Stories of People of Colour on Stigma, Racism and Severe Mental Distress

By

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Abstract

This thesis presents a qualitative exploration of the experiences of persons of colour who carry the label of ‘schizophrenia,’ focusing on stigma, help-seeking behaviours, and the efficacy of anti-stigma campaigns. The research comprises four interconnected studies, all utilizing the Interpretative Phenomenological Analysis (IPA) method to delve deeply into participants' perspectives. This research explored individual experiences of persons of colour living with ‘schizophrenia,’ uncovering the complex nature of stigma through in-depth semi-structured interviews. Trauma, fear of racism, and cultural barriers emerged as prominent factors inhibiting mental health support-seeking. The qualitative approach enriches our understanding of the challenges faced by people of colour living with ‘schizophrenia.’

This research also explored relatives' perspectives of individuals who carry the label of ‘schizophrenia’ revealing the impact of stigma on help-seeking behaviours within the family context. Qualitative analysis of family narratives highlights the profound effects of stigma, shame, and discrimination on seeking support for loved ones. The study emphasizes addressing family needs in mental health interventions. Study three assesses the effectiveness of anti-stigma campaigns targeting mental health stigma related to ‘schizophrenia’ within persons of colour. Through qualitative methods, including participant interviews, the study unveils scepticism among persons of colour, perceiving campaigns as performative and disconnected from systemic issues.

Tailored campaigns resonating with diverse communities are underscored. Furthermore, the thesis studies innovative approaches to addressing mental health stigma, incorporating a focus group discussion and performance art piece within a community context. The qualitative analysis captures unique insights and audience responses to the performance. Creative qualitative methods contribute to understanding stigma and its effects on persons of colour with ‘schizophrenia.’

In conclusion, this thesis offers a qualitative exploration of stigma, help-seeking behaviours, and anti-stigma campaigns concerning ‘schizophrenia’ among persons of colour. Utilizing IPA in all studies delves deep into participants' lived experiences. Culturally sensitive interventions addressing multifaceted challenges faced by marginalized populations are highlighted in the thesis.

The research's implications extend to mental health service providers, policymakers, and campaign designers seeking to create inclusive and effective mental health support systems for diverse communities. Amplifying the voices of persons of colour with ‘schizophrenia’ contributes to a comprehensive understanding of mental health experiences within marginalized populations.

Table of contents

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Thesis outline

This thesis explores the stigma associated with mental health, particularly ‘schizophrenia,’ among people of colour, focusing on help-seeking behaviours, family perspectives, and the effectiveness of anti-stigma campaigns. Using a Critical Race Theory framework, the research addresses how systemic racism and stigma intersect and affect mental health experiences in marginalized communities.

The introduction provides an overview of the research context and rationale, emphasizing the need to explore mental health stigma among people of colour. It also discusses the terminology used throughout the thesis, especially the implications of diagnostic labels like 'schizophrenia.' The chapter delves into the relationship between stigma and mental health, the intersection of race and psychiatry, and critiques current anti-stigma campaigns. It concludes by identifying gaps in existing research and stating the aims and research questions of the study.

The literature review outlines the strategy used to conduct the review and synthesizes key findings on stigma and help-seeking behaviours among people of colour diagnosed with ‘schizophrenia.’ It also examines the subjective experiences of their relatives and evaluates the impact of anti-stigma campaigns on these communities. The review highlights significant gaps in the literature, which this thesis aims to fill.

The methodology chapter describes the theoretical framework, primarily Critical Race Theory, and discusses its application in the study. It addresses methodological debates, particularly the use of personal narratives, and outlines the research process, including data collection and analysis methods. The chapter also reflects on the researcher’s positionality and its influence on the research.

The findings are presented in three main chapters, each focusing on various aspects of the research. The first findings chapter explores experiences of help-seeking and 'schizophrenia,' identifying themes such as disowning internalized stigma, identity conflicts, and interactions with mental health systems. The second findings chapter examines family perspectives, discussing courtesy stigma, supportive behaviours, and overcoming systemic racism. The third findings chapter analyses anti-stigma campaigns, critiquing their limitations and highlighting successful community-driven approaches.

The discussion chapter integrates these findings, exploring the intersections of race and mental distress, power dynamics in accessing mental health services, and the importance of counter-stories and alternative narratives. It suggests advocacy and policy implications to improve mental health outcomes for people of colour.

Chapter 1: Introduction

This chapter sets the stage for the thesis by providing a comprehensive understanding of the critical debates and issues associated with this PhD research. Stigma, people of colour, and severe mental distress are complex phenomena that require a nuanced understanding to explore fully. Thus, this chapter will delve into the existing literature on the topic, identify key areas of controversy, and provide an overview of relevant theories and concepts. Moreover, the chapter will outline why research in this area is essential and how it can contribute to the field of mental health. Finally, this chapter will also present the research questions and problems the thesis aims to address and explain why these questions are essential.

Research context and rationale

Stigma associated with mental health labels, particularly 'schizophrenia,' remains a prevalent and challenging issue, disproportionately affecting people of colour (see Misra et al, 2021). Conventional views of stigma risk blaming individuals and communities for their afflictions and disadvantages rather than acknowledging the importance of structural and institutional racism (Kapadia, 2023). This thesis explores the nuanced interplay between stigma, race, and mental health, with a particular focus on help-seeking behaviours and the effectiveness of anti-stigma campaigns among persons of colour diagnosed with 'schizophrenia.' By critically analysing the experiences of both individuals diagnosed with ‘schizophrenia’ and their family members and applying frameworks such as Critical Race Theory and Mad Studies, this research aims to uncover the unique challenges faced by this population.

Inspired by my personal journey as a woman of colour, familial experiences with severe mental distress and my academic role as a researcher, I aim to shed light on the intersection of race, mental health, and stigma. Despite numerous anti-stigma campaigns, there is a notable lack of understanding about how these initiatives resonate with minoritised communities. This disconnect is compounded by the paradoxical framing of most institutional anti-stigma campaigns as if they address a problem for mostly white people, with relative neglect of black faces and experiences within the campaigns, or that stigma is rife in minority communities and that this may explain low voluntary uptake of services, rather than be due to institutional oppressions, and justify erroneously targeted anti-stigma campaigns focused on these communities (Kapadia, 2023), This can then be juxtaposed against the stark overrepresentation of racialised individuals with ‘schizophrenia’ and other diagnoses within services, where other well documented racialised anomalous treatment then ensues which is further associated with stigmatisation (Stowell-Smith & McKeown, 2001). Such misconceptions contribute to significant inequalities, including exclusion and discrimination within and beyond these communities. This research seeks to highlight the limitations of current anti-stigma efforts, propose alternative approaches, and contribute to the development of more inclusive and effective mental health policies and practices.

The language used throughout the thesis

Before delving into the introduction and literature review, it is vital to consider the language used throughout the thesis. Language and terminology are essential to academic study, especially in domains that focus on sensitive and complicated themes like mental health, race, and ethnicity. The choice of words and phrases used in research may have a substantial effect on how readers perceive and comprehend the findings, as well as on the experiences of the persons who are the subject of the study. Therefore, it is essential for researchers to thoroughly analyse and justify the language and terminology they employ in their study. In this thesis, I will explore the experiences of people from racial and ethnic groups that have historically experienced marginalisation and oppression, who carry the label of 'schizophrenia' and justify using specific phrases, such as ‘mental distress’ and people of colour. By offering openness and clarity on my use of language, I intend to contribute to a more nuanced and respectful understanding of these people's experiences and encourage more productive and empathic conversations around mental health and racial and ethnic inequalities.

Race and Ethnicity

Conceptualising the terms race and ethnicity is vital for researchers. Race and ethnicity are sometimes used interchangeably to represent a population of racialised minority backgrounds, even when the terms are not the same. Ethnicity is the encompassing common ancestry, shared beliefs, cultural traditions, religion, and language (Duello et al.

2021). Ethnicity can also be argued to be a social construct, and some have argued against the separation of race and ethnicity, instead of using a mutually exclusive single race/ethnicity variable (Flanagin et al 2021).

Within academic discourse, it is now widely accepted that the term race is contested and not based on assumed biological differences (see Miles, 2014). Typically, in the social sciences, the language of race has been superseded by notions of ethnicity, constructed on cultural differences and kinship (Gunaratnam, 2003; Husband, 1986; Solomos and Back; Miles and Brown, 2003). Ethnicity is multi-faceted, including appearance, subjective identification, and cultural and religious association (Bhui, 2002). Various writers use race and ethnicity without appreciating their fundamental meaning (Ratcliffe, 1994). This is especially true in common parlance, and whilst race lacks meaning as an anthropological or sociological category, the detriment and upset of racism in people's lives is starkly real. While race and ethnicity differ, overlapping concepts are often used interchangeably (Bhopal, 2004). However, the term race has been strongly contested, and there is little consensus about race. Over the years, the term race has been used to describe different social and biological categories of people, often based on physical or genetic characteristics such as skin colour or ancestry. However, in recent times, the term "race" has been subject to increased scrutiny and criticism due to its social, cultural, and political implications. One of the earliest scholars to argue that race is a social construct was the French philosopher and sociologist Émile Durkheim (1858-1917). Durkheim believed that race was a cultural concept rather than a biological one. It was constructed and maintained through social processes and interactions.

Since then, scholars such as Franz Boas and Ashley Montagu, sociologists like Du Bois and Oliver Cox, and critical race theorists like Derrick Bell and Kimberle Crenshaw have argued that race is a social construct used historically to justify and perpetuate inequality and discrimination. Discursively, contemporary notions of race can be seen to have roots in narratives that emerged in earlier centuries that operated to dehumanise African people subject to slavery and thus help to rationalise and justify inhumane treatment (Fanon, 1986). They contend that race categories are not based on objective biological differences between people but on social and cultural beliefs and practices. They have also emphasised the importance of recognising the intersectionality of identities and how race intersects with other social categories such as gender, class, and sexuality. Moreover, the concept of race has been challenged by genetics, showing more genetic variation within racial groups than between them (Goodman, 2019). Therefore, due to the contested nature of the term race, it is essential to use language that acknowledges the diversity and complexity of human identity and avoids reinforcing harmful stereotypes or perpetuating discrimination.

I will use the terms race and ethnicity judiciously throughout this thesis, reflecting awareness of the intricacies and ambiguities related to this terminology in academic discourse.

People of Colour

The participants in this thesis are referred to as people of colour. The term "people of colour" is commonly used in academic and social discourse to refer to individuals who are not White. It is a term that acknowledges and highlights the experiences of discrimination and marginalisation that people from non-White backgrounds have faced historically and continue to face today. Using the term people of colour serves to recognise the diversity and intersectionality of identities within this group, including their experiences with racism and discrimination, which individuals from a White heritage may not share. It is also a way of challenging the dominant and normative discourse that privileges Whiteness and reinforces the marginalisation of non-White individuals.

However, the term people of colour have been critiqued for potentially homogenizing diverse groups with distinct cultural and historical backgrounds (Aspinall, 2020). It is essential to note that language constantly evolves. It is crucial to highlight that this terminology is not without controversy, as some believe it might homogenise the experiences of varied minoritised ethnic groups and ignore the unique problems of each group. Despite this, the phrase people of colour are still commonly employed in social justice movements and literature to recognise and resist racial and ethnic injustices. It is important to note that preferences for terminology can vary among individuals and communities, so it is always advisable to be respectful and sensitive to individual preferences and cultural contexts (Starr, 2023). As such, it is crucial to be mindful and respectful of the language used and to take cues from the individuals themselves when possible. Therefore, it is essential to approach this descriptor with care and an understanding of its limits and to be receptive to input and criticism from others who may have differing viewpoints on its appropriateness.

While it is crucial to recognise and respect all individuals' identities and diverse experiences, regardless of race or ethnicity, using specific terms for clarity and consistency in certain circumstances, such as academic research, may be necessary. For instance, I may prefer to refer to the individuals in my research simply as "people" in my PhD thesis. However, because my research focuses explicitly on the experiences of individuals from minoritised groups. It may be necessary to use the term "people of colour" to convey the focus of my study accurately and effectively. Additionally, I will be referring to each individual by the ethnic background they identify with to respect their unique identities and experiences when discussing the findings, for example, ‘participant from a Black Caribbean background.’

'BAME'

Much of the mainstream anti-stigma campaigns were developed within a multiculturalism policy frame, using such descriptors as BME and the later BAME as catch-all acronyms for ethnic minority groupings. Black, Asian, Minority, and Ethnic (BAME) is an acronym for Black, Asian, Minority, and Ethnic. Though these have now been put aside in most official rhetoric (Aspinall, 2021), using such terms can persist as a matter of personal and cultural preference. I mention them here because of their deployment in policy and practice during the period of my study. It has been argued that the term "BAME" is a broad and oversimplified label that fails to capture the diversity and complexity of ethnicities and experiences of individuals from different ethnic backgrounds (Milner and Jumbe, 2020). While the term BAME can help highlight structural inequalities and discrimination faced by individuals from non-White backgrounds, it can also be problematic in perpetuating the idea of a homogeneous group of people who share the same experiences and challenges (Khunti, 2020). Commission on Race and Ethnic Disparities (2021) recommended that aggregated terms such as BAME should not be used.

The experiences of individuals from different ethnic groups are shaped by several factors, including their identities, cultural backgrounds, socioeconomic status, and historical and political contexts. For example, the experiences of a Black person of African descent in the UK may differ from those of a Black person of Caribbean descent or South Asian background. Therefore, avoiding broad labels that may obscure these differences is important. Instead, engaging in meaningful dialogue with individuals and communities on their terms and listening to their voices and experiences is essential to understand better the challenges they face and the support they need. Finally, critics argue that adopting exact ethnic background descriptors when discussing research results provides explicit ethnic background descriptions when explaining findings (Bradby, 2003). To maintain authenticity and prevent oversimplification, I have opted not to use the term BAME in my thesis.

Notwithstanding the dedication to employing alternative terminology, the utilization of terms such as BME (Black and Minority Ethnic) or BAME (Black, Asian, and Minority Ethnic) will be employed when explicating the works of other authors, where the specific context or scholarly discourse necessitates such reference. Current conflict over BAME terminology has sparked significant debate about its effectiveness and appropriateness in accurately representing diverse ethnic groups (Khunti, 2020). One of the issues of the term is that it is being used as a noun to substitute people's own racialised identities. This criticism still exists indeed when the distinctive letters in B.A.M.E. are spelled out but this at slightest recognizes that the term is made up of groups.

The ongoing debate surrounding the terminology used to describe ethnic minority groups in the UK reflects a broader societal shift towards more nuanced and respectful language. The term "BAME" (Black, Asian, and Minority Ethnic) has come under scrutiny in recent years due to its perceived shortcomings in accurately representing the diverse array of ethnic identities within its umbrella. Consequently, there has been a move away from its usage in official capacities, signalling a recognition of the need for more specific and contextually relevant terminology. In response to these criticisms, there has been a push for more disaggregated data collection and analysis, as well as a greater emphasis on using specific terminology that acknowledges the unique experiences of different ethnic groups. This shift reflects a growing awareness of the importance of language in shaping perceptions and understanding, as well as a recognition of the need to move away from outdated and potentially harmful terminology.

However, the debate over terminology is not without its complexities and challenges (DaCosta et al. 2021). Some argue that the rejection of terms like "BAME" could lead to a fragmentation of solidarity among ethnic minority groups, potentially undermining collective efforts to address systemic inequalities and discrimination. Others question the practicality of constantly evolving terminology, highlighting the difficulties of ensuring consistency and clarity in communication.

The rationale behind the debate over terminology reflects broader societal conversations about identity, representation, and inclusivity. While there may not be a consensus on the "correct" terminology to use, the discussion itself highlights the importance of critically examining the language we use to describe ourselves and others, and the impact that it can have on shaping our perceptions and experiences.

In this thesis, I engage critically with the ongoing debate surrounding the terminology used to describe individuals belonging to racial and ethnic minority groups. The terms "people of colour," "racialized," and "minoritized" are not merely descriptors but are imbued with significant socio-political implications.

The terms "racialized" and "minoritized" offer a critical perspective by highlighting the processes and structures through which certain groups are socially constructed and marginalized. "Racialized" emphasizes the active process of ascribing racial identities to individuals and groups, often leading to their systemic disadvantage. "Minoritized" similarly underscores the systemic and relational nature of minority status, focusing on the power dynamics that render certain groups subordinate within societal hierarchies (Garner, 2017).

By using these terms, I aim to contribute to the nuanced understanding of racial and ethnic identities within the context of mental health stigma and policy. This study acknowledges the importance of terminology in shaping public discourse, policy development, and the lived experiences of individuals. Therefore, my use of "people of colour," "racialized," and "minoritized" reflects a deliberate and critical engagement with the ongoing scholarly and activist debates about the most appropriate and impactful ways to describe and address racial and ethnic inequalities.

Navigating Language in Mental Health

This thesis concerns the intersection between ethnicity and madness, specifically people of colour who carry the label of ‘schizophrenia' and connected family members. Such, often identity-forming, language can be pervasive and become incorporated into the discourses and self-definitions of individuals and families, especially those extensively engaged in services. Furthermore, this goes for associated clinical terminology such as the overlapping catch-all terms, psychosis, and severe mental illness. However, from a critical perspective, such as mad studies, these diagnostic terms are hugely problematic and contested. As a result, establishing a meaningful lexicon for writing a critical thesis that also authentically reflects the voices of participants is challenging. Diagnostic terminology is employed in clinical and policy literature and can be seen to be explicitly and implicitly implicated in mainstream anti-stigma campaigns. For clarity, I attempt to navigate terminological dilemmas in this thesis by using terms as they are taken up in policy and literature or participant discourse. Nevertheless, in my analysis and discussion of policies and data, I will take up a more critical disposition to such language; indeed, this will become a central part of my critique of the failings of anti-stigma campaigns. Regardless of the language used in this thesis, the subjective nature of experience is acknowledged.

Although people of colour in the UK make up a smaller percentage of the population than White communities, their numbers are substantial[1]. There is significant heterogeneity of beliefs of, experiences and identities within groups. At the same time, there might be an overlap in the cultural traditions of these groups; for example, significant differences separate various cultures subsumed within such vast signifiers such as "Asian", "African", or "Chinese" and consequential problems associated with a lack of finesse or nuance in the deployment or application of such broad-brush categorical terminology are mirrored in lay usage and prejudicial vernacular. Such terminological detriments can also be seen in the deficiencies of psychiatric categorical taxonomies such as the DSM-5 (Jones, 2012). Considerations arising from this appreciation of the complexity of available terminology will be considered later in consideration of balancing focus and desirable

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[1] The 2021 census data records 18% of residents of England and Wales as ethnic minority (either black, Asian, mixed or other ethnic group). This is around 10.8 million people.

heterogeneity of participant samples. Whilst being concerned with the intersections between ethnicity and madness, it is also problematic to suggest that race and ethnicity might be dominant factors within an array of intersecting inequalities that beset individuals within the mental healthcare system.

