depth about your experience of concerns about service users' medication.

Many Thanks,
Helen Childs
h.childs407@canterbury.ac.uk

LINK: https://cccusocialsciences.az1.qualtrics.com/jfe/form/SV_elf4lrIjj7XR2Hr

Appendix F: Initial Screening Questionnaire

Clinical psychologists’ concerns about clients' medication: an exploratory research study

My name is Helen Childs and I am a trainee clinical psychologist at Canterbury Christ Church University. I’d like to invite you to take part in my study. It aims to explore how clinical psychologists respond when they experience concerns about the effect of a service user’s medication.

The purpose is to build a model of these responses which we hope may increase the awareness of possible concerns and lead to increased support for psychologists in their efforts to address these situations.

I am inviting clinical psychologists who have worked with service users who are considered at risk of developing or have been diagnosed with a psychotic disorder (schizophrenia/psychosis/schizoaffective disorder) for a minimum of one year and have at some point experienced concerns about a service user’s medication.

If you are interested in taking part, please click the link below and answer the very brief online screening questionnaire. This will ask some short questions about your work and what setting you currently work in. This questionnaire will be anonymous. At the end of the questionnaire, you can leave an email to be contacted on if you would be happy to be contacted to take part in an online interview where you will be able to talk in-depth about your experience of concerns about service users’ medication.

Many Thanks,
Helen Childs

1) Have you had a concern about a service user’s medication within the last 12 months?
2) What was the nature of your concern?
3)How long have you been a qualified clinical psychologist?
4) What type of setting do you currently work in? e.g. CMHT
5) How long have you been working in this setting?
6) What type of clients do you see?
7) Are you full time or part time?
8) What sort of therapeutic work do you do with your clients?
9)How do you find out about the study?
10)Would you be willing to have an hour-long interview with me about your work if you are contacted?
11) If you are happy to take part in the study please leave an email address for me to contact you on
12) In the case you are not contacted for an interview, but have registered your interest to take part, would you like to receive a summary of the findings? Alternatively you can email me requesting the summary if you wish. My email is provided on the following page.

Appendix G: Information Sheet

Information about the research

Medication Concerns; a qualitative study looking at clinical psychologists' responses to concerns about service users' medication

Hello. My name is Helen Childs and I am a trainee clinical psychologist at Canterbury Christ Church University and lead researcher of this project. Supervisors of this project are;

- Dr Sue Holttum, CPsychol, AFBPsS, FHEA, Dip.AT. Senior Lecturer at Salomons Centre for Applied Psychology, Canterbury Christ Church University
- Dr Stephanie Phillips, Clinical Psychologist

We would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

Talk to others about the study if you wish.
(Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study).

What is the purpose of the study?
The aim of this study is to explore how clinical psychologists respond when they experience concerns about the effect of a service user's medication. The purpose is to build a model of these responses which we hope may increase the awareness of possible concerns and lead to increased support for psychologists in their efforts to address these situations.

Why have I been invited?
You have been invited to participate because you are a clinical psychologist who has worked with service users diagnosed with a psychotic disorder for a minimum of one year and has at some point experienced concerns about a service user's medication.

Do I have to take part?
It is up to you to decide whether to join the study. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?
You may be invited to take part in an interview that will take place over zoom with me, the primary researcher (Helen Childs). The interview will last up to one hour. You will be asked questions about what are the key concerns you have, or have had, about a service users' medication, an example/s of how you responded to a concern/s, what are the outcomes following on from those concerns and your responses, and what factors enable or inhibit you to discuss medication. The interviews will be audio-recorded so that I can accurately record what you say. There will be a space to discuss your experience of the interview process at the end, or there are other people you can contact if you would rather talk to someone other

than the researcher (see below). All of your experiences will remain anonymous and your data will be destroyed when no longer needed.

What are the possible disadvantages and risks of taking part?
Taking part requires personal reflection and could bring up emotive issues. You can share as much or as little as you like.

What are the possible benefits of taking part?
If you choose to take part in the study the opportunity for reflection can be experienced as beneficial for some participants. We cannot promise the study will help you, but we hope the findings will be used to offer better support for clinical psychologists in the future.

What if there is a problem?
Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

Will information from or about me from taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.