'Schizophrenia': a key term in the mainstream

Within the psychiatric mainstream, according to the Diagnostic Statistical Manual (DSM) 5 (p.87, 2013), ‘schizophrenia’ is defined by “abnormalities in one or more of the following five domains: delusions, hallucinations, disorganised thinking (speech), grossly disorganised or abnormal motor behaviour (including catatonia) and negative symptoms”. Using this diagnostic approach, ‘schizophrenia’ affects 1% of the population worldwide (Pediaditakis and Durand, 2018). However, critics point to large numbers of individuals who may have experienced auditory hallucinations but remain unknown to services and live relatively unproblematic lives, suggesting these experiences may be best considered in a continuum of human experience rather than indicating a visible defined categorical boundary between illness and wellness (Escher & Romme, 2012).

The term 'schizophrenia' is a product of psychiatry, associated clinical literature, government policy, anti-stigma campaigns and, hence, the lives of people caught up in the mental health system. The symptoms grouped under this label are highly heterogeneous and can vary widely between individuals, and critics often prefer to speak of experiences rather than symptoms concerning a phenomenology of 'schizophrenia', 'psychosis' or altered states. Diagnosis is based on subjective evaluations of observed or reported behaviour and experiences rather than objective biological markers. Secondly, ‘schizophrenia’ has been associated with negative stereotypes and stigmatisation. People diagnosed with ‘schizophrenia’ are often viewed as dangerous, unpredictable, or incompetent, leading to discrimination and social exclusion. Therefore, using quotation marks around the term ‘schizophrenia’ can serve as a reminder that the label is not an objective or neutral description of a specific medical condition but rather a socially constructed category that reflects the values, assumptions, and power relations of the society in which it is used.

Despite critical objections, a meaningful critique must at least occasionally name the objects of critique. Hence, in this thesis, the term 'schizophrenia' is written in quotation marks. This is to indicate a critical stance towards this diagnostic label but to be clear about what is spoken about in the mainstream and, where appropriate, accurately depict participants' language. It would be surprising that people inducted into the psychiatric system and their families were not to reflect pervasive psychiatric terminology in their own speech and thinking, including when they talk about stigma, even in instances where they reject the application of a category or label or link experiences of stigma to that label.

There are several other reasons for adopting a critical disposition to the term ‘schizophrenia,’ and such critique has a lengthy heritage and is more broadly based than the specific standpoints taken up within mad studies. Firstly, ‘schizophrenia’ has been criticised for lacking precision and scientific validity (Mesholam-Gately et al., 2021); effectively, the terminology fails on its terms to define a valid and distinct category of 'mental disorder'. Due to the widespread use of ‘schizophrenia’ and "psychosis" as terms in a significant portion of existing literature, this can be difficult to escape for researchers and commentators wishing to be published in the mainstream. Indeed, many, even critically minded scholars, find it difficult to deploy alternative language/categories within studies that are framed to challenge simplistic aspects of categorical taxonomies or perceived inadequacies of bio psychiatry. In this sense, the terminology must be wielded to marshal a critique. See, for example, the published work of Richard Bentall, an early and consistent critic of the imprecision and other failings of the construct 'schizophrenia', who, often, uses the term and available psychometric tools liberally in his published output (e.g. Bentall, 2021).

'Madness/Mental Distress'

Mad Studies is an interdisciplinary field that critically examines mental health and societal responses to mental health issues (Lefrancois et al. 2013). In Mad Studies, "madness" is understood as a socially constructed and politically charged term that encompasses experiences and behaviours deviating from societal norms. It challenges the pathologizing perspectives of traditional psychiatry and seeks to validate the lived experiences of those labelled as "mad." This approach emphasises the impact of societal, cultural, and economic factors on mental health and advocates for the recognition of diverse mental states as part of the human condition rather than as disorders to be eradicated. Mental distress refers to the wide range of emotional and psychological struggles individuals face (Timander et al, 2015). Rather than viewing these experiences solely as symptoms of a medical condition, Mad Studies considers them as responses to various life circumstances, including trauma, oppression, and societal pressures. It highlights the importance of understanding mental distress through a holistic and humanistic lens, advocating for supportive and non-coercive approaches to care. Mad Studies encourages a shift from viewing mental health issues purely through a biomedical lens to considering the broader socio-political contexts that shape individuals' experiences of madness and mental distress.

The term "madness" has been used in critical mental health literature to challenge traditional psychiatric models of understanding mental health and illness. Scholars argue that "madness" can describe experiences outside the normative bounds of mental health and illness (Rashed, 2019). This can be a helpful way of challenging the dominant biomedical model of mental health. However, it is essential to note that the term "madness" can also be stigmatizing and pathologizing, mainly when used to reinforce negative stereotypes about mental health conditions. As such, some critical mental health scholars prefer to use other terms, such as "mental distress", to describe experiences not easily captured by traditional diagnostic categories.

Despite the appeal of mad studies to me as a researcher and aspiring policy critic, many people who use services, family members, or people who work in services, including certain critically minded practitioners, can be variously ill-disposed to the language of madness as a blunt substitute (Beresford, 2020).

Nevertheless, regardless of the widespread contemporary policy rhetoric of coproduction or shared decision-making, diagnosis and labelling are, definitionally, acts done to people, often with minor consent, negotiation, or room for objection; and this alone merits a critical response. Within the thesis, I will adopt madness as a positive appellation associated with a specific politics of mental health and refer to arguably fewer stigmatising terms such as mental distress. Later in the thesis, I will also discuss the political and practical nuances of reconsidering notions of 'illness' within a mad studies context, as implied in the work of Peter Sedgwick (Cresswell & Spandler, 2009). Thus, the terminology of ‘schizophrenia’ does appear in the thesis, but this is typically tempered using qualifiers such as referring to the ‘diagnosis of schizophrenia,’ ‘living with a diagnosis of schizophrenia’ or ‘carrying the label of schizophrenia.’

In this thesis, I will use the term ‘mental distress’ to describe experiences that typically lead to the attachment of diagnostic labels or fall outside traditional diagnostic categories and challenge the dominant biomedical model of mental health. Using this term, I aim to promote a more nuanced and diverse understanding of the individual experience and challenge the stigma and pathologizing associated with assumed mental health conditions or diagnostic categories. Throughout this thesis, I have carefully considered and explained my rationale for the use of specific terms to provide clarity and transparency to my readers. While the terminology used may not always be perfect, it is important to recognize that language is constantly evolving and that the use of certain terms may vary across diverse cultural and linguistic contexts. The mad studies perspective, for example, mirrors psychiatry in having its conceptual/epistemological roots in the global north (Kidd et al., 2023).

Stigma and Mental Health

Mental distress is undoubtedly ubiquitous in contemporary society (Patel, 2014). This is associated with a perfect storm of income inequalities, recent health and capitalism crises, and impending climate catastrophe, which may contribute to an increase in mental distress (Zeira, 2022). In the public realm, it is often touted that an estimated 1 in 4 people experience a common mental health problem at any time in Western nations (MHFA, 2020) and such ratios are often emphasised in anti-stigma campaigns and social inclusion policy (Evans-Lacko et al. 2012). However, this statistic is ambiguous as to what it refers to, and there is a lack of supporting evidence (Ginn and Horder, 2012). Any such figure should be compared to its origins and assumptions. There may be discrepancies between what people know or believe and what they are told. Thus, cultural dangers are associated with exaggerating and understating the prevalence of what is counted as mental illness (Bebbington and McManus, 2020). Furthermore, this ratio can often be stigmatising as we can easily say everybody experiences mental distress. However, only some seek formal help, and a proportion receives a diagnosis.

Given the potential for ambiguity and cultural risks connected with data on the incidence of mental illness, it is crucial to explore how these numbers are interpreted and understood. One part of this is the stigma associated with mental distress and the effect this can have on people's lives. Stigma can discourage individuals from seeking care and contribute to underreporting mental health concerns. Some individuals with mental health problems face significant stigma and subsequently experience degrees of exclusion from mainstream society. This rejection resulting from discrimination causes many issues beyond mental health problems. Due to stigma and its complex intersections with inequalities, discrimination, and ease of access to help and support, physical healthcare is frequently inadequate for individuals diagnosed with mental health issues, resulting in significant health inequalities and lower lifespans (Stansfield and Bell, 2019). Additionally, erroneous or exaggerated preconceptions may damage access to employment, housing or health services and numerous personal and relational interactions.

Defining stigma

Since stigma can mean different things in different situations, there can be little consensus about what it means, including within psychiatric services. For example, some writers use the term stigma to describe a general characteristic of all socially disqualifying traits, however different they may be in other respects. For example, Emilie Durkheim was the first to conceptualise stigma in 1895.

> *Imagine a society of saints, a perfect cloister of exemplary individuals. Properly so-called, crimes will be unknown; but faults which appear venial to the layman will create the same scandal that the ordinary offense does in ordinary consciousness. If then, this society has the power to judge and punish, it will define these acts as criminal and will then treat them as much.*
>
> (Durkheim, 1938, p. 13)

The sociologist Erving Goffman conducted the first significant work on stigma in the mid-twentieth century. In 1963, Goffman published his seminal book *Stigma: Notes on the Management of Spoiled Identity*, locating the experiences of stigmatised people in an interactionist frame. In this book, Goffman explored the social and psychological consequences of stigma, drawing on examples from various contexts such as mental illness, physical disability, and race. Erving Goffman (1963) conducted preliminary research on stigma and laid the groundwork for thinking about stigma variants and their unequal impacts on stigmatised and non-stigmatised individuals. Goffman (1963) defined stigma as an attribute that is deeply discrediting and proposes that the stigmatised person is reduced "from a whole and usual person to a tainted, discounted one" (p.3.). Goffman (1963:2009) established the conceptual understanding of stigma that buttresses contemporary sociological thinking.

Goffman's work on stigma, while providing a valuable framework for understanding how individuals are stigmatised by society, has been criticised for not addressing the ways in which individuals may internalise and perpetuate stigma. This is particularly relevant to the concept of self-stigma, which suggests that individuals who experience stigma may internalise negative beliefs and attitudes about themselves. However, the concept of self-stigma has also been criticised for placing the responsibility of stigma on the individual rather than recognising the role of broader societal structures and institutions in perpetuating stigma. This suggests that while Goffman's work may provide a useful framework for understanding stigma, it is important to also consider the ways in which stigma is perpetuated by broader cultural and societal factors and to avoid placing blame on individuals for their experiences of stigma.

Following Goffman's preliminary work on stigma, numerous definitions have been presented. For example, Crocker (1999) described stigma as owning a trait that reflects a social identity undervalued in a social setting. This description is like that of Jones et al. (1984), who associate stigma with qualities that deviate from the norm of a given social unit and the repercussions associated with them but emphasise exclusion and labelling rather than repulsion. According to Jones et al. (1984), stigma is an open phenomenon, meaning that what constitutes stigma in one social unit may not constitute stigma in another. Additionally, Ainley et al. (2013) consider stigma due to definitional processes due to social interactions between those who obtain potential from discrediting conditions and the persons subject to the stigma.

Leonard I. Katz This definition of stigma in his 1981 book builds on Goffman's work but places emphasis on the social processes that devalue individuals based on certain attributes. Katz defines stigma as "an attribute that is deeply discrediting" that "reduces the bearer from a whole and usual person to a tainted, discounted one." Like Goffman, Katz emphasises the social and relational nature of stigma, highlighting how it involves attributing negative characteristics to an individual based on an attribute seen as undesirable or undesirable. Katz also emphasises the negative consequences of stigma, particularly for individuals stigmatised due to mental illness. He notes that stigma can lead to social isolation, discrimination, and even violence and that interactions with the criminal justice system can exacerbate these negative consequences.

Katz's definition of stigma has also been subject to critique. One critique of Katz's definition is that it does not account for the ways in which stigma can be socially constructed and perpetuated by broader social structures and institutions. This critique highlights the need to consider the social, economic, and political factors that contribute to the stigmatisation of certain groups and individuals. Another critique is that Katz's definition does not fully capture the complexity of the lived experiences of those who are stigmatised (Scambler and Hopkins, 1986).

In contrast to Katz's definition, some scholars have argued that stigma is better understood as a complex and multifaceted phenomenon that operates at multiple levels, and that includes not only negative labelling and discrimination but also power imbalances and structural barriers that perpetuate stigmatisation. Link and Phelan (2014), define stigma as the co-occurrence of labelling, stereotyping, discrimination (treating people differently), and power imbalance (unequal status) in a situation where people with a given attribute are negatively evaluated and excluded because of an attribute deemed undesirable. They argue that stigma operates at multiple levels, including individual, interpersonal, and structural levels, and can have profound effects on the health and well-being of stigmatised individuals. Link and Phelan (2001) proposed a sociological account of stigma as a broad umbrella concept linking interconnected stigma components. These are labelling, stereotyping, cognitive separation and emotional reactions. Like the social-psychological definitions, the first four components—labelling, stereotyping, cognitive separation, and emotional responses—identify social processes within the sociocultural environment whose effects can be observed within the individual. The fifth component of Link and Phelan's definition—status loss and discrimination—includes structural discrimination (when institutional practices disadvantage stigmatised groups). These factors describe the diverse ways the stigmatised are subject to disapproval and discrimination. Link and Phelan (2001) state that these five components do not occur linearly but co-occur independently.

Imogen Tyler, a sociologist, and commentator on contemporary society who has conducted extensive research on stigma and social inequality, has praised and critiqued Goffman's work on stigma. On the one hand, Tyler (2018) acknowledges Goffman's contributions to the field of stigma research, particularly his emphasis on the social and relational nature of stigma. She notes that Goffman's work has highlighted how stigmatisation is embedded in social structures and interactions rather than solely a product of individual pathology or deviance. On the other hand, Tyler (2018) is not alone in criticising some aspects of Goffman's work, focusing on individual coping strategies and the idea that stigmatised individuals are solely responsible for managing their identities. Finally, she argues that this individualistic perspective neglects the structural factors contributing to stigma and marginalisation, such as institutionalised discrimination and unequal power relations.

Tyler also critiques Goffman's emphasis on the "spoiled identity" of stigmatised individuals, arguing that this perspective reinforces the idea that stigmatised individuals are inherently flawed or defective, suggesting a passive relationship to their stigma. Instead, Tyler advocates for a more positive and empowering view of stigmatised individuals as agents of change who can challenge and resist stigmatisation. Overall, Tyler's critique of Goffman's work reflects a broader shift in stigma research towards a more critical and intersectional approach that recognises the multiple and intersecting forms of stigma and inequality that individuals may face.

All the definitions discussed suggest one way or another that stigma involves the devaluation of persons. These social-psychological definitions agree that stigma: (1) consists of an attribute that marks people as different and leads to devaluation; and (2) is dependent both on relationship and context—that stigma is socially constructed (Major & O'Brien, 2005). In conjunction with the insights provided by a perspective based on evolutionary psychology (Kurzban & Leary, 2001), these conceptualisations capture many crucial aspects of stigma. However, these frameworks have also been criticised for neglecting the stigmatised person's viewpoint and focusing too narrowly on forces within the individual rather than on the myriad societal forces that shape exclusion from social life (Parker & Aggleton, 2003).

This thesis adopts a comprehensive approach to understanding mental health stigma, moving beyond a singular focus on Goffman's definition. By incorporating insights from various scholarly sources, we explore the interplay between structure and agency, particularly in the context of individuals of colour facing mental health stigma. Additionally, we delve into Tyler's notion of agency within Mad Studies, examining its alignment with movement activism and its potential impact on stigma reduction.

Types of stigmas

In a mental health context, the literature describes that stigma can take different forms. The types of stigma focused on within this thesis are public, self, family, and structural stigma (Henderson et al., 2013). Multiple acquisitions of the types of stigmas may worsen barriers to mental health care (Henderson et al., 2013) and potentiate other social exclusions and discrimination. To develop an adequate understanding of stigma phenomena and experiences, one must consider the different forms stigma may take.

Mental health stigma is not limited to the unapprised public, as healthcare professionals from mental health areas endorse mental illness stereotypes and, in turn, make their own contribution to stigmatising forces. Diagnoses of mental illnesses are based on differences from sociocultural or behavioural norms, according to Rao et al. (2007). Some people deemed to possess mental illnesses are stigmatised because of outdated stereotypes. This social exclusion trend may profoundly impact individuals who carry a diagnosis of mental illness (Kvaale and Haslam, 2015).

Stereotypes of mental illnesses resonate across childhood, mass media, and everyday conversations (Wahl, 1992). Stereotypes are viewpoints about a stigmatized group (Acosta, 2014). The imagery of mental health illnesses is learned early in childhood and is reaffirmed in social interaction. When an individual's deviance becomes a public issue in a crisis, the traditional stereotype of mental health illness becomes the guiding imagery for action, both for those reacting to deviance and, at times, for the designated deviant.

Public stigma

Clinically oriented researchers such as Corrigan (2000) have played a crucial role in advancing the understanding of stigma within services. Notably, their contributions extend beyond theoretical insights and include designing and evaluating anti-stigma campaigns. Their work encompasses various forms of stigma, including self-stigma and public stigma, providing valuable insights into the complex dynamics of stigmatization. Additionally, Corrigan and colleagues have worked extensively on understanding public stigma, which focuses on the attitudes and discriminatory behaviours of the public towards individuals with stigmatized identities. Their research has unveiled the negative impact of public stigma on individuals' mental health outcomes and overall quality of life. By exploring the drivers and manifestations of public stigma, they have contributed to the development of effective anti-stigma interventions and campaigns.

Few studies have specifically assessed the relationship between public stigma and help-seeking attitudes. Most researchers do not clearly define the types of stigmas being investigated (e.g., Marques et al., 2011; Goodman, 2009; Bruffaerts et al., 2011) or assess both public and self-stigma together as a unitary construct (e.g., Ting & Hwang, 2009). Those who have specifically assessed public stigma have found mixed evidence regarding the impact on attitudes to help-seeking (Interian et al., 2010; Deen, Bridges, McGahan, & Andrews, 2011).

Those with a mental health diagnosis occasionally face a triple threat of stigma (West et al., 2014). This comprises their beliefs about the causes of mental illness, their 'silence' because of their stigmatising ideologies, and community-level maintenance of the stigma. As such, stigma was reported to occur at a three-tiered stratum that was both interconnected and self-reinforcing – comprising the 'self', 'social', and 'structural' strata.

Self-stigma

The mainstream stigma literature refers to the contested term of self-stigma. Such contestation is not least linked with the potential for this concept to segue into victim blaming. Self-stigma is "what members of a stigmatised group may do to themselves if they internalise the public stigma" (Corrigan, 2004, p. 616). People diagnosed with mental health problems may internalise stigma and experience diminished self-esteem and self-efficacy. According to this view, individuals construct their social networks and opportunities in expectation of exclusion due to stigma, which leads to loneliness, unemployment, and lower pay. In addition, such stigma decreases self-esteem due to an individual's belief that they are socially unacceptable (Vogel et al., 2007). Self stigma is believed to arise when people encounter mental illness or seek self-labelling support as someone who is socially inappropriate and extends derogatory societal views to themselves and suffers from decreased self-esteem and self-efficiency (Corrigan and Shapiro, 2010).

One area where Corrigan and colleagues have made significant contributions is in the realm of self-stigma research (Corrigan and Rao, 2012; Corrigan and Nieweglowski, 2019; Ben et al., 2021). They have delved into the internalized experiences of individuals who face stigmatization due to mental health conditions or other identity factors. Self-stigma refers to the adoption of societal prejudices and stereotypes by the stigmatized individuals themselves, leading to reduced self-esteem, decreased help seeking behaviour, and limited social participation.

The impact of stigma is intertwined with a complex interplay of several factors beyond stigma itself. For instance, the combination of racial stigma and socioeconomic disadvantages can exacerbate health disparities among marginalized communities. Moreover, stigma's effects are often difficult to disentangle from the influence of other social determinants of health, making it challenging to pinpoint the sole contribution of stigma to health outcomes. Research has shown that individuals who experience self-stigma have decreased self-esteem (Link et al. 2001), increased depression (Manos et al. 2009), negative attitudes towards psychiatric treatment (O’Connor et al. 2014), and decreased compliance with treatment (Fung et al. 2007). Common self-stigma demonstrations include feeling ashamed and restricting integration with others (Kranke et al., 2011).

Researchers also observed that self-stigmatisation might delay obtaining psychiatric treatment to avoid being identified as having a mental illness (Link et al., 2001). Socioeconomic status, cultural background, access to resources, and historical experiences all play significant roles in shaping the consequences of stigma. Research has also shown that individuals who carry the label of 'schizophrenia' who report greater self-stigma associated with finding treatment are less likely to return for subsequent sessions (Wade et al., 2011). In other words, it is claimed that self-stigma plays a substantial and unique role in mental illness behaviours and the pursuit of help and support services.

Structural stigma

Structural stigma refers to societal ideologies and institutions that perpetuate or exacerbate a stigmatised status (Corrigan & Lam, 2007). Structural stigma can be defined as a set of norms, policies, and procedures from public and private bodies that bind individuals' rights and opportunities with mental health illnesses and continue social exclusion and inequalities (Mora-Rios & Bautista, 2014). Structural stigma has roots in structural racism theories, which recognise that racial discrimination can occur in interpersonal interactions and institutions (Corrigan et al., 2004).

Lastly, Madera and Hebl (2012) discuss structural stigma at an organisational level. Their study investigates how staffing policies and interview structure can exacerbate the stigmatisation of Black individuals and conclude that identity-blind procedures and unstructured interviews allow for greater stigmatisation. Societal structures promoting stigmatisation vary cross-culturally and historically; as a result, examining structural stigma requires exploring the social context in which that stigma occurs and the local knowledge systems that contribute to structural stigma (Foucault, 1977).

Cultural differences and stigma

Western societies, such as those found in Europe and North America and Australia, are often referred to as individualistic cultures. This is because they place greater emphasis on individualism, autonomy, and self-expression. In these societies, people tend to define themselves in terms of their own unique characteristics, preferences, and achievements and are encouraged to pursue their own individual goals and aspirations. Shin et al. (2013) shows how aspects of cultures can exacerbate (or alleviate) individuals' tendency to stigmatise others. Shin et al. (2013) explored the culture's role in stigmatising reactions through an examination of archival data and found that group-oriented cultures are more likely than individual-oriented cultures to stigmatise nonnormative groups. They also showed that the cultural value of uniqueness predicts more considerable differences in stigmatisation than behavioural conformity.

When a culture highly values uniqueness, it emphasizes the importance of standing out, being different, and expressing one's individuality. In such cultures, conforming to societal norms or behaving in ways that are considered conventional might be less prioritized, and individuality may be celebrated. On the other hand, in cultures that highly emphasize behavioural conformity, adherence to established norms and customs may be seen as more essential, and standing out or deviating from these norms may be frowned upon. On the other hand, in cultures that highly emphasize behavioural conformity, individuals with mental health conditions might be stigmatized more significantly. This is because their behaviour, which deviates from the established norms, is perceived as a threat to social order and conformity.

In contrast, non-Western societies are often referred to as collectivistic cultures. These cultures place greater emphasis on the importance of the group, and people tend to define themselves in terms of their social relationships, family ties, and group memberships. In these societies, people are often expected to prioritise the needs of the group over their own individual needs and desires, and conformity and interconnection are valued over autonomy and individuality. These cultural differences can have important implications for how mental illness is perceived and experienced. As such, there can be a contrast between a Western emphasis, or even hegemony, idealising independence, and non-Western affinities for interdependence.

Cultural differences play a significant role in shaping how stigma is perceived and experienced by individuals in different societies (Ran et al., 2021). The social and cultural context in which individuals live can influence how they understand and react to mental health issues and stigma. In many cultures, mental illness is heavily stigmatised, and seeking help is seen as a sign of weakness or failure (Koschorke et al. 2017). This stigma can be exacerbated for marginalised communities, such as people of colour, who may experience discrimination and prejudice in addition to the stigma associated with mental illness.

The intersection of race and mental illness represents a complex and significant area where individuals may experience heightened stigmatization. The confluence of cultural stereotypes, historical biases, and misconceptions about mental health conditions can lead to the perpetuation of stigma, resulting in the unequal and adverse treatment of individuals from racially diverse backgrounds who also face mental health challenges. The intersection between racial identity and mental illness stigma creates unique and layered experiences for individuals who belong to marginalized communities. These individuals may confront a compounding effect of stigma, where they not only face the burdens of racial discrimination but also encounter additional prejudice and misconceptions related to their mental health conditions. This dual stigmatization underscores the urgent need for culturally sensitive and intersectional approaches in addressing mental health disparities and promoting inclusivity and equity within mental health care systems.

Similar issues exist across cultures, where mental illness may be seen as a personal failing or weakness. In many Asian cultures, for example, mental illness is often stigmatised due to cultural beliefs that mental health is a personal responsibility rather than a medical issue (Martinez et al., 2020). This can lead to a reluctance to seek help, which may be seen as a sign of weakness or shame. For example, in some African cultures, mental illness is seen as a spiritual issue that can be addressed through traditional healing practices (Tuffour et al., 2019).

Cultural norms mediate the experience of mental health stigma in the enmeshment of likelihood, history, and values. In collectivistic cultures, where individuals view the self as interdependent, people with mental illness may be perceived as not conforming to group norms (different from others and not fitting in). Therefore, other group members may not wish to form relationships with them or include them as part of the group. As a result, people with mental illness may be forced to create an outgroup and thus be treated less favourably. This also links with social identity theory's ingroup/outgroup bias (Capozza et al., 2000; Fischer, 2016).

Ingroup/outgroup bias has been linked to cultural differences and mental illness in ethnic minority communities. In some cultures, mental illness is stigmatised and viewed as a personal weakness or a moral failing, which can lead to individuals with mental illness being ostracised from their communities. This stigma can reinforce ingroup/outgroup biases, with individuals with mental illness being seen as an outgroup and excluded from the ingroup. A study by Kleinman (2011) found that in China, mental illness is often viewed to be a result of moral failing or personal weakness, and individuals with mental illness may be stigmatised and excluded from social networks. The authors suggest that this stigma may be reinforced by the Confucian value of filial piety, which emphasises the importance of maintaining family harmony and reputation.

Collectivism can stifle personal healing because it places a more significant stigma on severe mental illness, oppressing and socially controlling those who experience it. Stigma is less apparent in non-Western countries (Schomerus et al. 2021). Corrigan and Watson (2002) contend that this finding may be due to a lack of research within these societies. Although attitudes toward mental illness differ among non-Western cultures (Bignall et al. 2015); Altweck et al. 2015), research suggests that mental illness stigma in non-Western cultures may be less prevalent than in Western cultures (Martensen et al. 2018). According to Fabrega (1991), one of the most key factors is the lack of distinction between psychiatric and nonpsychiatric disease in the three great non-Western medical practises: Islam, China, and India. Although non-Western societies can stigmatise mental disease, it tends to be limited to the more severe forms of mental distress that do not respond to conventional therapies.

The universality of mental distress across cultures is well acknowledged (Weine et al., 2020), though its salience and interpretation are mediated by culture (Rogers & Pilgrim, 2021). Similarly, what is understood as selfhood can be seen to be socially negotiated and constructed in culture. Individualistic Western traditions see the self as a "*bounded, unique, more or less integrated motivational and cognitive universe, a dynamic centre of awareness, emotion, judgement, and action, organised into a distinctive whole and set contrastively against other such wholes and against a social and natural background*. (Geertz, 1979, p229).

This notion of selfhood can be seen to operate as an archetype, underpinning psychiatric and psychological frames (Henriques et al., 1984). As a result, people who exhibit the sort of behaviours that attract a diagnosis of psychiatric illness can be viewed as in some way essentially different (different than me), and this can be the basis for their stigmatisation and differential treatment: difference translates quickly into 'otherness', and the 'other' is readily denigrated or demonised (Foster, 2017). In this way, the individualism of Western cultures can be seen to predicate a route into stigmatisation; it is precisely because selves are seen as separate and distinct from 'ourselves' those transgressions of social norms, such as madness, easily usher in negative dispositions between self and other. In this way, difference and alterity are the foundation stone for stigma. Of course, these self-other distinctions are not restricted to madness and also apply in the context of ethnicity; indeed, the previously explored fiction of racial categories can be seen as relatively unimportant if presumed racial difference functions to stigmatise and exclude in ways that are functional for sections of society (Miles, 1989; 2014).

For people of colour, Goffman's work on stigma is particularly relevant, as they may face significant barriers in society due to racism and discrimination. In addition to the negative effects of racism on mental health, people of colour may also feel pressure to conform to certain cultural norms to avoid being stigmatised. This can include aspects of identity such as language, dress, and cultural practices. Goffman (1963) claims that people of colour who bear the mark of their status within society are likely to find themselves functioning as stigmatised individuals (Tyler, 2018). In other terms, individuals who are racialised as Black and are managing a spoiled identity mean interacting in public in ways that protect White people from the myths of Blackness.

Rack (1982) claimed that it is essential to diagnose but not misdiagnose due to the individual's consequences. Symptoms may be psychological in one form of culture but not in another. For example, linguistic misunderstandings between patients and doctors can occur. However, delusions to some cultural groups may be a valid belief to others. For example, suppose the psychiatrist does not share the same language as the service user. In that case, it is impossible to determine whether the hesitations and discontinuities to open experiences are linguistic or stem from psychosis. These divergent findings indicate the need for more in-depth examinations of mental health concepts, experiences, and attitudes across cultures.

Consequently, linguistic, and categorical misunderstandings between patients and doctors can occur. Beliefs considered delusional to some cultural groups or psychiatry, a valid belief to others. More complexly, if the psychiatrist does not share the same language as the service user, it may prove impossible to determine whether the hesitations and discontinuities to open experiences are linguistic or stemming from psychosis. These divergent findings indicate the need for more sophisticated, nuanced, or in-depth examinations of mental health concepts, experiences, and attitudes across cultures. The so-called transcultural psychiatry movement begins with such concerns regarding the propensity of psychiatry to be insensitive to cultural variation and thus prone to misdiagnosis (see, e.g. Fernando, 2005; Littlewood & Lipsedge, 1987). This movement was itself pre-dated by the critical concerns of Frantz Fanon, linking such erroneous practice to endemic consequences of colonialism (see Khalifa & Young, 2018), and critics of the contemporary global psychiatry movement highlight a colonising impulse of the part of Western psychiatry (see Mills, 2017).

Race and Psychiatry

The complex and multidisciplinary area of race and psychiatry explores the convergence of race, ethnicity, and mental health. Any appreciation of this context spans a vast array of themes, including the effects of racism and discrimination on mental health, the cultural elements that influence psychiatric diagnosis and treatment, and the experiences of racial and ethnic minorities within the mental health system. The history of the intersection between race and psychiatry has been marked by numerous controversies, such as the use of psychiatric diagnoses to pathologize and stigmatise racial and ethnic minorities, the overrepresentation of certain groups in psychiatric institutions, discrepancies in the use of powers of detention, and the unequal distribution of mental health resources and services (Barnett et al., 2019; Nazroo et al., 2020). Numerous racial and ethnic minorities continue to suffer severe hurdles to receiving high-quality mental health care. Therefore, these problems remain pertinent. However, race and psychiatry also present numerous potentials for creativity and development. With a greater focus on cultural sensitivity and responsiveness in mental health care and rising acknowledgement of the need to address social determinants of mental health, there is considerable potential to improve mental health outcomes for all persons, regardless of race or ethnicity. Moreover, mad studies focus on survivor perspectives, including critically thought out and creative use of personal narratives, alternative and creative forms of help and support that respect intersectionality add to this potential.

To better understand the contemporary issues and debates within the field of race and psychiatry, it is important to first examine the history of this intersection. In this discussion, I will explore the evolution of race in relation to psychiatry, including its early roots in colonialism and eugenics, the challenges posed by the civil rights and anti-colonial movements, and the ongoing struggles to address issues of racism, discrimination, and unequal access to mental health care. By delving into this history, we can gain a deeper appreciation for the complexity and urgency of the issues facing racial and ethnic minorities within the mental health system today.

The idea that race is associated with embodied social signification is frequently referred to as the social-cognitive approach to race (Fiske & Taylor 1991; Loury 2002). It is critical to note that this is a conceptually distinct approach from biological-taxonomic concepts of race classification. There is no requirement that an objective racial taxonomy be correct to justify the personal usage of racial classifications. In a social-cognitive sense, "races" might be identified within a culture, accepted over generations, and believed to be biologically determined, even if such groups do not exist biologically or taxonomically (Templeton, 2013).

Frantz Fanon's work on mental illness and race is a significant contribution to critical race theory and the study of psychology. In his book "Black Skin, White Masks," Fanon (2016) examines the psychological effects of colonialism and racism on Black individuals. He argues that the experience of colonisation and racism results in a "colonised mind" that can lead to a range of mental health issues, including self-hatred, anxiety, and depression. Fanon (1961) begins by examining the techniques, ideas, and disciplines he must conduct the diagnostic. In other words, if he analysed Black people's problems through the lenses of philosophical, social, political, and psychiatric theories that not only ignored the Black condition but were also built on their dehumanisation, he would arrive at the same conclusion: the construction of inferior and pathological human types.

According to Fanon (1961), the social meaning of health and sickness cannot be predetermined. Based on its aggression against certain people, a society might be peaceful and just. From the coloniser's perspective, the exploitation and dehumanisation of Black and colonised people were not unfair nor violent; they were a necessary component of the normative understanding of normalcy and health. Within a racist normative framework, human standards, the meaning of health and sickness, and the idea of normalcy and abnormality are defined differently for Black and White people, for Europeans and colonial people. In this setting, the alienated Black is natural. Thus, he is confronted with what it means for a Black person to be disadvantaged as a human being and what healing involves in an oppressive environment. If the psychiatrist adapts patients to society, his psychiatric methods will create damaged and alienated individuals.

Metzl (2010) argues for a link between race and mental illness diagnosis in the United States. Before the civil rights movement, Metzl argued that persons diagnosed with the 'schizophrenia' label were most frequently White, believed to be harmless, and middle-class women. In the southern states, the US psychiatric system was ethnically segregated like the rest of society, and substantial racism was evident within the system, and much of this persisted despite reforms to end segregation (Smith, 2021). Metzl (2014) notes that this perspective has evolved through time. Additionally, he asserts that African American patients reported schizophrenic symptoms were confused with civil rights rallies' so-called ‘schizophrenia,’ a name linked with Black organizations such as the Black Panther Party and the Nation of Islam.

By individualising "the consequences of political violence (for both perpetrators and victims), revolt and agitation are portrayed as symptoms" of disordered persons rather than oppressed populations (Gibson and Beneduce, 2017: 15). Following the 11 September 2001 attacks in the United States, colonial psychiatry has created new. classifications based on madness and irrationality. A reductive pathological and psychoanalytic interpretation of the "mad Muslim terrorist" ignores the pathogenic geographical and historical relationships that terrorism develops (Patel, 2014). The colonised accounts, language, and manifestations like those of the postcolonial refugee, migrant, and human trafficking victim, whose humanity and identity are questioned and self-questioning, overdetermined and devoid of humanity.

The epidemiological high prevalence of psychosis found in Black minority ethnic communities is open to contestation and different explanation (Qassem et al., 2015). Cultural differences and vulnerability to stress in different ethnic minorities are two factors that have been suggested explain the apparent overrepresentation of African Caribbean people with 'schizophrenia' and the corollary under-representation of Asian people (Rogers & Pilgrim, 2021). The stresses of migration, cultural dislocation, and societal racism, amongst others, might plausibly increase mental distress for minoritized individuals and groups. The proponents of trans-cultural psychiatry argue that some of the noted over-representation is due to the ways in which a lack of cultural sensitivity might lead to misdiagnosis. An alternative view is that the ways that both race and mental health are socially constructed, the insidious operation of stereotypes, plays into the bio-psychiatric enterprise of pathologizing, rendering Black men, in particular, more likely to receive diagnoses of brain illnesses like ‘schizophrenia’ because this fits with an emphasis on Black physicality rather than White intellect (Stowell-Smith & McKeown, 1999). Thus, there are three broad explanations for this over-representation: the higher incidence of ‘schizophrenia’ is real and caused by stress, genetics, or an interaction between the two; rates of diagnosis result from practitioner mistakes and can be remedied by more culturally sensitive practice; the higher incidence is a fiction resulting from the negative impact of available social representations of madness and race.

According to Fernando (2013), 'schizophrenia' may play a political role when Black people are the targets of this diagnosis. It is far more difficult for Black people (in contrast to their White counterparts) to withstand the repercussions of this occurrence, particularly today when community treatment orders and the expanding forensic system are in place (Fernando, 2013). That means not just trying to 'understand' 'schizophrenia' as a diagnosis, a label that stigmatises how it may play out in a family, and so on, but also to understand and address the political event of 'schizophrenia' as oppression (Fernando, 2005). The experience is also quite negative for minoritised ethnic groups. The societal urge to regulate and (in a way) penalise Black people for being 'the other' may now be extending to include other racialised groups — asylum seekers, refugees, illegal migrants, and Muslims.

It is a misconception to assert that race and ethnicity are responsible for variations in attitudes about mental illness. Issues regarding the label of 'schizophrenia' are problematic (Fernando, 2017). While it is critical to acknowledge race and ethnicity when discussing mental illness and stigma, it is also crucial to recognise that race and ethnicity are only a subset of the factors that shape worldview, and that identity is intersectional. Research must delve further into the distinctions between 'races' and ethnic groups while also addressing within-group variances, which this research attempts to do. Finally, research that elicits information, thoughts, and perspectives from individuals with diverse cultural origins will help us better understand the diversity of perceptions and prejudices against mental illness and hopefully influence more successful anti-stigma efforts.

People of colour are overly represented in most mental health and psychiatric diagnoses. Additionally, racial disparities in mental health services have been widely documented. According to research, people of colour are diagnosed with various mental health diagnoses at varying rates. For example, Black Caribbeans are more likely to be diagnosed with ‘schizophrenia,’ and Pakistani women face a significantly increased risk of depression compared to White women (Bignall, 2019). A growing body of research recognises that Black people have an anomalous relationship with psychiatric services, with numerous differences in their experiences of care and treatment when compared to their White counterparts (Gajwani et al., 2016; O’Reilly et al., 2015; Rotenberg et al. 2017).