This completes part 1.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet
What will happen if I don't want to carry on with the study?
If you decide you do not want to take part, then you can withdraw at any point up to the submission of data at the end of the questionnaire. After this point data will be non-retrievable.

Concerns and Complaints
If you have a concern about any aspect of this study, you should ask to speak to me (Helen Childs) and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for Helen Childs and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology –fergal.jones@canterbury.ac.uk

Will information from or about me from taking part in the study be kept confidential?
Anything you tell the researcher will be kept strictly confidential and your name and any other identifiable details will be removed. These data will be kept on a secure, password protected memory stick and stored on password protected computers during the course of the project. Interview audio recordings will be destroyed at the end of project. After completion of the project the anonymised transcripts of the recordings will be kept for 10 years and stored in the Canterbury Christ Church University office in a locked cabinet. After 10 years this data will be disposed of securely.

The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become concerned about your safety or the safety of someone else. You have the right to check the accuracy of data held about yourself and correct any errors.

As part of the data analysis, an annoymised transcript of your interview will be read and coded by a trainee colleague who is also on the Salomons course.

What will happen to the results of the research study?
The write-up of this study will be examined as partial qualification for the Doctorate in Clinical Psychology. A paper will then be submitted for publication in a psychology journal. Anonymised quotes from your interview may be used in published reports. However, you will not be identified in any publication.

Who is sponsoring and funding the research?
The research is being funded by Canterbury Christ Church University as partial qualification for the Doctorate in Clinical Psychology.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by The Salomons Ethics Panel (Salomons Institute for Applied Psychology, Canterbury Christ Church University).

Further information and contact details
If you would like to speak to me and find out more about the study of have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070 or email me: h.childs407@canterbury.ac.uk. Please say that the message is for me, Helen Childs, and leave a contact number so that I can get back to you.

Appendix H: Consent Form

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Ethics approval number: V:\075\Ethics\2019-20
Version number: 1
Participant Identification number for this study:

CONSENT FORM

Medication concerns; a qualitative study looking at clinical psychologists' responses to concerns about service users' medication

Name of Researcher: Helen Childs

Please initial box

1. I confirm that I have read and understand the information sheet for the study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐

5. I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings. ☐

6. I agree for my anonymous data to be used in further research studies. ☐

7. I agree to take part in the above study. ☐

Name of Participant____________________ Date________________

Signature ___________________

Name of Person taking consent ______________ Date_____________

Signature ____________________

Appendix I: End of Study Report

Dear Participant,

Re: 'Walking the tight rope': a qualitative study looking at clinical psychologists' responses to concerns about service users' medication

Thank you for taking part in the above study. I am writing to inform you that I have now completed the research. Please find below a brief summary. If you would like to be emailed a copy of the full report, please let me know.

Objective

There is a growing body of evidence regarding the potential harmful effects of 'antipsychotics', which are the recommended primary treatment for psychosis-related diagnoses in Western countries. Concerns have also been raised about the overreliance of 'antipsychotics'. This includes issues with polypharmacy (being prescribed more than one psychotropic medication at one time) and clinicians being reluctant to reduce or discontinue medication due to concerns over risk and 'relapse' (Cooper et al., 2019; Roberts et al., 2018). Furthermore, despite NICE (2014) guidelines stating 'antipsychotic' medication decisions should be made by service user and healthcare professional together, evidence suggests shared decision making is seemingly not routinely used or effective.

Psychologists are possibly meeting some service users more frequently than prescribing psychiatrists and therefore might have more opportunities to become aware of medication being problematic. This inevitably might cause dilemmas for psychologists in knowing how to respond. The study sought to build a grounded theory about how psychologists respond when they become concerned about medication. The following specific questions were posed in relation to a sample of psychologists who have ever felt concern about a service user's medication:

e. In what ways do participants describe becoming aware that medication may be problematic?

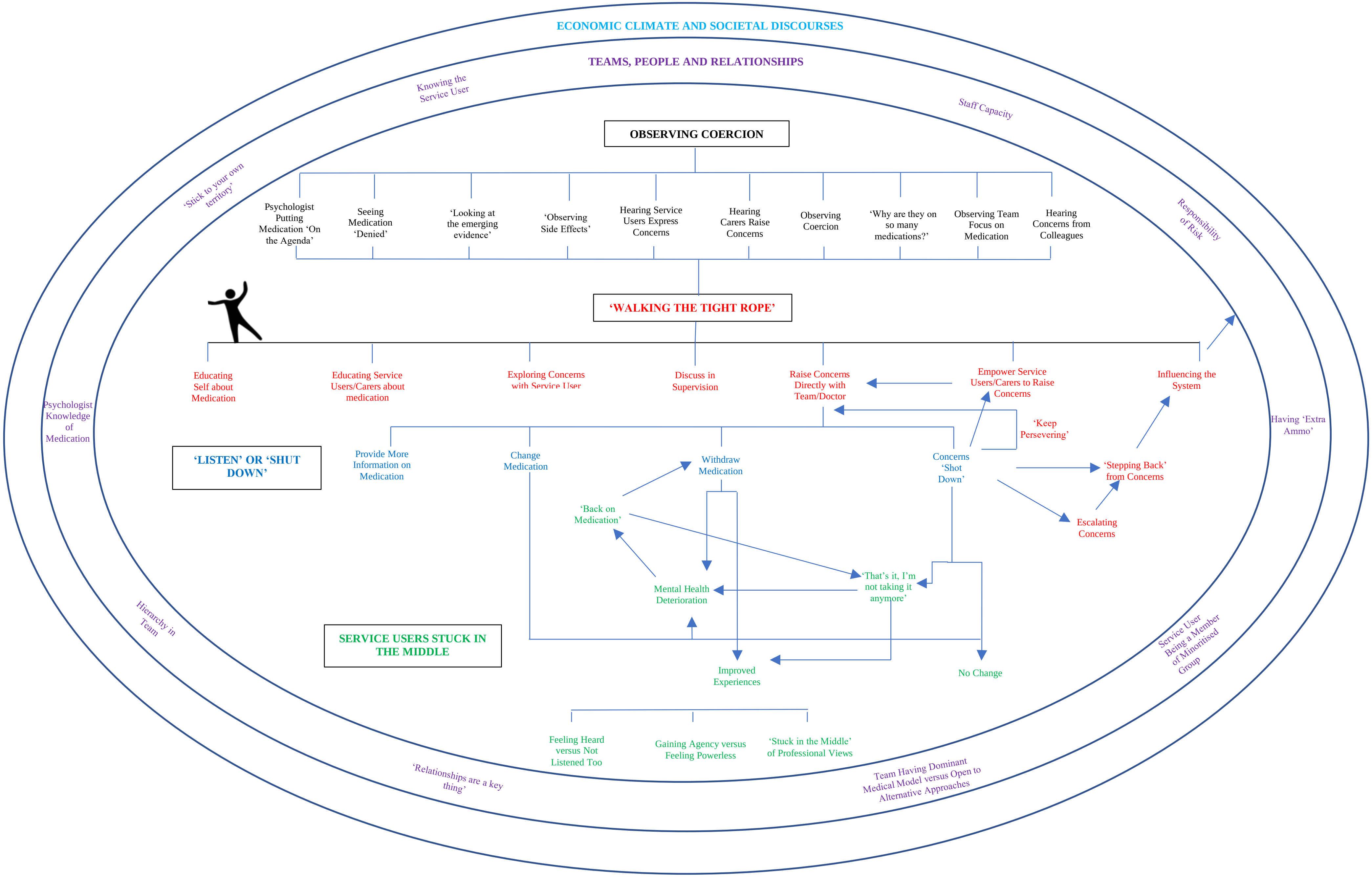
f. When they have concerns about their client's medication how do they respond to these concerns?
g. What outcomes do participants describe following on from those concerns and from their responses?
h. What factors do participants feel enable or inhibit them in discussing medication with their clients and with their team?

Method

This study utilised a qualitative, interview-based design, guided by an abbreviated critical realist grounded theory. Twelve clinical psychologists working with individuals given a psychosis-related diagnoses, across a range of service settings, participated in semi-structured interviews via Zoom or telephone. Data were analysed following an abbreviated version of Corbin and Strauss' (2008) grounded theory approach.