One consistent finding has been a lack of satisfaction with available treatment options. In a review by Das Munshi et al. (2018), ethnic minority service users, except those of mixed ethnicity, were less likely to be offered cognitive behavioural therapy compared to White service users. Black service users were less likely to have been provided family therapy, and Asian service users were less likely to receive copies of care plans than White service users. Black people reported being less satisfied with their access to talking therapies. These findings were corroborated by the AESOP study (Morgan et al. 2018), which found that individuals of colour were less satisfied with certain aspects of their treatments. Black Caribbean service users were dissatisfied with the admission process and believed they were not receiving appropriate treatment. Consistent with this, 77% of participants in the National Survivor User Network study believed that their background, including race, ethnic origin, and culture, affected the type of support they received, including access to psychological therapies and an overreliance on medication (Faulkner, 2014).

The understanding of race and ethnicity has become increasingly magnified in the context of Covid-19, as research has revealed the disproportionate impact of the pandemic on certain racial and ethnic groups. Reports described increased Covid-19 deaths in people of colour in the UK (Markus and Brainin, 2020). Healthcare workers of non-White origin are 1.5 times more likely to acquire Covid-19 (Chakravoty et al., 2020). According to Khunti et al. (2020), this may be due to socioeconomic factors, cultural or lifestyle factors, genetic predisposition, or pathophysiological differences. However, institutional racism may play a role in this (Razaq et al. 2020) as people of colour who may be experiencing symptoms of Covid-19 may fear or expect that racism may be faced when accessing support services and then inevitably delay help seeking.

The brutal killing of George Floyd occurred in May 2020, during the COVID-19 pandemic, and sparked a wave of protests and social unrest across the United States and around the world. Floyd, a Black man, met his death at the hands of a Minneapolis police officer who kneeled on his neck for nine minutes, despite his protestations of not being able to breathe. The incident was captured on video and circulated widely on social media, leading to widespread outrage and demands for systemic change in policing and racial justice.

The timing of Floyd's death during the COVID-19 pandemic highlighted the systemic and structural inequalities that disproportionately impact communities of colour. The protests and social unrest that followed Floyd's death brought attention to these inequities and amplified demands for systemic change in healthcare, policing, and other areas of society. The events of 2020 have spurred important conversations and actions around racial justice and equity and have highlighted the need for systemic change to address a more just and equitable society for all. The death has symbolically become the culmination of raising awareness of the systematic racism embedded in public service systems. Racism and discrimination against people of colour remain the primary source of conflict and social uprising, including a resurrection of a politics of abolition democracy (Davies, 2011) that has also emerged in relation to psychiatry (see Burstow, 2019; Róisín S, 2022).

Sean Rigg, a Black man diagnosed with paranoid 'schizophrenia,' died in police custody in London after being restrained for eight minutes in a prone position. An inquest into Rigg's death found that the police officers involved in his arrest and detention had used excessive force and failed to accurately assess his mental health needs. The inquest also found that there were multiple failures in the care and treatment of Rigg while he was in custody. Rigg’s death, along with other high-profile cases of Black people dying in police custody, has sparked important conversations about systemic racism and police violence in the UK. The case highlighted the intersection of racial disparities and mental health inequalities and the need for better support and care for individuals with mental health problems who meet the criminal justice system (Afzal, 2020).

Institutional racism can be 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” (Mckenzie and Bhui, 2007. p60). This can be portrayed through discriminatory acts through prejudice and stereotyping, which disadvantage members of minority groups. The well-known public debate on institutional racism began with the inquiry into the investigation of the murder of Stephen Lawrence by the Metropolitan Police. The report concluded that there was no evidence of direct discrimination on the part of individuals but widespread and deep systemic failings.

The controversial UK government’s Commission on Race and Ethnic Disparities report (2021), released in March 2021, has been controversial, and has faced significant criticism. The report was commissioned in the wake of the Black Lives Matter protests in the UK and aimed to examine the extent and causes of racial disparities in the UK. The report acknowledged that racial disparities exist in the UK but concluded that the UK is not a systemically racist country. It argued that factors such as family structure, culture, and geography are more important than race in explaining disparities in areas such as education, employment, and health outcomes. The report also downplayed the impact of racism, arguing that factors such as social class and family structure were more significant in determining outcomes. The report was met with widespread criticism from academics, experts, and activists. Many argued that the report’s findings were flawed, relied on outdated data, and failed to consider the experiences of people from minority ethnic backgrounds. Critics argued that the report downplayed the impact of racism and structural inequalities and failed to provide recommendations for addressing these issues (Razai et al., 2021;Lacobucci, 2021). The report’s authors defended their findings, arguing that they were based on an evidence-based approach and that they aimed to promote a more optimistic and positive view of race relations in the UK.

To expose racism in healthcare, a recounting of the political background and historical brutality would be necessary. Black and Brown individuals have suffered from colonisation to the current neo-colonial age, in which opportunistic exploitation of human labour is prioritised without regard for life, living circumstances, dignity, or health (Tyler, 2020). The UK’s complex and violent relationship with Black and Brown bodies is evident throughout history, where they have been enslaved, colonised, and indentured as builders of the UK economy, as commonwealth subjects as British nationals (British Nationality Act 1948), migrants (Commonwealth Immigrants Act 1962), and considered illegal aliens (Windrush generation and forced migrations). However, when they faced prejudice and discrimination, the UK was sluggish in pursuing reparations for ‘used’ Black and Brown bodies. Tyler (2020) has also argued that a better understanding of stigma as embedded within capitalism’s social relations and as a form of power entangled with capitalism’s, colonialism’s, and patriarchal histories’ is necessary as much writing focuses exclusively on individual experiences in ways that obscure an understanding of stigma as a material force, a structural and structuring form of power.

‘Schizophrenia’ and diagnostic labels

‘Schizophrenia’ is an interesting diagnostic category in that it is hugely contested but occupies a key position in the history of psychiatric taxonomy. It also occupies a recognisable place in the popular consciousness regarding what constitutes madness. The use of inverted commas around the term '‘schizophrenia’' represents this kept open attitude, and they are extended to other medical words, such as ‘symptoms.

Splitting umbrella concepts of mental illness into categories brings new challenges. First, whilst putting mental illness on a continuum might promise to ameliorate some degree of stigma; the *Each of Us* anti-stigma campaign begins from this premise[2]. However, there remains an implicit re-creation of a ‘*them and us’* dichotomy or ‘two groups of humanity’ (Pilgrim 2005, p.123). In other words, it may be said - *we* have minor depression, but *they* have serious mental illnesses, such as ‘schizophrenia’ (Everett, 2006; Pilgrim, 2022). Determining the differences between mental illnesses does not reduce the stigma

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[2] https://www.mhe-sme.org/each-of-us/ This European campaign emphasises the commonality of mental health difficulties and stresses a collective role in finding solutions to stigma; effectively this amounts to – it is everyone’s problem; it is for all of us to act.

associated with “serious mental illnesses.” In reality, it may just serve to reaffirm their already tarnished status. Secondly, as Pilgrim and Rogers (2005) suggest, removing specific mental illness stigmas does not waive stigma but starts with specific diagnoses at the other end of the lens. Diagnostic classifications and stigmas are naturalised as a result. This obscures how contentious these categories are and how they may mystify our understanding of the social forces that produce and define them (Pilgrim and Rogers, 2005).

When considering stigma, this is more likely to be felt more severely by individuals with more serious mental health problems (Burke et al., 2019). For example, the Schizophrenia Commission (2012) reported that 87% of individuals with ‘schizophrenia’ had experienced public stigma and discrimination. Within mental health services, the diagnostic label of ‘schizophrenia’ is most typically applied to the group defined as most seriously mentally ill. As such, ‘schizophrenia’ is one of the archetypal stigmatised categories within psychiatric taxonomy.

‘Schizophrenia’ is a psychiatric diagnostic category, and yet it is a concept difficult to define precisely. The label ‘schizophrenia’ has been a source of contestation, with various disputes, such as those led by anti-psychiatrists[3] such as Szasz, a controversialist (1988), contesting its legitimacy as an illness. Indeed, Szasz presented the question, ‘What is ‘schizophrenia’?’:

> *In its most elementary sense, we might say ‘schizophrenia’ is a word – an idea and a ‘disease’ invented by Eugen Bleuler, just as psychoanalysis is a word – an idea and a ‘treatment’ – invented by Sigmund Freud [...] The point I wish to emphasise here [...] is that the claim that some people have a disease called ‘schizophrenia’ [...] was based not on any medical discovery but only on medical authority stigma* (Szasz, 1988:3).

Although the 1960s antipsychiatry has been regarded as a past era in the history of psychiatry (Nasser, 1995), its influence has persisted into the modern era (Whitley, 2015; O’Reilly et al., 2017), and there is certainly a contemporary thread of antipsychiatry and abolition thinking that, despite differences, to some extent crosses over with mad studies (Reaume, 2021). Szasz (1976) argued that mental illness is a myth because it does not

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[3] The notion of anti-psychiatry is itself contested. The appellation was applied to several critical figures in the 1960s and 1970s, but many of the most notable of these rejected the label.

meet the diagnostic verifiability applicable to actual physical illnesses. He argues that mental illness does not adequately describe reality, and that the mental illness designation should be used metaphorically only. Szasz builds on the conventional medical assumption that establishing the presence of disease requires the presence of both signs and symptoms to make an assured diagnosis. However, diagnostic procedures in psychiatry do not and cannot be entirely predicated on identifying symptoms of illness. Szasz distinguishes between neurological illnesses with psychological consequences and other forms of mental illness (Szasz, 1976). Szasz constantly refuted the presence of mental illness based on his belief in the applicability of physiological abnormality, or the so-called 'medical-pathological definition of disease,' to mental illness (Benning, 2016). Szasz is well-known for his rejection of the notion taken up in many anti-stigma campaigns that what we refer to as 'mental illness' is an 'illness like any other' (Moncrief and Middleton, 2015).

The stigma and resulting discrimination associated with a diagnosis of 'schizophrenia' are substantial barriers to this population obtaining well-being and fully participating in society. 'Schizophrenia' is a stigmatised label, and the diagnosis of 'schizophrenia' is a violent introduction to this stigmatised condition. Public understandings of mental health or madness are essential in considering the transaction of stigma and its impact. How the public make sense of these matters is not always congruent with psychiatric constructs or knowledge and is just as likely to be influenced by media representations and misrepresentation, which are an enduring feature of popular culture. Hence, in popular culture, notions of 'Schizophrenia' and psychosis are often conflated or confused with other psychiatric categories, for example, being understood by members of the public as referring to dissociative personality illness ("multiple personalities").

Much research has been dedicated to determining to what extent people with 'schizophrenia' is dangerous due to their diagnostic label (Balfour, 2019; Granello and Gorby, 2021; Orentas et al., 2023). Most research on the relationship between mental illness and violence indicates that a mental health condition like schizophrenia' is a statistically significant but limited risk factor of violence, especially during and following symptoms (Dellazizzo et al. (2019; Wolf et al., 2023). Despite the extent to which contemporary policies and service rhetoric stress the importance of individual users' voices in psychiatric care, concerns about "epistemic injustice" are growing (Chapman and Carel, 2022; Kidd et al., 2016). According to Miranda Fricker, epistemic injustice is an injustice that affects a person's "knower" status (Fricker, 2017)[4]. Fricker contends that epistemic injustice manifests itself in two unique ways: testimonial injustice and hermeneutical injustice. Testimonial injustice occurs when a person's treatment preferences are discounted based on a psychiatric diagnosis implying that they cannot think clearly or rationally about their options.

A case of hermeneutic injustice occurs when a person who hears voices but has internalised societal stereotypes that unusual experiences such as hearing voices are entirely negative feels shame and estrangement from their voices, even though they occasionally assist them in coping with stressful life events. This inaccurate perception of individuals diagnosed with psychotic illnesses may account for that population's susceptibility to hermeneutical injustice (Kurs and Grinshpoon, 2018). Thus, in relation to psychiatry, epistemic injustice occurs when the credibility of a speaker's testimony is diminished either due to prejudice about the speaker's cognitive and emotional state (testimonial injustice) or because their voice is excluded from the psychiatric interpretive framework (hermeneutical injustice) (Crichton et al. 2017). This is detrimental to both the medical task at hand and the person's sense-making about their experiences, as emerging research on epistemic injustice in psychiatric services shows (Groot et al. 2022; Kidd et al. 2023).

Despite available criticisms, The American Psychiatric Association has maintained its endorsement of ‘schizophrenia’ as a diagnostic entity, and the term is now included in the DSM-5. Scientific journals are replete with articles reporting on research projects focused on the ‘schizophrenia’ construct; mental health practises continue to rely on categorical diagnostic systems, with ‘schizophrenia’ still conceptualised as a ‘severe and progressive brain disease'; and the public is still being 'educated' about the nature of this mental illness partly to offset widespread stigma associated with the label and partly to reinforce the aetiology of the label (Poland, 2007). There are doubts about the term's validity, but

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[4] Interestingly, the foundational principle of mad studies to privilege mad persons as the knowers, arbiters, and agents of their own experiences, politics and strategic actions resonates deeply with theories of epistemic injustice (LeFrançois et al., 2016).

linguistic changes can help (Maatz and ILG, 2020). Guloksuz and van Vos (2018) outlined five reasons why the label ‘schizophrenia’ should change:

- It is a confusing and frightening term.
- ‘Schizophrenia’ is associated with ‘insanity,’ hopelessness, stigma, and discrimination.
- There is a fear of disclosing symptoms.
- Represents 30% of poor outcomes fraction of a much broader psychosis spectrum but receives all attention.
- People predict gloomy perspectives.

Due to ‘schizophrenia’ often being referred to as ‘split mind’ and its stigmatising attributes, discussion to change the name is ongoing (Gaibel and Kerst, 2019). However, a study by Chen et al. (2019) concluded that renaming the label ‘schizophrenia’ alone cannot decrease the stigma. Alternately, Gaebel and Kerst (2018) challenge the proposals to rename and reconceptualise ‘schizophrenia’, arguing that it is still a scientifically valid construct that has shown reliability and clinical utility over the years. Further, they maintain that a name change would not resolve its stigma. They acknowledge that ‘schizophrenia’ is a stigmatised condition like many other mental illnesses; even with a new name, the illness would not run a better course until further improved treatment and care options are available. Moreover, aspects of cultural diversity need to be taken into consideration. Chen et al.’s (2019) study could be criticised as it based its conclusion on research conducted in Asian countries (Japan, Taiwan); if a name change were successful in Asian countries, this does not necessarily imply that changing the ‘schizophrenia’ name would result in a similar improvement in Western countries.

In conclusion, it is important to emphasize the significance of racism and its intersections with other forms of disadvantage and unequal treatment when considering stigma and experiences related to psychiatric services. Despite efforts to downplay its influence, racism remains a crucial factor in shaping these experiences.

Conceptually, social-economic status may be viewed as an objectified proxy for perceived social stratification. However, racism directly measures social stratification (Bhui, 2002). This distinction highlights the unique impact of racism on stigmatization and access to psychiatric services for marginalized communities, particularly for individuals of colour. Considering the complex interplay of factors contributing to stigma, it becomes evident that addressing stigma requires acknowledging and addressing the role of racism and its compounding effects. By recognizing the influence of racism and its intersections with other forms of disadvantage, policymakers and healthcare providers can develop more inclusive and culturally sensitive approaches to mental health services. Such efforts are essential to ensure equitable access to care and support for all individuals, regardless of their racial or ethnic background.

Mad studies

Racism and the experiences of people of colour are central to the work of mad studies. Mad studies seek to challenge these biases and injustices by centring the perspectives and experiences of people identifying as mad, including people of colour. Authors writing within the mad studies oeuvre have argued that Fanon, arguably occupying a liminal space betwixt psychiatry and antipsychiatry, deserves to be appreciated in a critical engagement with mad discourse (Eromosele, 2020). Yet, for others, Fanon's work as a psychiatrist, despite his anti-colonial innovations to practice, renders the value of his ideas contra-psychiatry confusing (Mills, 2014).

In the lineage of anti-psychiatry, a loose theoretical, political, and practice-based approach known collectively as critical psychiatry has arisen in recent years. According to Beresford and Russo (2016), there is disagreement over what constitutes this new discourse: "There is no clear or accepted concept of Mad Studies, which is perhaps not surprising given that it is still in its infancy" (p.271). According to Ingram (2016), Mad Studies constitutes both a discipline and a multifaceted praxis, characterized by diverse voices and perspectives. It embodies qualities of insurgency and agitation, leading to the perception of Mad Studies as an (un)discipline. It exists beyond ownership, continuously evolving, with no singular authority dictating its boundaries or trajectory (Costa 2014, LeFrançois et al. 2016).

Madness has been revived in academic and activist settings, and Mad Studies is becoming increasingly established. There is no agreement among people who have dealt with mental health problems on whether it can be used as a positive person, group, or political concept. For this emerging debate, Reville, a Canadian Mad Studies activist, has promoted new terms: Mad-identified: a person who has been cast as insane by an institutional authority/expert; mad-positive: a person who does not consider themselves to be insane but shares the goals of others who do (Reville 2013, p.170). Beresford et al. (2010) found users/survivors in their study on a relational model of depression who dismissed mad as constructive because it was derogatory, labelling, and stigmatising. Activists and academics oppose the appropriation and use of such language. Burstow (2013) believes that there are drawbacks of mad terminology because although it "facilitates celebration and dignity" (p.85), she advises that words like victim, prisoner, and patient be avoided. She claims that the utility of mad language can be determined by the research that goes into its use and the respect with which it is used.

It has also become an intersectional discipline that has been inspired and informed by allied social movements' conflicts and pedagogies. Mad Studies has learned from previous and present collaborations with other disadvantaged communities and intersectional interactions. Mad Studies has a long association with survivor movements, according to Costa (2014), and has been inspired by their approaches, processes, and analysis. In addition, women's, Queer and Critical Race Studies have also impacted the field (Spandler, 2017).

Mad Studies arose from the mad movement and related social trends and critical pedagogies, and these remain inextricably linked. The user/survivor campaign and other important allies have driven Mad Studies' creation for many decades with their proposals and resistance. Gorman and LeFrançois (2018) define a trend that embraces mad events without pathologizing, glamorising or eliding the reality of distress.

Jones and Kelly (2015) emphasise the importance of understanding the interplay between the patriarchal impacts of madness and other identities and the diversity of those impacts in their analysis of the intersectionality of madness and disability and the oppressive effects of intersectional identities. “A central tenet of the intersectional theory is that confluences of social and biopolitical identity change interactions not only in degree (that is additive) but also in kind,” they argue (p.50). Tam warns of the mad movement's new intersectional study of race and madness pitfalls. She criticises the additive and comparison theories of inequality that have been dominant in the intersectional approach.