Findings

The final constructed grounded theory model identified 43 sub-categories organised within six main categories: Observing Coercion; 'Walking the Tight Rope'; 'Listen' or 'Shut Down'; Service Users 'Stuck in the Middle'; Teams, People and Relationships; Economic Climate and Societal Discourses. This can be viewed in the figure below.


ECONOMIC CLIMATE AND SOCIETAL DISCOURSES
TEAMS, PEOPLE AND RELATIONSHIPS
Knowing the Service User
Staff Capacity
'Stick to your own territory'
Responsibility of Risk
OBSERVING COERCION
Psychologist Putting Medication 'On the Agenda'
Seeing Medication 'Denied'
'Looking at the emerging evidence'
'Observing Side Effects'
Hearing Service Users Express Concerns
Hearing Carers Raise Concerns
Observing Coercion
'Why are they on so many medications?'
Observing Team Focus on Medication
Hearing Concerns from Colleagues
'WALKING THE TIGHT ROPE'
Educating Self about Medication
Educating Service Users/Carers about medication
Exploring Concerns with Service User
Discuss in Supervision
Raise Concerns Directly with Team/Doctor
Empower Service Users/Carers to Raise Concerns
Influencing the System
'Keep Persevering'
Psychologist Knowledge of Medication
Having 'Extra Ammo'
'LISTEN' OR 'SHUT DOWN'
Provide More Information on Medication
Change Medication
Withdraw Medication
Concerns 'Shot Down'
'Stepping Back' from Concerns
Escalating Concerns
'Back on Medication'
'That's it, I'm not taking it anymore'
Mental Health Deterioration
Hierarchy in Team
SERVICE USERS STUCK IN THE MIDDLE
Improved Experiences
No Change
Service User Being a Member of Minoritised Group
Feeling Heard versus Not Listened Too
Gaining Agency versus Feeling Powerless
'Stuck in the Middle' of Professional Views
'Relationships are a key thing'
Team Having Dominant Medical Model versus Open to Alternative Approaches

The above constructed model illustrates the way participants described becoming concerned about medication, such as through observing coercion and adverse effects, hearing concerns from carers, service users and colleagues, observing polypharmacy, and seeing medication denied. Participants' responses to concerns were identified, such as raising concerns directly with teams/doctors, empowering service users and carers to raise concerns, educating service users/carers about medication, and discussing concerns in supervision. Participants' overall impression of negotiating how to respond felt like 'Walking the tight rope'; a balancing act between taking a risk and gaining a benefit for the service user. Teams and/or doctors were experienced as either unwilling to make changes, or agreeing to swap, reduce, or withdraw medication. Consequently, service users' experiences were described as either improving, not changing, or deteriorating. Participants felt this contributed to service users feeling either listened to or not heard, gaining agency or feeling powerless, and feeling stuck in the middle of professional views. Many contextual factors were described as impacting concerns and how they were responded to (illustrated by the outer circles of the model). This included responsibility of risk, team hierarchy, the service user being a member of a minoritised group, the openness of the psychiatrist, staff capacity, participant knowledge of medication, having colleagues in agreement with your concerns, and the economic climate.

Clinical Implications

This study highlights some dilemmas psychologists have about medication and is therefore important in its acknowledgement of how difficult it can be to negotiate these dilemmas, as represented by 'Walking the tight rope'. This reinforces the need for the recent BPS guidelines 'Enabling conversations with clients taking or withdrawing from prescribed psychiatric drugs' (Rizq et al., 2020) available for psychological practitioners. The category 'observing coercion' indicates the need for clearer information to be shared with service users about medication and its adverse effects to ensure service users have a fully informed choice. The findings also suggest there should be increased support for the withdrawal of medication. To address hierarchies and power dynamics more services might benefit from training staff in an Open Dialogue approach (Seikkula, 2003) to help ensure the opinions of colleagues, service users, and key individuals in their social network are considered. Organisations would benefit from exploring ways to make serious incident investigations feel less threatening. This might enable teams to take more positive risks with clients, rather than feel pressurised to prioritise short-term risk management over client choice.

Research Implications

Research implications were also identified. There is a need for further research to test some of the theoretical principles in the model on larger and more diverse samples, perhaps operationalising some key concepts to determine more clearly when psychologists feel able to move to more open and successful challenging of medication decisions, and who they may find as allies. Research should also be directed at prescriber decision-making to determine the type of training that may enable them to take more positive risks in relation to prescribing.

Dissemination

The study is planned to be submitted for publication in Psychosis: Psychological, Social and Integrative Approaches.

Please do get in touch if you would like a copy of the full report.

Yours sincerely,
Helen Childs
Trainee Clinical Psychologist

Appendix J: Interview Schedule

Below is the first version of the interview schedule:

a) When did you first start to experience a concern about a service user's medication?

b) What are the key concerns you have or have had about a service user's medication?

c) How does it come to your attention that that a service user's psychotropic medication is problematic?

Possible modifications (in light of answers to the questions a and b)

- *You mentioned… Are there other ways in which it has come to your attention that the psychotropic medication is problematic?*

d) Could you tell me about a specific situation where you became aware that medication could be problematic?

Prompts (to bring story to come to natural conclusion):

- *Could you tell me more about that? How did you become aware/become concerned?*
- *What was it about …. That made you …. ?*
- *How did things play out in that particular situation?*
- *What happened next?*
- *What did you feel like you were able to do?*
- *What did you feel like you were not able to do?*
- *What was your sense of how the service user experienced the situation?*

e) Have there been other situations where you have felt concerns?

Prompts:

- *Tell me more?*
- *What happened next?*

f) Are there situations where you feel more able to discuss concerns about a client's medication?

Prompts:

- *What makes it easier for you to address these concerns?*

g) Are there situations where you feel/have felt less able to discuss concerns about a client's medication?

Prompts:

- *What do you see as the barriers to addressing your concerns?*

If applicable in light of question g)

h) How do you manage your concerns when you feel they are not being heard?

Possible question in light of h)

If they have described a really good way of dealing with things, note that it seems really good practice and that many others may not feel able to do that and ask how they manage it

h) Do you have a sense of what processes could be like for service users in your service if they were really well designed around their needs? Would something have to change, and if so, what?

i) Is there anything else you would like to say about this issue?

[Switch off recorder]
Thanks
Debrief –
I am aware that the issue we have discussed can tap into conflicted or difficult feelings. So I would like to check with you what it has been like to discuss this issue?
Are you left with any concerns about your experiences that you think might stay with you after the interview or might prompt you to seek advice [e.g. whether you might want to seek some way of acting on a concern?] [If yes] Do you have a sense of where you could seek advice or how you might voice a concern?
[Discuss options if they wish]

Appendix K: Example memos written after interviews and meetings with supervisors

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Appendix L: Excerpt from Initial Open Coded Transcript

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Appendix M: Example Memos written during coding