In madness and racism, intersectionality is a method of analysing identity gaps that overlap on several levels. This paradigm lacks the idea that patriarchal institutions and structures are always inextricably related to the creation and inequality of identities and discourses (Tam 2013).

According to LeFrançois and Gorman (2018), Mad Studies has always had a transnational, vital race and post-colonial interpretation, but contributions from the global north have dominated, and mad studies itself needs a more inclusive, nuanced and sophisticated approach to global mental health that is, crucially, informed from the global south (Beresford & Rose, 2023). Gorman (2013), Tam (2013), and Voronka (2013), McWade (2016, 2020), are leading contributors to the debate. They argue that Mad Studies should support racialised and colonised Black experiences and narratives within the psychiatric culture; psychiatry's profiling, overrepresentation, and oppression must be challenged. King (2016), a Black African medical survivor and scholar, explores these perspectives, arguing that post-colonial bias in White European psychiatry has a detrimental effect on the overdiagnosis of ‘schizophrenia’ and the treatment of Black African men. He claims that Western psychology must recognise its "invisible Whiteness," which manifests in Eurocentric and ethnocentric methods that harm Black men. The development of a Eurocentric construction of mental illness is revealed by the variously noted anomalies in how people of colour experience mental health systems.

Whatever Mad studies may or may not include, it falls into a long tradition of popular psychiatric critiques, as well as more general attempts to redefine what we understand by terms like crazy, 'psychosis,' or ‘schizophrenia.’ Mad studies occupy a critical space not dissimilar from other lineages of the critique of psychiatry as a controlling and disciplinary force. These include currents of anti-psychiatry, internally and externally generated critical voices, including critical practitioner groupings such as critical psychiatry and abolitionist movements. The crucial distinguishing characteristic of mad studies is the commitment to privilege the voice of the mad identified themselves and to escape the definitional constraints of bio-psychiatric terminology such as ‘illness’:

Most discussion about mental distress continues to be framed in biomedical terms as ‘mental illness’/ ‘disorder.’ This is not only true of dominant professional and political debates but also of much discussion from mental health service users – even where that challenges the bio-medical direction of prevailing policy and thinking. While there is *some tendency to use euphemisms like ‘mental health’ and ‘mental health problems,’ this discourse is still essentially imprisoned within a mental health paradigm* (Beresford, 2020: 1337).

Writing before the advent of mad studies, Peter Sedgwick (1982), notable author of *Psycho Politics* (1982), was less troubled by the terminology of illness, though he argued for a particular usage that involved a more broadly based critique of biomedical reductionism and a corollary, unashamedly political, critique of wider society and the need for state-provided care and welfare. For Sedgwick, a politicised notion of illness can then be a lever by which people make demands upon services and welfare systems. Latterly, Sedgwick’s ideas have been revisited as urgently necessary for our neoliberal times (Spandler et al., 2016), and he has been claimed as something of a proto-mad studies scholar (Beresford, 2016).

Mad Pride activists represent something of a rupturing with the stigma hypothesis. These narratives illustrate activists’ refusal to uncritically self-identify with processes of psychiatric classification and resistance to co-optation or confessional practices. While creditable in their goals, current mainstream tactics to target the stigma associated with mental illnesses ultimately function to inhibit other forms of experiencing and engaging and understanding madness.

Mad studies, as a critical perspective, seeks to challenge the dominant narratives surrounding mental health and interrogate the social, cultural, and political factors that contribute to the stigmatization of individuals with mental distress. Cinema, for example, could be one vehicle to explore or provoke more critical readings of madness in society. Various mad scholars have suggested creative arts as an interesting crucible for such criticality, ideally arts and creative processes that are led by mad people themselves (see Reid et al., 2019). Arguably, such approaches could be of value in designing mad studies inspired anti-stigma initiatives (Qasim et al., 2020) but critical artists and creatives clearly also operate in the mainstream art world.

Albeit produced by fairly mainstream creatives, the movie Joker provides an intriguing lens through which we can examine these issues as it delves into the origins and experiences of a character grappling with mental health challenges (The Joker, 2019). One key aspect to consider is the film's portrayal of the protagonist's journey and how it intersects with wider societal attitudes towards mental health. The character of the Joker, played by Joaquin Phoenix, is depicted as a marginalized individual who faces various forms of social exclusion, including economic hardship, systemic neglect, and limited access to mental health services. By exploring the Joker's story within the framework of Mad studies, we can critically analyse the ways in which societal structures and power dynamics contribute to his experiences of stigma and marginalization (Preston and Rath-Paillé, 2023).

Moreover, the movie challenges traditional notions of villainy and heroism by humanizing the Joker and inviting the audience to empathize with his struggles. This narrative approach aligns with the goals of Mad studies, which seeks to amplify the voices and experiences of individuals with mental distress, disrupting stereotypes and dismantling the dichotomy of "us" versus "them." Through this critical lens, we can explore how the movie challenges societal perceptions and highlights the complex realities faced by those living with mental health challenges (Young, 2021).

Furthermore, the film prompts us to question the systems and institutions that perpetuate stigma and hinder individuals from accessing the support they need. It raises important issues related to the portrayal of mental health in popular media, as well as the influence of cultural representations on public perceptions. By engaging with various media and artistic portrayals of mental distress through a Mad studies perspective, we can analyse how these contribute to broader discussions around destigmatization, representation, and the need for more inclusive and compassionate approaches to mental distress. Through this critical connection, we can foster a more nuanced understanding of madness, and mental health issues, challenge dominant narratives, and work towards creating a society that embraces and supports individuals in mental distress or, indeed, leaves them alone to organise their own support. This raises questions about the impact of cultural representations on public perceptions and challenges the sensationalized and stigmatizing depictions often seen in mainstream media. Alternative anti-stigma initiatives, such as performances and community discussions, can use this critique to promote accurate and responsible portrayals of mental health, encouraging media outlets to adopt more nuanced and empathetic representations. By either establishing survivor-led initiatives or collaborating with media organizations and influencers, campaigns can work towards dismantling harmful stereotypes and promoting positive narratives surrounding mental health.

Anti-stigma campaigns

Building upon the critical insights from Mad studies, it is essential to explore how these findings can inform and enhance anti-stigma campaigns aimed at challenging mental health stigma and fostering a more inclusive and empathetic society, or how these mainstream narratives can operate to close the space for alternative more critical discourse (Fey & Mills, 2021). Mental illness perceptions are impossible to alter when receiving, however well-meaning, constant but unknowing help from the public and daily mass media dialogue. Analysing simplistic media messages and stereotypical lay audience perceptions, lumping all illnesses into one definition of "mental disease" is oversimplified and unhelpful. Overlain on this is the previously mentioned disputed territory of categorisations of madness, distress, and disability. As a result, scholars can be trapped in comprehending mental distress in terms of psychiatric illnesses occurring on multiple (yet frequently related) intensity and perception spectrums. From this perspective, emotional impairments, such as addiction, are broader than ‘reality perception' impairments, such as madness, but all are referred to in one way or another as mental illness. Moreover, this taken for granted operating within the frames of psychiatric and neoliberal hegemony, leaves the foundations of psychiatric orthodoxy and its enmeshment with state interests completely intact. This alone both fails to address the stigmatising impact of being engaged with psychiatry and subject to its labels and treatment and ignores the salience of structural political-economic forces in disadvantaging those persons deemed to be mentally ill.

As we have seen, the stigma associated with various designated illnesses varies. As a result, public health experts who want to reduce health-related stigma should arguably avoid overgeneralising disabilities in broad brush terms, like "mental illness." As previously said, grouping all of these anomalous experiences together makes no sense because categories of experience like autism and ‘schizophrenia’ are phenomenologically and experientially, physically and psychologically distinct. Although multiple defined illnesses may share similar characteristics, focusing only on eradicating a stereotype of "mental disorder" is doomed to be ineffective. Each set of madness experiences has a particular social significance based on the bearer's social background.

Although the DSM-5 definitions might for practitioners better describe individual differences within mental disabilities, they are too linear, categorical and reductionist for a social definition of disability. Moreover, the language of disability and recourse to legal protections framed by notions of disability may not appeal to all mental health system service users or survivors, leaving mental distress in its broadest sense ill served by both psychiatric and disability concepts (Spandler et al., 2015). For example, not all deemed to have ‘schizophrenia’ share the same experience with their symptoms, and only a few individuals fall into one category; indeed, one of the criticisms of DSM is that each iteration has increased the likelihood of all illnesses being comorbid with every other illness. Any two individuals with the same label may have no symptoms in common, and people with different labels often share symptoms (Pilgrim, 2014).

A number of critically minded researchers and commentators have persuasively pointed out epistemological and practical shortcomings and inaccuracies of mainstream anti-stigma campaigns, notably because they fail to recognise that the concepts of mental illness presented and reproduced uncritically are themselves causative of stigma (Harper 2005; Pilgrim & Rogers, 2005; Speed & Taggart, 2019). The biogenetic approach to stigma reduction employs an "illness philosophy," which uses the same biological and medical theories applicable to physical illness to mental health issues (Read, 2007). In essence, this medical approach to identifying and addressing mental health issues and behaviour considers hormones, organic brain impairments, or biology as the cause (Read, 2007). Psychosis is regarded as a "mental disease like any other illness" in this regard (Read et al., 2006; Read & Law, 1999). This is mirrored in anti-stigma advocates' terminology; for example, mental health conditions are often referred to as diseases (Read, 2007). Since the individual's genes control the origins of mental health illnesses, this approach means that a biogenetic view of the causes would minimise the public's ability to blame people for their mental health issues (Angermeyer & Matschinger, 2005).

Much of the stigma research done so far has used Western studies, which could be skewed by Western views of psychology and culture (Corrigan, 2004). To fully understand the concept of stigma in ‘schizophrenia,’ more research into the intersection of race and ‘schizophrenia’ is required. Consequently, the focus of this research will be on race and severe mental illness stigma. Both factors have significant health consequences, such as establishing appropriate anti-stigma campaigns and further recognising the construct of stigma and how mental illness is construed in various communities. Noted cultural differences between the West and the global South are evident, but we should also be a little wary of broad-brush generalisations. There will be vast variety and nuances within and between cultures, and we mustn’t forget that Western psychiatry is itself associated with colonialist imperialism (see Fanon) and the global spread of a homogenising bio-medical lens for identifying, making sense of and treating human experiences deemed to be a mental illness. Indeed, the global psychiatry movement exists to bring the Western model of bio-psychiatry to developing nations on the basis of meeting an assumed human right to adequate psychiatric care wrapped up with international sustainable development goals (Vigo et al., 2019). This, in turn, has been criticised as a neo-colonial enterprise (Cosgrove et al., 2020).

Although cultural disparities exist, the research is limited to whether race predisposes a person to mental illness or whether mental illness responds to the social context in which the person of colour lives. In the United Kingdom, the connection between psychiatry and Black communities is fraught with difficulties. As has been highlighted, psychiatry has been justifiably accused of racism (Knowles, 1991; Kalin, 2021; Mensah et al., 2021; Shim, 2021) for failing to address the mental health requirements of Black communities and for its confinement and surveillance capabilities over Black families' problems. In addition, racism stems from Western diagnostic classifications regarded as insufficient for diagnosing mental illnesses in many cultural situations. (Knowles, 1991). Relatedly, global anti-stigma campaigns continue to reproduce such failings (Fey & Mills, 2021). Furthermore, such mainstream anti-stigma campaigns have recently been powerfully criticised for neglect of the role racism plays in combination with structural inequalities in the stigmatised lives of people of colour experiencing mental illness, requiring a shift away from an anti-stigma discourse that apparently blames individuals and communities for their own predicaments (Kapadia, 2023).

Additionally, beliefs within groups are not homogeneous (Anglin et al., 2006), so claiming that one group is more or less likely to stigmatise another gives an incomplete picture. Cultural norms and values profoundly affect people's perceptions of what they think, believe, and do; they also play a critical role in establishing notions of normalcy, abnormal and stigmatised behaviour. Until now, researchers in the United Kingdom who study mental distress have primarily focused on gathering data to improve conceptualisation and understanding of mental illness within a narrow sphere – they have done a poor job of collecting data that would aid in the cross cultural understanding of mental distress (Abdullah & Brown, 2011).

Arguably, the totality of the mad studies enterprise is effectively a programme challenging the stigma of madness. This can be seen at least in terms of critiquing the legitimacy of psychiatric knowledge and how this plays out in the various understandings of stigma, how best to challenge it, and which voices are excluded (see Fey & Mills, 2021). Because prevailing anti-stigma campaigns are so tied up with the mainstream psychiatric episteme and practices that are seen from a mad studies perspective to be essentially the problem, it could be easy to go no further than offering a cogent critique of these mainstream campaigns. The stigma associated with madness and its consequent amplification of distress and disadvantage is, however, very real. So, here in this study, I offer a mad studies-inspired exploration of this mainstream and some ideas for what an alternative challenge to stigma at the intersections of race and madness might look like. In this latter regard, I look to those elements of mad studies that explore creative mad arts as vehicles for counter-cultural contributions to subversion of the mainstream, either with a view to large-scale transformation of anti-stigma work or, more likely, smaller scale, situated, prefigurative initiatives.

Gaps in the research

Currently, no research examines the subjective experience of the effectiveness of anti-stigma campaigns in increasing help-seeking that targets all people of colour. However, there is a lack of representation of ethnically diverse individuals in anti-stigma campaign measures. It suggests that in recent years, there has been an observed lack of substantial involvement by individuals from marginalized and minority communities in participation initiatives. Furthermore, those individuals from racialized groups who do manage to secure representation often point out power imbalances arising from marginalization and discrimination as significant barriers to collaborative knowledge production. In essence, it highlights systemic challenges in achieving meaningful inclusion and equity in decision-making processes (Kalathil, 2013). The effect of the underrepresentation of racial and ethnic minority groups in the media ‘schizophrenia’ on members of various communities is unknown (Owen, 2012). However, such underrepresentation raises an intriguing question about whether the absence of non-White individuals influences the help-seeking behaviours of people of colour diagnosed with ‘schizophrenia’ and even contributes to a stronger endorsement of stigma by members of these groups toward persons in mental distress. There is also a need to examine experiences and understandings of ‘schizophrenia’ and more specific recognition of stigma in diverse communities.

Studies with more ethnically diverse samples would be beneficial to gauge the difference in experience between people of colour and their White counterparts. For example, the processes involved in overcoming stigma within different communities require the involvement of a comprehensive social network in the initiation of help seeking behaviour (i.e. family, colleagues, teachers, priests, imams) and different types of stigma that may be more prominent in diverse groups are issues that will be explored in this PhD research project.

Research surrounding anti-stigma campaigns assumes that stigma exists and that stigmatising attitudes and beliefs are accessible through questionnaires. This is not to argue that the questionnaires are not helpful or that stigma does not exist. The use of questionnaires allows for quantifying attitudes, behaviours, and knowledge. This, in turn, means that links between attitudes and behaviours and knowledge can be explored. However, these questionnaires are limited when used as the sole data collection method. This is due to the lack of understanding of the nuances of what an individual believes and how they react to messages from anti-stigma initiatives. Qualitative methods can provide a more profound and meaningful understanding of such matters and understandings or preferences for what might be effective in challenging stigma. Pathways to understanding and any associated help-seeking behaviours help us identify impediments to securing help and support. Understanding how people seek help for mental distress is essential for planning or critiquing mental health services, coordinating referrals, or opening up the contemplation of alternative approaches.

By analysing stigma through qualitative methods, we can better understand the effects of stigma on individuals, their families, mental health service utilisation or other community support. This research may also impact public health authorities or organic community initiatives, informing future developments for addressing stigma among people of colour. In this sense, I am interested in a quite loose or broadly cast conceptualisation of ‘services and support. There may be something of an irony in taking up a mad studies critique of many inadequacies of services in the mainstream but also being interested in ease of access. This may, however, not be as contradictory as it might seem at first sight. Help-seeking need not be tied to a bio-medical frame; much mental distress is just that, highly distressing for individuals and families, and people desire to be helped. This is reflected in my findings. In later discussions, I will attempt to navigate any seeming paradoxes and draw upon critical commentators such as Sedgwick and allied thinkers who attempt to square the circle of recognised service failings and a real need for the provision of help and support at the appropriate scale (Cresswell & Spandler, 2016; Spandler et al., 2016). The depredations and degradations of austerity further compound these issues, necessitating attention to the potential for neoliberal hijacking of well-intentioned criticisms to legitimate further cuts to services (McWade, 2016; Spandler, 2017).

The possible real-world impact of this research is to inform a new way to address the issues surrounding anti-stigma campaigns and assist in developing a new anti-stigma campaign that benefits the engagement of people and communities of colour in addressing stigma.

Aims and research questions of this research

The overarching aim of this thesis is to understand how stigma affects the lives of people of colour who seek help for ‘schizophrenia.’ To achieve this, four broad aims were set:

The main aims of this PhD research study are:

- To analyse and explain help-seeking experiences by focusing on the influence of stigma on help-seeking experiences through the lens of persons of colour who carry a diagnosis of ‘schizophrenia.’
- To understand and explain the subjective help-seeking experience, particularly among relatives of people of colour who carry a diagnosis of ‘schizophrenia.’

- To explore how people of colour experience anti-stigma campaigns who carry a diagnosis of ‘schizophrenia.’

The research questions that this thesis aims to answer are:

- How does stigma influence the help-seeking experiences of persons of colour who carry a diagnosis of 'schizophrenia'?
- What are the subjective experiences of help-seeking among relatives of people of colour who carry a diagnosis of 'schizophrenia'?
- How do people of colour experience anti-stigma campaigns aimed at reducing mental health stigma for individuals diagnosed with 'schizophrenia', and how do these experiences intersect with their racialized identities?

Chapter 2: Literature Review

This chapter provides a comprehensive review of the existing literature on stigma and mental health in minority communities. The purpose of this chapter is to examine how stigma impacts help-seeking behaviours and the lived experiences of individuals who carry the label of ‘schizophrenia.’ By exploring the current research on this topic, this chapter identifies gaps in the literature and develops a framework for the study that is grounded in existing theories and empirical evidence. The review examines the impact of stigma on help-seeking behaviours in ethnic minority communities and the barriers to accessing mental health services. This includes a critical analysis of the different approaches that have been used to address stigma in these communities, such as community-based interventions and anti-stigma campaigns. Finally, the review explores the lived experiences of people of colour who carry the label of ‘schizophrenia,’ focusing on the subjective experiences of stigma, discrimination, and social exclusion. This includes a discussion of the role of family, culture, and spirituality in coping with mental distress within these communities.

Literature search strategy

This section outlines the comprehensive literature search strategy employed to identify relevant research studies for this PhD thesis. The primary aims of this study are to analyse and explain help-seeking experiences among persons of colour diagnosed with ‘schizophrenia,’ understand the subjective help-seeking experiences of their relatives, and explore how these individuals experience anti-stigma campaigns.