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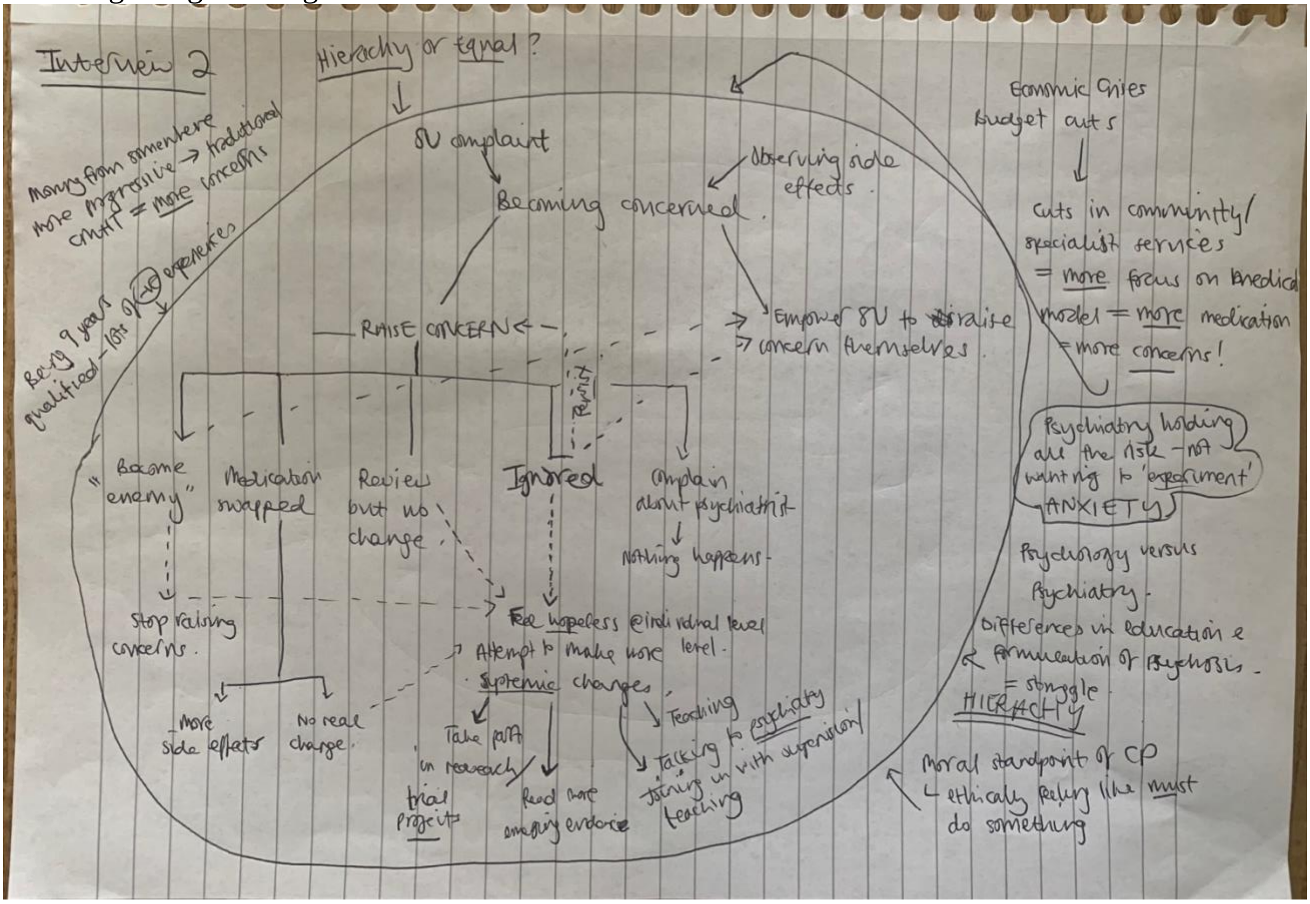
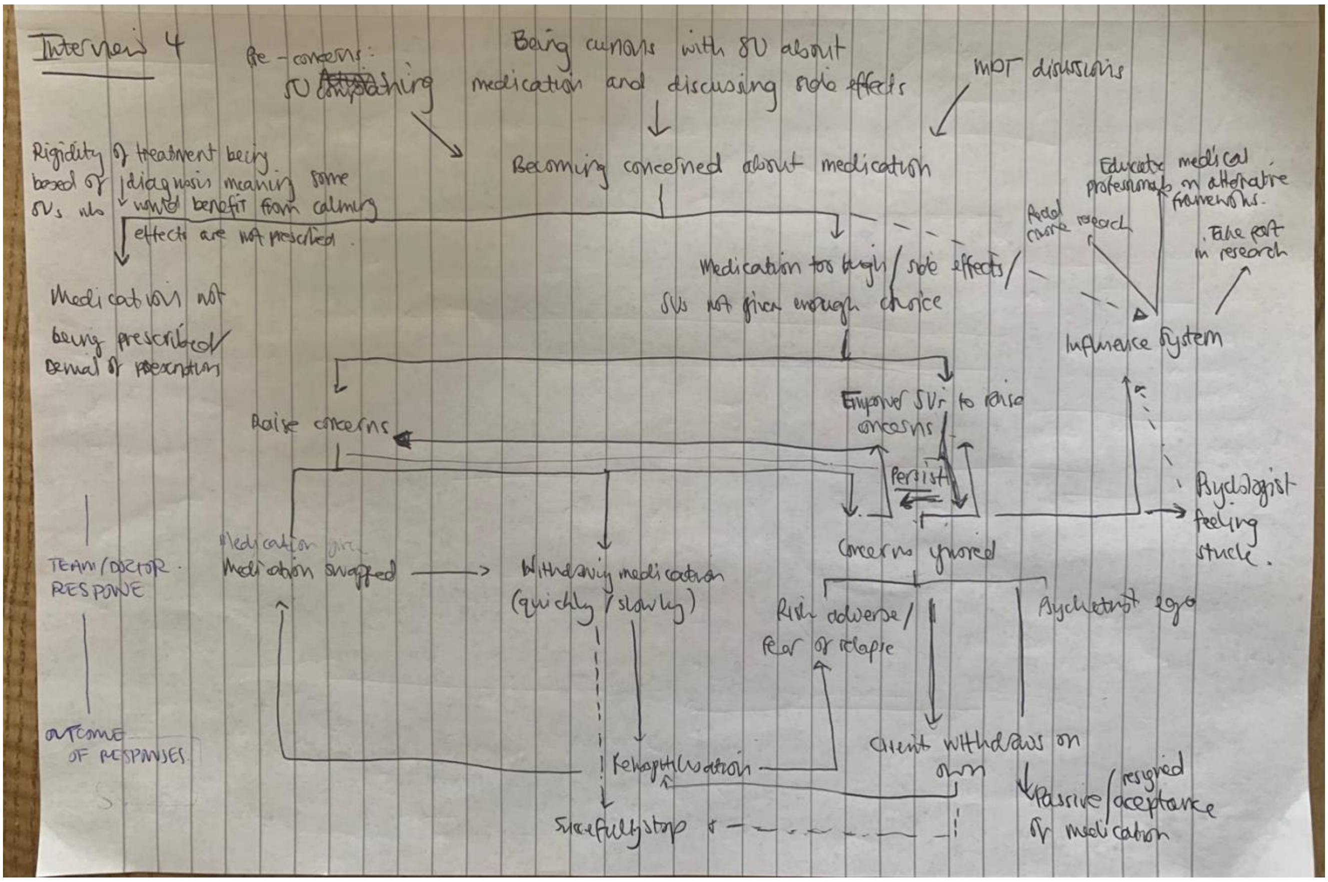