Defining Key Concepts and Keywords

The main themes of this research include stigma, help-seeking behaviour, persons of colour with ‘schizophrenia,’ relatives' perspectives, and anti-stigma campaigns. To ensure a comprehensive search, the following key concepts and associated keywords were defined:

- **Help-seeking**: *help-seeking behaviour, mental health services, support seeking, treatment seeking.*
- **People of colour:** *people of colour, minority groups, ethnic minorities, racial minorities, African American, Black, Asian, Arab, non-White, BAME, BME, racialised, race*
- **'Schizophrenia'**: *'schizophrenia,' psychotic disorders, severe mental illness, psychosis*
- ***Relatives****: family members, caregivers, relatives,*
- **Anti-stigma campaigns**: *anti-stigma, stigma reduction, public awareness campaigns, mental health campaigns*
- **Madness and mental distress:** *madness, mental distress, emotional distress, psychiatric survivor, user survivor, psychiatric survivor movement, survivor perspective*

Developing search strategy

Based on the identified key concepts and keywords, the following specific search strategies were formulated to guide the search process:

- ("stigma" OR "discrimination" OR "social stigma") AND ("help-seeking" OR "mental health services" OR "treatment-seeking") AND ("persons of colour" OR "people of colour" OR "minority groups" OR "racial minorities") AND ("schizophrenia" OR "psychotic disorders") AND ("madness" OR "mental distress" OR "psychiatric survivor" OR "user survivor" OR "psychiatric survivor movement" OR "survivor perspective")
- ("relatives" OR "family members" OR "caregivers") AND ("help-seeking" OR "support seeking") AND ("persons of colour" OR "people of colour" OR "minority groups") AND ("schizophrenia" OR "psychotic disorders") AND ("madness" OR "mental distress" OR "psychiatric survivor" OR "user survivor" OR "psychiatric survivor movement" OR "survivor perspective")
- ("anti-stigma campaigns" OR "stigma reduction" OR "public awareness campaigns") AND ("persons of colour" OR "people of colour" OR "minority groups") AND ("schizophrenia" OR "psychotic disorders") AND ("madness" OR "mental distress" OR "psychiatric survivor" OR "user survivor" OR "psychiatric survivor movement" OR "survivor perspective")

Selecting Databases

A combination of academic and multidisciplinary databases was used to ensure comprehensive coverage of relevant literature. The selected databases included: PubMed, PsycINFO, CINAHL, MEDLINE, Web of Science, Google Scholar, JSTOR, ProQuest Dissertations & Theses

Inclusion and Exclusion Criteria

To ensure the relevance and quality of the included studies, specific inclusion and exclusion criteria were established:

Inclusion Criteria

- Studies employing qualitative research methods (e.g., interviews, focus groups, ethnography).
- Research focusing on persons of colour with a diagnosis of 'schizophrenia.'
- Studies addressing help-seeking behaviours, stigma, and anti-stigma campaigns.
- Articles published in peer-reviewed journals.
- Studies written in English.
- Publications from the last 20 years (2004-2023).

Exclusion Criteria:

- Studies not involving persons of colour.
- Research not specific to 'schizophrenia.'
- Articles not peer-reviewed.
- Non-English publications.
- Studies published before 2003.

Search Process

An initial search was conducted using the developed search strings across the selected databases. Titles and abstracts were screened for relevance based on the inclusion and exclusion criteria. Full texts of potentially relevant studies were obtained and reviewed in detail to confirm their relevance and methodological quality. Reference lists of key articles were reviewed to identify additional relevant studies that may have been missed in the initial search. Grey literature, including dissertations, theses, and reports from relevant organizations, was also searched to ensure comprehensive coverage. To organize and manage citations, reference management software such as EndNote and Mendeley was used.

Data Extraction and Synthesis

Key information from each included study, such as study aims, methods, participants, key findings, and conclusions were extracted. The findings were synthesized thematically, aligning with the research questions and aims of this thesis. By following this structured literature search strategy, a thorough review of the relevant qualitative research was conducted, providing a solid foundation for the subsequent analysis and discussion in this thesis.

Stigma within Ethnic Minorities

Numerous studies have been conducted on various aspects of help-seeking in the mental health sector, and research repeatedly reveals that help is not always sought when required (McCarthy & Horgan, 2016; Snell-Rood et al., 2017). Many people opt not to seek treatment because they do not wish to identify with the widely stigmatised segment of the community who suffer from mental health problems, and obtaining help only makes it "real" and "official" for them (Biddle et al., 2007). The proclivity to either seek assistance from services or avoid engaging with them seems to emanate from a multifaceted interplay of negative societal perceptions, apprehension about external evaluations, and internalized appraisals. It is less about what others think and more about internalised judgments in this circumstance, though the two may be related (Salaheddin and Mason, 2016).

More precisely, Black identity may be employed as a coping method for people of colour experiencing mental health difficulties. For example, Campbell (2013) studied the sociocultural determinants influencing help-seeking behaviour among Black people suffering from depression. This study identified crucial theoretical principles for comprehending individuals' health behaviour. According to the interviews she conducted with her subjects, a critical aspect affecting health behaviour was the negotiation of identity. The consequence of being deemed to have a mental illness frequently contrasted with preferred racial/ethnic and gender identities for many of these participants.

With people of colour, shame emerged as the most prevalent response associated with avoiding help-seeking from health services. Psychiatric notions of severe mental health problems such as ‘schizophrenia’ were not seen as medical conditions but instead conceived of negatively as ‘madness’ (Knifton, 2012). Gary (2005) showed that individuals from ethnic minority groups experience ‘double stigma’ whereby racism within and outside mental health services contributes to the public and internalised stigma of mental illness that prevents help-seeking. This indicates a need to understand the various perceptions of the stigma amongst people of colour.

The cultural variations in discursive perception of mental illness and mental health stigma have been explored in recent studies. For example, in Hong Kong, Fung et al. (2011) developed a self-stigma reduction initiative for sixty-six individuals with ‘schizophrenia’. They believe that stigmatisation of people with diagnoses such as ‘schizophrenia’ is more common in China than in Western cultures, owing to the collectivist essence of Chinese society or the propensity to emphasise the interests of in-groups over persons' needs (Lam et al., 2010). According to Fung et al. (2011), deviant behaviours in ‘schizophrenia’ are interpreted as psychological defects or poor moral values of collectivistic thought, resulting in higher degrees of stigma.

Most of the general community has a mixture of incomplete and incorrect knowledge regarding mental distress and apprehensive and cautious attitudes towards individuals with mental health problems. As a result, individuals are frequently slow to notice emerging mental health problems in themselves, family members, or acquaintances. However, they can be hesitant to seek treatment out of fear of the consequences. From a mainstream perspective, reluctance to seek help and associated stigma is often understood in terms of a lack of ‘knowledge;’ in this sense, knowledge equates to understandings framed by or permitted within psychiatry. For example, knowledge of psychiatric disease categories such as ‘schizophrenia’ is felt to be lacking in various cultures, and this is implicated in medical responses and the design of anti-stigma campaigns. Interestingly, in a study centred on Pakistani culture, Hussain et al. (2017) found that patients believed the causation of ‘schizophrenia’ was stress, family problems, lack of friends and financial worries and deemed such understandings to be ‘incorrect’ and likely to hinder treatment compliance. Yet arguably even a more broadly based psychosocial framing of psychiatry would allow such social stress factors to be important in the genesis of mental distress. More critical perspectives might also use the same findings to argue for political-economic understandings and interventions as well as relational support for these individuals and communities. This shows that it is essential to acknowledge that knowledge, the sense that people make of their own experiences, admittedly can hinder seeking support for mental health care and support, but these understandings are very much contested and contestable.

Family and generational factors

Much of the mainstream literature has focused on the negative consequences of psychiatric stigma, and now there is a growing awareness that stigma can also extend to families (Phelan et al., 1998). Family members experience stigma through their relationship with the person diagnosed with mental illness. Goffman (2009) called this courtesy stigma experienced by the people close to individuals with mental illness (i.e. siblings, spouses, and parents). Self-stigma moderates the relationship between these family members’ insight into their relative’s severe mental distress. Individuals experience prejudice and discrimination through associations with their relatives (Larson and Corrigan, 2008).

Research into the intersection of different generational structures in individuals of colour is also limited. For example, many second-generation individuals in contemporary society have differing yet fearful views regarding the label of mental illness. For example, a study conducted by Vyas et al. (2021) looked at help-seeking experiences in British second-generation South Asians experiencing psychosis. Being positioned between different cultures and generations felt difficult for participants, which has been identified in previous literature. Participants described fragmented identities with difficulties managing the South-Asian and Western parts of themselves as distressing. As Karasz et al. (2016) describe, South Asian societies are collectivist, valuing family harmony and deference to elders, which may cause individuals to repress feelings of stress and more frequently identify symptoms as somatic in origin. Seeking genuine mental health treatment would be viewed as a failure on the family's part and would be sought only as a last option (Gilbert et al., 2007; Han & Pong, 2015; Ng, 1997). In addition, South Asians who have a higher degree of acculturation to Western culture are more likely to embrace Western diagnostic paradigms that are more individualistic and focused on biological processes of sickness (Han & Pong, 2015; Karasz et al., 2016; Khaleque et al., 2015; Patel & Shaw, 2009; Rastogi et al., 2014).

Angermeyer and Dietrich (2003) identified four stigma domains found within families of individuals diagnosed with ‘schizophrenia’. The domains were interpersonal interaction, structural discrimination, the public image of mental illness, and access to social relationships. The first two domains, interpersonal interaction, and structural discrimination, include direct and indirect experiences, and relatives’ statements for the latter two domains almost exclusively refer to indirect stigma experiences. Direct experiences allude to the stigma encountered by family members themselves. Indirect experiences are stigma experiences of the persons carrying the ‘schizophrenia’ diagnosis, observed, and identified by their relatives. It is also important to note that Angermeyer and Dietrich (2003) established these domains as those experienced by caregivers of individuals with severe mental illness; other areas within family stigma also need essential attention. For example, Yang et al. (2013) conducted a study in America through a questionnaire. Through a sample of seventy-eight female college Asian-American students, they found that intergenerational and familial conflict emerged due to cultural dissonance between the first and second Asian-American generations.

Similarly, in a sample of college students, Zaidi et al. (2014) conducted semi structured interviews. They found the second generation following migration is caught between two cultures in which they must navigate and change their demeanour and behaviours based on the notion of wanting to belong both inside and outside their homes, and this can lead to clashes between first and second-generation South Asians over delicate matters. Marginalised individuals suffer the most psychological distress, including self-identification and cultural alienation, adversely affecting their self-esteem (Zimmerman, 2011). Therefore, it would be essential to research second-generation individuals from different ethnic backgrounds to explore if such acculturational difficulties and differences between them and the first-generation regarding acculturation affect their mental health and to what extent. Finally, Cifti (2012) found that the differences between first-generation immigrants and their second-generation children were significant for overall health, but mental health was not explicitly examined. Crane et al. (2015) observed that immigrant parents retain traditional beliefs about reliance while their children embrace Western notions of independence in a study on family functioning and parent-adolescent acculturation. This was also discovered in a study on immigrant parents and children (Khaleque et al., 2015).

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Despite recognition of intergenerational patterns and beliefs about mental health problems, little is known about how this process happens and what role family stories may play in influencing the experience of mental distress. Societal and cultural discourses influence intergenerational narratives about mental illness, and given the prevalence of mental health stigma, most families are likely to contain some stigmatising attitudes and beliefs about mental illness. These will impact families’ experiences of living with mental health difficulties and providing familial support.

The behaviour exhibited by an individual who carries the label of ‘schizophrenia’ may isolate family members and disrupt relationships with friends and neighbours. There is also an iatrogenic component in mental illness that may reinforce families' self-stigmatisation (Lefley, 1989). This means that within the context of mental illness, there exists a significant aspect known as the iatrogenic component, which inadvertently contributes to the reinforcement of self-stigmatization within families.

The iatrogenic component refers to factors or elements within the mental health system and treatment approaches that unintentionally exacerbate the stigma experienced by individuals and their families. This inadvertent reinforcement of stigma occurs through various mechanisms, such as the language used in treatment approaches, the labelling and identity formation associated with mental health conditions, the extent of family involvement in the treatment process, and the prevailing public perception of mental health treatment. Additionally, inadequate education and awareness regarding mental health conditions can further perpetuate stigmatizing beliefs and attitudes. Consequently, the impact of the iatrogenic component can be significant, contributing to increased feelings of shame, isolation, and a sense of being "lesser" than others among both individuals with mental health diagnoses and their family members.

There are three critical attributes of family stigma identified by Park and Park (2014). These are other people’s negative perceptions towards the family member; other people’s belief that the unusualness of the family is harmful/dangerous; other’s belief that the deemed to be problematic family member directly/indirectly taints the family. The consequences of stigma for individuals and their families include reduced self confidence and self-esteem, feelings of shame and futility, social exclusion and an inability to enter into the community, reduced psychological well-being, decreased quality of life, sleep illnesses, the permeation of the disease burden, and not seeking treatment (van der Sanden, 2014:2016;). Research shows that family members of people with severe mental illness know of the negative attitudes towards them and define several unpleasant experiences, including being gossiped about in the community, being blamed for their family member’s illness, being devalued and receiving inadequate support (Shamsaei et al. 2013; Rezayet et al., 2018; Banerjee and Dixit, 2021).

Stigma experiences for family members of persons living with a ‘schizophrenia’ diagnosis spanned four levels of respondents’ lives. The overarching issues were (1) a general lack of understanding and misconceptions about mental illness; (2) structural discrimination and paucity of governmental and public support systems; and (3) the burden of ‘pervasive and unlimited’ care and the inability of independent living (Krupchanka et al. 2018). As a result of societal misunderstandings or a lack of awareness regarding mental distress, family members face stigma at all levels of their life (Yin et al., 2020). On a larger scale, families of persons with mental illnesses confront insufficient medical care and a lack of regulation. On a micro level, family members encounter unfavourable attitudes and discriminatory behaviours in their personal relationships with others and while interacting with mental health experts. Furthermore, Wong et al. (2018)’s study in China shows that caregivers scored high on the Affiliate Stigma Scale.

The historical, socioeconomic, educational, and cultural features of the society they belong to shape the stigma faced by individuals with ‘schizophrenia’ and their family members. This means that extrapolating results from one party to another is often difficult. While stigma towards people with mental health difficulties is well documented and researched, there is limited understanding of stigma in families. When addressing this topic, there is a need to consider the stigma and discrimination people experience from their family members and how family members themselves may be subjected to stigma by association.

Migration

There is a complex relationship between migration, racism, ‘schizophrenia,’ and people of colour, and it is important to approach this topic with sensitivity and nuance. Some research has suggested that there may be a link between migration and an increased risk of ‘schizophrenia’ (Henssler et al. 2020; Morgan et al. 2019). This has been attributed to a number of factors, including the experience of migration and the stress and trauma that can accompany it, as well as factors such as social isolation and discrimination. Yet, the risk of ‘schizophrenia’ is not increased in all migrant groups but in those with a visible minority status (Henssler et al., 2020). For example, in Sweden, refugees were 66% more likely to develop ‘schizophrenia’ than native born populations (Hollander et al., 2016). Through a psychiatric lens, migrant communities are more likely to have been exposed to traumatic events, affecting the development of psychosis and ‘schizophrenia’ (Cantor-Graae et al., 2003; Zolkowska et al., 2001). Al-Saffar et al. (2004) affirms the increased prevalence of ‘schizophrenia’ among East Africans living in Sweden and claim that a weak social network in an individualist culture could be a salient factor.

Treatment of migrants and ethnopsychiatry are still considered developing fields of study, and earlier scholarship flirted with matters of White supremacy, scientific racism and eugenics, issues that linger in the field, for example, in research into constructs of intelligence (see Yakushko, 2019). For example, initial attempts to explain racial disparities in epidemiology and patterns of diagnosis led to a genetic explanation for Black s' inferiority alongside a co-option of psychiatry into wider colonial and imperial enterprises (Fanon, 1986). Frantz Fanon (1986) understood that colonial forces had been firmly ingrained in the psyche of Black people living in both colonised nations and White-majority countries, resulting in profound alienations and estrangement. For Fanon, a psychiatrist, albeit a critical one, this resulted in an increased risk of acquiring psychiatric illnesses juxtaposed with treatment systems inadequate to the task of healing this colonial dysfunction.

Mainstream psychiatric epidemiological studies show people of colour who resided in the UK for a more extended period had a significantly increased risk of getting a psychotic illness. Before the age of eleven, those who arrived in the UK were more likely to develop psychosis later in life (Bhui, Stansfeld, Hull, & Priebe, 2003; National Centre for Social Research, 2002). One possible reason is that events or life changes such as acculturation, which occur between their arrival in the UK and their period of adaption, increase psychosocial stress and raise the risk of developing ‘schizophrenia’ (Bhugra, 2004). Fanon's notion of racism and cultural alienation remains germane to this context.

Barriers to seeking help

Voluntary engagement with mental health services is low among people of colour diagnosed with ‘schizophrenia.’ Wagstaff et al. (2018) investigated the experiences of men diagnosed with ‘schizophrenia’ who identified as 'Black ' and had a history of disengagement from mental health services. The findings of this study indicate that participants felt "hounded" by services, and several expressed a desire for services to leave them alone. The older participants reflected on their changing attitudes toward mental health services over time, and most participants could point to some positive aspects of their experiences with services. The findings of this study indicate that carrying a diagnosis of mental illness and using services continues to be associated with a high level of stigma, which had a detrimental effect on participants' identities and thus played a significant role in their disengagement experience. However, this study is limited because it only includes men and people of African descent, excluding other ethnicities. Additionally, it does not mention how ethnic identity influences engagement and disengagement with mental health services.

Stigma relating to mental health and distress appears to be prevalent across cultures and contact with services often amplifies this stigma. Shidhaye and Kermode (2012) suggested that in India, stigma heavily influences the family members of an individual diagnosed with a mental health illness. This stigma prompts families to contain the individual, which further provides a barrier to seeking help. Research has shown that in many Indian cultures, the family holds the key responsibility for treatment and care for a person diagnosed with mental illness (Khandelwal et al., 2004; Moorkath et al., 2019). It is more likely that professional help is sought when the ingroup endorses this (Shankar et al., 2006). Individuals from Indian backgrounds support lay help to a greater extent than professional help (Altweck et al., 2015). This supports previous studies that professional help is viewed as supplementary to help organised within communities. The critical determinant of help-seeking behaviour can be a stigma and fear of disclosing feelings of psychosis to loved ones in fear of being rejected by the community and the inability to enter a marriage (Loganathan and Murthy, 2008). Traditional methods of help-seeking and provision of support are passed across generations and may be deeply ingrained in local culture and communities. These sociocultural embedded methods of help-seeking persist regardless of increasing affluence or socioeconomic progress (Naik et al., 2012).

Various psychiatric commentators and researchers have highlighted cultural phenomena felt to be uniquely problematic in complicating the assumed virtues of psychiatric support and intervention. For example, Shafiq (2020), amongst others, identifies culturally based supernatural belief systems deployed by South Asian communities as problematic for global mental health objectives. From this perspective, people prefer to understand experiences more ‘appropriately’ deemed to be psychiatric pathology in spiritual or supernatural terms or tend to somatise psychiatric ‘symptoms,’ which can steer people to ‘mistakenly’ seek help from either general practitioners or faith healers.

Local or culturally specific beliefs about the causation and meaning of mental distress may influence individuals from different cultures' help-seeking behaviour. This is, in turn, complicated by the expectations of psychiatric orthodoxy. Response to the possible influence of culture on symptoms and motivation to seek help has led to various developments in psychiatry designed to address cultural perceptions of cause, context, and support. For example, a case report from India presents an attempt at ‘cultural formulation’ (Dhanasekaran et al., 2017). Arguably, however, despite making efforts to appreciate cultural and spiritual factors, the overarching bio-medical frame remains intact, and medication is prioritised in treatment.

In the mainstream literature, apart from stigma but often associated with it, other reasons for not getting help include believing that one does not require it (i.e., an illusion of normalcy), a scarcity of resources, and a lack of faith in specialists (SnellRood et al., 2017). Biddle et al. (2007) coined the term "cycle of avoidance" to describe barriers to getting help. That is, individuals refuse to recognise their anguish as "genuine" or "severe" and continually push the threshold for help-seeking back until a crisis occurs (Picco et al., 2018). In other instances, that threshold may be lowered to where individuals struggle to initiate the help-seeking process.

Whilst it has been suggested that self-stigmatisation may function as a barrier to accessing mental health services, there has been very little research to support this claim. In a study of the effects of self-stigma and perceived stigmatisation by others, Cheng et al. (2013) reported that people who were fearful of being stigmatised by others for seeking professional psychological help were more likely to experience self-stigmatisation about help-seeking, suggesting that increased expectation of public stigma may predict self-stigma. Additionally, their findings indicated that minoritised ethnic groups experienced lower levels of self-stigma associated with seeking psychological help among African Americans.

Furthermore, Shepherd and Rickard (2011) found that whilst self-stigma was predictive of help-seeking intentions, personal attitudes towards help-seeking fully mediated the relationship. This finding was corroborated by Bathje and Prior (2011) in their study of American college student attitudes to help-seeking. Other evidence suggests that agreement with the public stigma of mental illness partially mediates the relationship between the perceived public stigma of help-seeking and the predicted internalisation of stigma as a result of help-seeking (Bathje & Prior, 2011; Yu et al., 2022), suggesting that it is necessary to agree with public stigma for self-stigmatisation to occur. However, it appears that whilst endorsement of the belief that people with mental health problems are unworthy of help and sympathy predicted self-stigma, attitudes of anger, fear, controllability, and avoidance were not predictive of self-stigma. Morgades – Bamba (2019) propose that individuals diagnosed with ‘schizophrenia’ might agree with such negative stereotypes and feel a little alienated but, at the same time, think that they are unique, which could reduce the harm.

Research conducted on individuals from Arab ethnic backgrounds concerning help seeking behaviour is sparse. Alhomaizi et al. (2018) conducted a research study on help-seeking behaviour in Arab individuals. The authors argue that individuals, similarly to other remarked upon ethnic groups, initially seek help for their mental health issues from faith leaders due to the decreased stigma associated with visiting a faith leader compared to seeing mental health services. The family also provided a decisive factor in the initiation of help-seeking. The findings of Alhomaizi et al. (2018) are consistent with Hasan (2017). They point out that it is apparent that psychiatrists are preferred the least because of stigma. Within a psychiatric frame, psychiatric illness is often accompanied by social stigma, leading to the sufferer and his family's tendency to hide the problem and avoid psychiatric treatment. Individuals diagnosed with ‘schizophrenia’ had a high prevalence of contacting their faith leaders before presenting at mental health facilities.

Professional treatment is not usually sought in Arab communities, even though mental health illnesses can deteriorate without support (Okasha, 2003). For example, families fear that women with mental health problems (whether daughter, wife, or sister) will bring a ‘stain’ to their family name (Okasha, 2003), which is a significant reason why women face greater stigma when seeking mental health professionals help than men do, and why men are admitted to the hospital at a higher rate (Dalky, 2012). Arab families who enter hospitals for mental health problems frequently face social stigma, resulting in rejection, nonmarriage, or divorce (Al-Sawafi, 2021). Despite the widespread perception that attitudes and behaviour toward persons with mental health illnesses are changing, many Arab families continue to be impacted by rigid cultural beliefs and social standards.

In Arab societies, the family holds a central place in both Muslim and Christian communities, providing unwavering support and reflecting shared values. Family involvement is crucial during crises, and mental illness is treated as a family concern. Patients often seek treatment accompanied by family members who function as "cotherapists." However, this supportive role is complicated by a fear of damaging the family’s reputation. Mental illness can lead to "stigma by association," affecting the family’s social standing, marital prospects, and business relationships. Public visibility of mental illness can bring social shame, prompting families to protect their reputation and prevent the manifestation of mental illness within the family. Arabs have a historical pride in their contributions to medicine, with notable figures like Avicenna and Al-Razi shaping early neuropsychiatry. Studies show that Muslims often prefer seeking help from religious leaders over mental health professionals, reflecting a reliance on faith for healing.

In a global context, different Arab countries exhibit distinct cultural beliefs and attitudes towards mental health, shaped by their unique social, historical, and religious contexts. Common themes across the Arab world include the importance of family and the influence of religion, but the specifics can vary significantly from one country to another. Fekih-Romdhane (2023) found significant differences in attitudes towards help-seeking based on age, gender, family psychiatric history, causal beliefs, and knowledge and attitudes about mental illness in 16 Arab countries. It also highlighted variations across Arab countries in public views of mental illnesses, their causal attributions, help-seeking behaviours, and preferred help sources. For example, in Lebanon, there is a comparatively more open attitude towards mental health (Aramouny et al. 2020), influenced by its diverse religious and cultural landscape. Awareness of mental health issues is growing, especially in urban areas, and there is an increasing acceptance of psychiatric treatment. In comparison to Iran, where 88.90% of the families of individuals who carry the label of ‘schizophrenia’ had a negative attitude towards mental illness (Rahmani et al 2015).

A rapid review reveals that few studies have systematically explored the dimensions, prevalence, and consequences of stigma in Arab countries and research is scarce within this field (Sweileh, 2024). This underscores the need for more comprehensive and systematic studies to better understand these aspects of stigma in the Arab context.

From a critical perspective, it is worth noting that globally there are a range of culturally located forms of support for individuals in mental distress. Some of these will be helpful, some not so helpful (it may be that different things help different people in different circumstances), and some responses will be abusive or neglectful. Very similar observations can be made of Western psychiatry, which is not immune from reproducing its own cultural biases. Indeed, a paradox for psychiatry has been the noted better recovery rates for serious mental health problems in the developing world[5] in comparison to the West and the incompatibilities of psychiatry applied uncritically across cultures. For these reasons, critical voices over a lengthy period of time, even within the psychiatric discipline, have argued for adaptations and mutual learning across cultures. In this way, elements of the global mental health movement seek to build upon certain local, culturally approved approaches to help and support, such as traditional healers, rather than transplant Western psychiatry wholesale (Nortje et al., 2016). In the UK, Black communities have, over the years, developed their own place-based alternative community mental health and advocacy services (see Wainwright et al., 2019). These have variously been wholly independent of or allied to mainstream mental health services, so they may not have consistently substituted for psychiatric care, but they do offer an alternative, often creative spaces for help and support acceptable to racialised and discriminated against people.

From an anti-psychiatry or abolitionist perspective, merely modifying psychiatry to render it more culturally sensitive does not address more fundamental critique and also, arguably, minimises intersectional issues, such as the pervasive impact of patriarchal dominance or

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[5] According to critical commentators such as Whitaker, this may be simply because people lack ready access to antipsychotic medication which is implicated in iatrogenic chronicity. This is not the same as saying people in serious mental distress are having their needs met, and many experience lives of exclusion and neglect.

other social hierarchies and economic disadvantages integral to, or overlain on, prevailing cultures.

Much of the psychiatric literature on cultural differences is wrapped up with, implicitly or explicitly, locating the psychiatric episteme as the superior font of knowledge and, by extension, disputing or denigrating culturally located alternative understandings. These authors arguably make the mistake of assuming that their knowledge, or way of understanding mental distress, is the only knowledge worth having or, to put it simply, psychiatry is right. Everyone who disagrees is wrong. Yet critical voices, like those emerging in mad studies, dispute this and make the case that Black, indigenous and people of colour must be at the centre of generating their own understandings of mental distress, which can then better inform offers of help and support that work with the grain of these understandings rather than against them.

The stigma associated with mental health services and their staff is a complex issue that has been extensively studied in the literature (McKenzie et al., 2022). What's concerning is that some staff within psychiatric services may also hold stigmatizing attitudes towards the individuals they are meant to support (Koutra et al., 2022). Despite their professional roles, they can unknowingly perpetuate harmful stereotypes and beliefs about mental health, mirroring the stigmatizing attitudes found in the general public. Such attitudes can negatively impact the quality of care and support provided to those seeking help, further reinforcing the cycle of stigma.

At this juncture, it is worth noting the seeming paradox that people of colour are overrepresented in diagnoses, especially of severe mental illness, and find themselves concentrated in inpatient and secure services but seem to face barriers to accessing services in the first place. This dynamic is in part predicated upon stigma as one of the barriers to help-seeking but also amplifies stigma as people of colour find themselves accessing care via compulsory and coercive pathways, including the police and the courts. They then find themselves labelled with the most extreme and stigmatised signifiers of illness and madness. This, in turn, exacerbates mistrust and fears within and towards minority communities. Delayed help-seeking or inadequate or lacking responses from services exacerbate distress, consequent deteriorations, and disturbed behaviour, then invite the aforementioned coercive responses. The explanation for any seeming contradiction is, thus, that these factors of overrepresentation, frustrated help-seeking, and stigma are indeed synergistic but in a negative way for people of colour. Different factors and influences compound each other in escalating cycles and layers of disadvantage and exclusion. Service users, refusers of services, family members, and the staff who work in services are all bound up in the associated production and reproduction of stigma. Taken together, a case can be argued for both stigma minimisation efforts and the development of more acceptable, culturally appropriate services or alternative forms of help and support that better meet the needs of individuals in distress, their families, and communities. To date, however, attempts to tackle stigma have proved problematic in some quite general ways but also in terms of engagement with race, ethnicity, and culture.

Disparities in treatment

Burke (2008) and Collins (2017) report that people of African-Caribbean heritage are more likely to be overmedicated relative to other ethnic groups and not be given enough information about the medications prescribed to them. Indeed, a literature search originating in Belgium concluded that the issue of disparities in pharmacological treatment for service users from ethnic minorities relative to White peers is a global issue (Lepiece et al., 2014). In general, White people were more likely to complete a course of treatment, move to recovery and see an improvement compared to people of colour. However, a substantial minority of patients wait longer than 12 weeks to start treatment after a referral from the Early Intervention Service. Halvorsrud et al. (2019) suggested that the risk for diagnosis was higher in people of colour. Minority status could be a risk factor for increased rates of mental distress, subsequently diagnosed as an illness, for instance, in relation to the psychosocial stresses of racism and dislocations of migration. But these rates are also complicated by culturally insensitive misdiagnosis and the operation within psychiatry of a negative intersection between socially constructed notions of race and illness (Stowell-Smith & McKeown, 2001). Due to a lack of information and insensitive responses from front-line professionals, Black people frequently take extremely tortuous paths to obtain needed assistance or give up entirely (Rabidee et al., 2013). Therefore, we need to understand various discriminatory responses by mental health services.

Impact of Racism

Experiencing racism when accessing healthcare services has been highlighted during the global Covid-19 pandemic. The current outbreak of the novel coronavirus epicentred in China has spread to many other countries (Velevan and Meyer, 2020). Reports have described increased Covid-19 deaths in people of colour in the UK (Markus and Brainin, 2020). This may be due to socioeconomic factors, cultural or lifestyle factors, genetic predisposition, or pathophysiological differences (Khunti et al., 2020). Healthcare workers who are a person of colour are 1.5 times more likely to acquire Covid-19 (Chakravoty et al. 2020). Racism may play a role in this (Razaq et al. 2020) as people of colour, who may be experiencing symptoms of Covid-19, may fear or expect that racism may be faced when accessing support services and then inevitably delay help-seeking. The evidence is still limited; however, research questions such as why ethnicity/race seems to be linked to the acquisition of Covid-19 need to be addressed urgently. The experiences of racism during the Covid-19 pandemic, particularly among people of colour seeking healthcare services, are highly relevant to the thesis on stigma, help-seeking, and people of colour with 'schizophrenia.' These experiences highlight the intersectionality of stigmatization, drawing attention to the layered challenges faced by people of colour in accessing mental health support. The potential fear of racism when seeking help may function as a significant barrier for individuals with 'Schizophrenia' from minority backgrounds, impacting their willingness to seek professional mental health services.

People of colour are more likely to be detained under the Mental Health Act 1983 than their White counterparts (Gajwani et al., 2016). According to the Adult Psychiatric Morbidity Survey conducted in 2021, people of colour have low treatment rates. Ethnic disparities in service use may arise only after the first episode of psychosis; this may be due to increased stigma within ethnic minority communities (Jongsma, 2021), mistrust and fearfulness surrounding engagement with mainstream services (e.g. Hall et al., 2022), or complex combinations of social factors grounded in a negative experience and stereotyping (Boast & Chesterman, 1995). Those from a minority group may choose to avoid seeking out support from mental health services to avoid being labelled in a stigmatising way in their community (Corrigan, 2004). This may be one of the most critical ways stigma hinders seeking help.

Considerations of race, racism and disadvantage have been explicitly applied to theorising stigma. Abdi Kusow's study with Somali immigrants in Canada illustrates how micro-sociological techniques have been used to extend and complicate Goffman's original conceptualisation of stigma. Kusow questions one of Goffman's central assumptions, namely the presence of a normatively agreed knowledge of the criteria for and distribution of stigma, by focusing on racial stigmatisation (Kusow, 2004). He demonstrates how the existence of mutually unintelligible or opposing social and cultural ideas within the same geographical region alters who and what is stigmatised and how stigma is fought and, in some circumstances, reversed (Kusow, 2004). Through this study of the social contacts of Somali migrants in Canada, Kusow concludes that stigma is constantly dynamic, unpredictable, and changeable. He describes how this group of migrants resists the stigmas connected with being Black, African, migrant, and Muslim in contemporary Canadian culture by performing an alternative Somali value system. Indeed, the Somalis in his research said that they had never heard the term 'race' or encountered racism before their interactions with (racist) White Canadians. More precisely, they were unfamiliar with North American race epistemologies, in which racism typically centres on observable judgments of skin colour.

Karlsen et al. (2005) determined that African Caribbeans faced the most racial harassment in the United Kingdom, followed by Pakistanis and Indians, Bangladeshis, and Irish groupings. Fanon's (1986) theoretical perspective on racial discrimination also supports the notion that, as a result of an imagined White superiority in European countries, Black groups subconsciously created a protective bubble around themselves, resulting, perhaps paradoxically, in increased levels of alienation and a greater propensity for mental distress.

The utilisation of mental health services by people of colour whose experiences and contact with services attract a diagnosis of ‘schizophrenia’ is multifaceted. From a psychiatric perspective, there is evidence that the duration of untreated psychosis and treatment initiation is a prognostic factor in ‘schizophrenia’ (Souaiby et al., 2019). Arguably, regardless of one’s favoured conceptual framework, barriers to seeking help can lead to exacerbations of mental distress, however defined. Various anomalies afflict the accommodation of race/ethnicity within the psychiatric system, including overrepresentation in diagnoses such as ‘schizophrenia’ and concentration at the hard end of services, such as secure units, or receipt of more coercive practices, higher doses of medication and less psychotherapy; even members of the psychiatric profession have acknowledged structural racisms in the system (Shim, 2021).

Community-led services prioritize the involvement of individuals with lived experiences of mental health challenges, as well as their families and support networks, in designing and delivering care. By involving those directly affected by mental health issues, these services can better understand and address the unique needs and concerns of the community. Additionally, community-led services may be more culturally sensitive and responsive to diverse populations, including those facing intersections between racism and stigma, which are often inadequately addressed in mainstream mental health services (McMorrow et al., 2021).

The mainstream services do not provide adequate family support (Fadden 2018). Furthermore, most family support and therapy models are ethnocentric, resulting in a lack of meaningfully designed culturally sensitive family support. Contrary to the preferred Western model of autonomous, independent individualism, people of colour have observed networks of inter-dependencies; therefore, family interventions for people of colour and their family members who carry the diagnosis of ‘schizophrenia’ should focus on incorporating this in treatment.

Anti-Stigma Campaigns

Anti-stigma campaigns are a popular approach for addressing the stigma and discrimination associated with mental illness, including ‘schizophrenia.’ These campaigns aim to increase awareness and understanding of mental illness and reduce negative attitudes towards people living with mental illness. Over the years, several different anti-stigma campaigns have been developed and implemented across the world, with varying degrees of success.

Anti-stigma campaigns are integral to public health strategies aimed at reducing the stigma associated with mental health conditions. These campaigns operate on several foundational principles. Education and awareness are primary components, with campaigns seeking to increase public knowledge about mental health conditions, their prevalence, and their impact on individuals. The underlying rationale is that misconceptions and a lack of information significantly contribute to stigma. By disseminating accurate information, these campaigns aim to dispel myths, reduce fear, and correct misunderstandings surrounding mental health issues (Corrigan & Watson, 2002).

Another critical strategy employed in anti-stigma campaigns is contact-based interventions. These initiatives facilitate direct interactions between the public and individuals who have mental health conditions. The rationale here is grounded in social psychology, where personal contact with individuals experiencing mental health issues can humanize these conditions and reduce prejudice. Personal stories and testimonials are particularly effective in fostering empathy and breaking down stereotypes, as they provide a relatable and human perspective on mental health conditions (Pettigrew & Tropp, 2006).

Normalization is another pivotal element of anti-stigma efforts. Campaigns often aim to portray mental health conditions as common and treatable, which helps to reduce the perception that these conditions are abnormal or shameful. By emphasizing the widespread nature of mental health issues and the availability of effective treatments, these campaigns strive to lessen the sense of isolation and shame that individuals might experience (Stuart, 2005). Normalization efforts are designed to integrate mental health discussions into everyday conversations, making them a routine part of public discourse.

Finally, empowerment and advocacy are crucial aspects of anti-stigma campaigns. Encouraging individuals with mental health conditions to share their experiences and advocate for their rights is a powerful method of challenging societal norms and promoting systemic change. Empowerment initiatives aim to give a voice to those affected, fostering a sense of agency and community among individuals with mental health conditions. This aspect of anti-stigma work not only helps to reduce internalized stigma but also promotes broader social acceptance and policy changes (Corrigan et al., 2012).

Types of initiatives

Anti-stigma initiatives aimed at mental health conditions can be broadly categorized into charitable initiatives and activist/community-led initiatives. Although both types strive to mitigate the stigma associated with mental health issues, they differ significantly in their objectives, methodologies, and underlying philosophies.