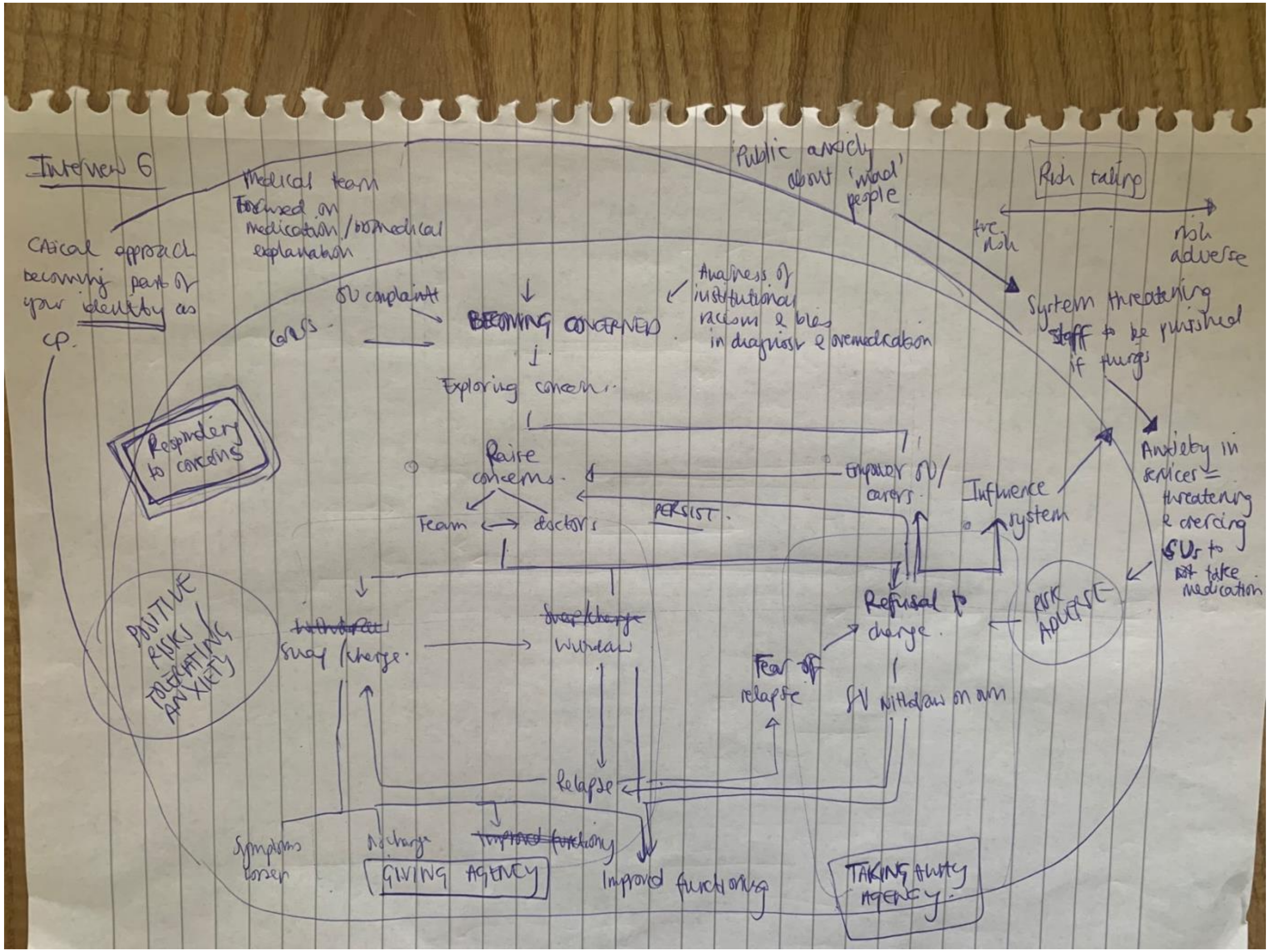
Appendix N: Examples of Theory Development through Diagramming

The following are some of example images which illustrate the development of the theory through diagramming.






Interview 6
Critical approach becoming part of your identity as CP.
Medical team focused on medication/biomedical explanation
Public anxiety about 'mad' people
Risk taking
+ve risk
risk adverse
System threatening staff to be punished if things
Anxiety in services = threatening & coercing SUs to ~~not~~ take medication
Awareness of institutional racism & bias in diagnosis & overmedication
SU complaint
Carers
~~BECOMING~~ CONCERNED
Exploring concern.
Responding to concerns
Raise concerns.
Empower SU/carers.
Influence system
PERSIST.
Team ⟷ doctors
~~Withdraw~~
Swap/change.
~~Swap/change~~
Withdraw
Refusal to change.
RISK ADVERSE
Fear of relapse
SU withdraw on own
POSITIVE RISKS/ TOLERATING ANXIETY
Relapse
Symptoms worsen
No change
~~Improved functioning~~
GIVING AGENCY
Improved functioning
TAKING AWAY AGENCY.

Appendix O: Anonymised copy of respondent validation response

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Appendix P: Ethical Approval

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Appendix Q: Information Page with Contact Details for Seeking Support

Included below is some information which offers some details for where to seek support should any current concerns be having an emotional impact, or whether you are seeking practical advice regarding what to do.

Whistleblowing

If you have a concern which feels serious because it might affect people receiving care, colleagues, or your whole organisation, you may wish to raise your concern to NHS England.

The following link takes to the NHS England website which sets out guidance on their whilsteblowing policy.

The guidance sets out:

- who can raise a concern
- the process for raising a concern
- how the concern will be investigated
- what will be done with the findings of the investigation

Website:
https://www.england.nhs.uk/ourwork/whistleblowing/raising-a-concern/

Employee Assistance Programme

If you are needing to talk over personal or professional issues you can contact your NHS trust's employee assistance programme. Programmes are usually a free, confidential service providing information, support and counselling. Details of how to get in contact should be found your trust intranet.

'Guidance for psychological therapists: Enabling conversations with clients taking or withdrawing from prescribed psychiatric drugs.' (Guy, Davies & Rizq, 2019)

The recently published paper aims to equip psychological therapists with the information and guidance necessary to help them better inform and support clients who are either taking or withdrawing from psychiatric drugs.