Charitable initiatives are typically organized by non-profit organizations, governmental agencies, or large health charities. These initiatives usually have structured programs and receive funding from donations, grants, or governmental support. Their primary objectives include raising awareness, reducing stigma, and promoting access to mental health services.

A central goal of charitable initiatives is to increase public knowledge about mental health conditions. In addition to public awareness, charitable initiatives often employ contact-based strategies. These initiatives facilitate direct interactions between the public and individuals who have mental health conditions, grounded in the idea that personal contact can humanize these conditions and reduce prejudice. Examples of charitable initiatives include "Time to Change," a well-known campaign in the UK aimed at changing attitudes towards mental health through public education and engagement, and information produced by "Mind," a UK-based mental health charity offering information and advice to people with mental health problems while campaigning to improve services, raise awareness, and promote understanding.

Activist/community-led initiatives often engage in public demonstrations and advocacy to raise awareness and demand policy changes. They organize protests, rallies, and advocacy campaigns to highlight issues related to mental health stigma and to advocate for systemic changes that address these issues. These initiatives also establish peer support groups, where individuals with lived experiences can share their stories, provide mutual support, and advocate for change.

Examples of activist/community-led initiatives include "Mad Pride," an international movement that celebrates the identities and communities of people with mental health conditions, challenging stereotypes and advocating for human rights, and challenges posed by the "Hearing Voices Network," a grassroots organization that provides support and advocacy for individuals who experience auditory hallucinations, promoting the acceptance of diverse mental health experiences.

Arts, performance, and community mental health

There is growing evidence that participation in creative artistic activities can have certain therapeutic or well-being benefits, though the quality of such evidence has been remarked upon as being anecdotal (Clift 2012; Leckey 2011). These have included endeavours deploying drama as the focus of therapeutic activity (Orkibi et al. 2014), opening up interest in the power of imagination in healing (Chapman 2014). It may be the case that such initiatives are most in tune with engendering those outcomes latterly associated with a turn to recovery within services, such as strengthening a sense of self, meaning and purpose, building coping strategies and fostering hope (Spandler et al. 2007).

Similarly, linking arts and mental health, for example within exhibitions, programmes of performing arts or film screenings, and national festivals, has become part of the repertoire of anti-stigma interventions; among other impacts, engaging people at the level of their emotions (Lamb 2009; Michalak et al. 2014; Quinn et al. 2011; Twardzicki 2008). Under the rubric of a Disability Arts Movement, performance art and associated curricula have been exhorted to take on board the tenets of disabled people’s movements to explicitly challenge discrimination and stigma (Barnes and Mercer 2001; Eisenhauer 2007). Furthermore, in the context of serious mental health problems, theatre can be used to create more democratic spaces that bridge art and science, connecting lived experience with an audience (Boydell, 2011).

Comedy can offer positive potential in highlighting and addressing stigma (Corrigan et al. 2014; Jones et al. 2014; Twardzicki and Jones 2017; Valenta 2018) or, in some instances, be a negative influence that contributes to stigma or reinforces lazily stereotypical representations (Nemeth 2009). Comedy also traverses the intersection of race and mental health, with both affirming and stigmatising tropes (Haggins 2007). There is a rightful objection to latter-day media gawping at mental distress, such as that experienced by celebrities, and this can seem not so far removed from the earlier parading of asylum patients as objects of ridicule and entertainment for visiting sightseers (Porter 1987). Media commentators who have pointed out such continuities of bad taste humour also recognise some legitimacy in poking fun at the peculiarities of psychiatry and refrain from placing madness itself completely off-limits for comedy. Indeed, such comedy has been exploited for progressive ends by comics with lived experience of mental distress and organised service user and survivor movements to counteract processes of psychiatric othering (Cross 2013). Mainstream anti-stigma campaigns also use comic elements, such as the use of ironic postcard messages highlighting absurdities of othering or the alienation of stigma in the Time to Change programme. Yet these remain framed by a totalising bio-medical view of mental distress, suggesting an opening for alternatively conceived approaches.

Mad Studies and Anti-Anti-Stigma Interventions

The central message of many anti-stigma campaigns, that mental illness is an illness just like any other, somatic, illness, has been challenged from critical perspectives, which view the message as a fallacy (Chrtkova 2016). Similarly, this core message has been challenged by researchers within the psychiatric field, who see it as particularly ineffective, as the public do not agree with it, and highlight the lack of evaluation of many anti-stigma campaigns (Lauber 2008). Henderson (2018) has drawn attention to the tendency within television drama to consolidate mainstream orthodoxies, because psychiatric interventions such as medication can “work” dramatically as a simple and comprehensible set of solutions for complex storylines. This author went on to suggest that alternative perspectives reflecting the political context and debates within the survivor movement: “might provide a productive alternative vein of storytelling that could broaden our understanding of the social meaning of suffering and thus help to challenge stigma” (Henderson 2018, p. 115). Several critics have addressed perceived inadequacies of mainstream anti-stigma campaigns, and certain of these failings have, indeed, been recognised by some key protagonists within the mainstream (Sartorius 2002; Stuart et al. 2011). The weight of critique, however, comes from commentators situated externally to the psychiatric orthodoxy, and new voices have emerged latterly, associated with the relatively new field of mad studies (LeFrançois et al. 2013).

One such set of alternative discourses can be found within mad studies; a field not averse to mixing activist, artistic, and scholarly endeavours and interests to challenge psychiatric orthodoxies and injustices. Taggart and Speed (2019) developed a critique of the theoretical and conceptual basis of standard anti-stigma campaign messages and argued that critical knowledge and ideas from survivor perspectives, such as those propounded within the emergent mad studies movement, offer the potential for “epistemic resistances” that better reflect the available plurality of understandings of mental health within the mission to challenge stigma.

Mad Studies scholars argue that conventional anti-stigma campaigns, while well-intentioned, often reinforce existing power dynamics and fail to address the systemic issues underpinning mental health stigma, including, crucially, who gets to decide what knowledge is legitimate. Effectively, anti-stigma campaigns, though often well-meaning, merely reproduce the mainstream orthodoxy, which from a mad studies perspective is responsible for much that is detrimental and stigmatising in the first place. These critiques form the basis of what has been termed "anti-anti-stigma" interventions (Berger, 2013).

From a broader critical perspective, Pilgrim and Rogers (2005) raised important questions about whose interests are being served in anti-stigma campaigns and highlighted implicit and explicit tendencies within a psychiatric paternalism to reinforce singularly medical-psychiatric understandings of mental health problems, the importance of psychiatric interventions, and necessary compliance with these. Harper (2005), indeed, has pointed out that much of the critique of the media in this regard is, itself, guilty of misrepresentation, lack of theoretical sophistication and weak argumentation. The wide-ranging focus of anti-stigma campaigns, attempting to influence the general public as a whole, has been questioned, given that people who spend more time with individuals in mental distress, such as psychiatric professionals, are just as likely to hold stereotypical, negative, and stigmatising views (Lauber et al. 2006). Bates and Stickley (2013) further contended that professional tendencies towards risk aversion and the undermining of personal autonomy implicit within mental health legislation both contribute to the consolidation and perpetuation of stigma. Indeed, when asked, people subject to mental health stigma prioritise changes within services they rely on, over and above action within society at large (Pinfold et al. 2015).

Anti-anti-stigma interventions, informed by Mad Studies, seek to challenge the dominant medical model of mental health that often pathologizes and marginalizes individuals with mental health conditions. Instead of merely aiming to reduce stigma through increased awareness and contact, these interventions emphasize the importance of understanding mental health through a socio-political lens. This approach highlights the role of social, economic, and political factors in shaping mental health experiences and advocates for systemic change to address these root causes.

Moreover, anti-anti-stigma interventions prioritize the voices and experiences of individuals who have lived with mental health conditions. They emphasize narrative sovereignty, where people with mental health conditions have control over their own stories, the way these stories are used in public discourse, and that such survivor accounts are placed in the foreground. This approach seeks to move beyond tokenistic inclusion, advocating for genuine participation and leadership of people with lived experiences in mental health advocacy and policymaking (Daley, 2018).

Researchers have studied how stigma can be minimised by designing anti-stigma initiatives and analysing national anti-stigma campaigns' efficacy after Goffman's (1963) work on the issue. The media is an essential source of information and arguably disinformation about mental distress. This can be a positive source of learning for the general public, with television and newspapers/magazines being two of the most prominent sources (Naim, 2011) or provide the vectors by which stigma is transmitted or reinforced.

History of Anti-stigma campaigns

The history of anti-stigma campaigns in the United Kingdom exemplifies a significant transformation in societal attitudes towards mental health. Historically, stigma associated with mental illness has served as a substantial impediment to individuals seeking assistance and receiving appropriate care. Over the decades, numerous campaigns have endeavoured to dismantle these prejudices, thereby fostering a more understanding and supportive societal environment.

In the UK, the Mental Health Act of 1959 marked a significant shift in the treatment and perception of mental health. By putting an emphasis on moving away from institutionalisation towards community care, this legislation can be seen to have laid the groundwork for state-sponsored future advocacy and anti-stigma efforts. In this context various organisations outside of the state, such as the National Association for Mental Health (1946) renamed MIND (Toms, 2017; Blakemore, 2013), can be seen to have been pivotal in advocating for mental health awareness and combating stigma. Over the decades, MIND has launched various initiatives to support individuals with mental health issues and promote public education. Nevertheless, such organisations have been criticised for becoming too close to orthodox psychiatric and government systems; moving away from more radical roots to a more co-opted positioning close to the mainstream (Crossley, 1998; Toms, 2022). Though co-optation threats exist in a broader sense for all critical voices, outside of the mainstream have been various self-organised mental health survivor movements which arguably pose different questions about stigma, discrimination and disadvantage and could offer different solutions (Barnetz & Gefen, 2022).

A number of mainstream anti stigma programmes have been enacted in the UK. Run by the Royal College of Psychiatrists, the Changing Minds Campaign (1998 – 2003) aimed to reduce stigma through public education and awareness activities. It represented one of the first coordinated efforts to address mental health stigma at a national level in the UK. This campaign employed a multi-faceted approach, utilizing media campaigns, educational resources, and partnerships with other organizations to shift public attitudes. Key components included television advertisements, brochures, and public service announcements designed to dispel myths and promote understanding about mental illness (Luty, 2007).

Time to Change (2007-2021)

A collaboration between MIND and Rethink Mental Illness, Time to Change was the largest anti-stigma campaign in the UK. It employed mass media, social engagement, and educational resources to change public perceptions and encourage open conversations about mental health. Notable initiatives include national advertising, personal storytelling, and workplace training programs. One of the campaign's most impactful strategies has been the use of real-life stories shared by individuals with lived experience of mental health issues. This personal approach humanizes mental health conditions and fosters empathy and understanding. Additionally, Time to Change has implemented workplace training programs aimed at reducing stigma in professional environments, thereby creating more supportive workplaces. It has come to an end due to lack of funding after 15 years (Hermaszewska et al. 2022).

Heads Together (2016-present)

Launched by the Royal Foundation of The Prince and Princess of Wales and Prince Harry, Heads Together focuses on high-profile advocacy and partnerships to tackle mental health stigma (Glasper, 2017). Leveraging the influence of the royal family and prominent public figures, this campaign has significantly increased the visibility and acceptance of mental health discussions. Heads Together integrates multiple initiatives, including the "Mentally Healthy Schools" program, which provides resources to improve mental health support in educational settings, and the "Mind Over Marathon" documentary, which follows marathon runners with mental health challenges, illustrating their journeys and the importance of mental health support. *Every Mind Matters (2019-present)*

Initiated by Public Health England, Every Mind Matters provides practical advice and tools for managing mental health (Farrell, 2020). This campaign aims to empower individuals to take control of their mental well-being and reduce the stigma associated with seeking help (Stuart et al. 2023). It offers a range of resources, including personalized "Mind Plans" that provide tailored advice based on individual mental health needs. The campaign also collaborates with well-known personalities and public figures to raise awareness and encourage public participation in mental health self-care.

Another example of an anti-stigma campaign targeted at people of colour is the 'Racism. It Stops With Me' campaign, launched by the Australian Human Rights Commission in 2012. The campaign aimed to address the issue of racism towards Indigenous Australians, as well as people from culturally and linguistically diverse backgrounds. The initiative included a range of activities, such as community events, social media campaigns, and partnerships with sports organizations, to promote the message that racism is unacceptable. The campaign's success was evaluated using a range of methods, including surveys and focus groups with participants. The findings indicated that the campaign had a positive impact on attitudes towards racism, with an increase in people reporting that they would speak up if they witnessed racism towards others. The campaign was particularly effective in engaging younger audiences, who were more likely to participate in social media campaigns and attend community events.

The issue of racism towards people of colour is pervasive, with many individuals experiencing discrimination and prejudice based on their race or ethnicity. This can manifest in different ways, such as racial profiling, stereotyping, and microaggressions. These experiences can be harmful to an individual's mental health, leading to feelings of isolation, shame, and low self-esteem. Anti-stigma mental health campaigns aim to challenge and dismantle these negative attitudes, with the goal of promoting greater understanding and acceptance of people from diverse backgrounds. One of the challenges of designing effective anti-stigma campaigns is ensuring that the messages resonate with the target audience. People of colour are not a homogeneous group, and experiences of stigma can vary significantly depending on factors such as age, gender, socio-economic status, and cultural background. Therefore, campaigns must be tailored to the specific needs and experiences of different communities to be effective.

Any discussion of the effectiveness of anti-stigma campaigns ought to distinguish between research and commentary that is largely sympathetic to the psychiatric paradigm and other work that proceeds from a more critical perspective. The former attempts to take an instrumental view of the measurable impact of stigma whilst leaving psychiatric intervention untouched as an assumed positive social force. The latter body of work begins with a critical standpoint on psychiatry and, for instance, problematizes the observed fact that most anti-stigma campaigns reproduce a notion of the correctness of psychiatric knowledge such that improving public knowledge of psychiatric understandings then equates to stigma reduction. If, however, the foundational idea that mental illness is an illness like any other extends or compounds stigma, there is a real problem. Once we factor in race and ethnicity, other avenues of criticism are opened up: do these campaigns reach or influence Black communities?; to what extent are anti-stigma campaigns blind or neglectful of ethnic minorities and racism?; to what extent do these campaigns take up the challenge of thinking intersectionally about stigma and people of colour?

Given the negative impact of stigma and the media's potential to influence attitudes, there is concern that media portrayals of people diagnosed with ‘schizophrenia’ contribute to stigma perpetuation (Huang and Priebe, 2003). In the media, several anti-stigma programmes have been promoted. Time to Change[6] is an example of a substantial national programme that aimed to raise awareness of, normalises, and destigmatise mental illness as a formalised type of experience and mental disability. On its own terms, this campaign claimed to be built on unique mental disease perspectives from various sources (i.e., people carrying varying diagnoses and from diverse walks of life). It also provided resources for running seminars to reduce the stigma associated with mental disease that has been created in the media, such as on social media sites. One of the most critical aspects of this campaign was to educate the public about mental illnesses and debunk common "myths" while promoting a more caring and equitable mental health community.

Anti-stigma campaigns targeted at people of colour and specific diagnostic categories, such as ‘schizophrenia,’ aim to raise awareness and challenge negative attitudes towards mental illness and ethnicity. One example of such a campaign is the ‘Like Minds, Like Mine’ campaign in New Zealand. The campaign was designed to reduce the stigma and discrimination associated with mental illness and targeted a range of ethnic groups, including Māori, Pacific Island, and Asian communities. The campaign utilized a range of strategies, including media campaigns, community engagement, and education programs, and was found to increase awareness and reduce discrimination towards mental illness within the targeted communities.

However, there have been criticisms that the campaign may not have addressed the underlying systemic issues that contribute to discrimination and prejudice (Thornicroft et al., 2014). Overall, the 'Like Minds, Like Mine' campaign is an example of a successful anti-stigma campaign that aimed to address the unique challenges faced by different ethnic communities.

Additionally, in the UK, an NHS trust ran a series of Let’s Talk focus groups in London. The report titled "Let's Talk: Engaging Black, Asian and Minority Ethnic (BAME) Communities in Mental Health Stigma Reduction" presents the findings of a

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[6] Time to Change was in its own words ‘England's most ambitious programme to end discrimination faced by people who experience mental health problems’. It was run between 2007 and 2021 by Mind and Rethink, and was funded by the Big Lottery Fund and Comic Relief.

study conducted by the East London NHS Foundation Trust (ELFT) in partnership with City, University of London (ELFT, 2021). The study aimed to understand the views and experiences of BAME communities regarding mental health stigma and explore strategies to engage them in stigma reduction efforts. The report highlights that BAME communities face unique challenges when it comes to mental health, including cultural stigma, discrimination, and lack of trust in mental health services. The study found that BAME communities are more likely to seek support from family and friends rather than mental health services and often turn to religious and spiritual practices to cope with mental health problems. By centring the perspectives and experiences of people with mental health conditions, anti-stigma campaigns that use a mad studies approach can provide a more holistic and inclusive approach to mental health advocacy that acknowledges the unique experiences and needs of people of colour. This can help to address some of the systemic barriers to mental health care faced by people of colour, including racism, poverty, and lack of access to culturally appropriate care.

Moreover, anti-stigma campaigns that are tailored to specific cultural and ethnic groups have been found to be more effective at reducing mental health stigma. This is because these campaigns can better address the cultural factors that impact mental health stigma and can better engage with communities that may be mistrustful of traditional biomedical approaches to mental illness. For example, the "BAME Let's Talk" campaign in the UK used a culturally sensitive approach to engage with Black, Asian, and minority ethnic (BAME) communities and promote mental health awareness (ELFT, 2021). The campaign used community outreach, social media, and peer support networks to address the cultural factors that impact mental health stigma and promote a more inclusive and culturally responsive approach to mental health advocacy. Similarly, the "Like Minds, Like Mine" campaign in New Zealand incorporated the perspectives and experiences of people from diverse cultural backgrounds, including Māori and Pasifika communities.

Despite these successes, critics argue that anti-stigma campaigns targeted at people of colour may not be effective in addressing the underlying systemic issues that contribute to discrimination and prejudice. For example, campaigns may focus on individual attitudes and behaviours rather than the structural factors that contribute to racism and discrimination. Additionally, campaigns may perpetuate stereotypes or tokenism if not carefully designed and implemented. To address these concerns, some researchers have suggested that anti-stigma campaigns should be combined with broader efforts to promote social justice and equality. For example, initiatives that aim to increase diversity and inclusion in workplaces and education systems may have a more significant impact on reducing discrimination towards people of colour than anti-stigma campaigns alone. Furthermore, campaigns should be developed in consultation with affected communities to ensure that messages are culturally appropriate.

Strategies for developing culturally sensitive anti-stigma campaigns for persons of colour

One of the strategies used by some psychiatrically oriented anti-stigma campaigns has been to advocate for a change in the terminology used to describe mental health conditions. For example, the term ‘schizophrenia’ has been criticized for its stigmatizing and inaccurate connotations, and some campaigns have advocated for a name change to promote a more accurate and less stigmatizing understanding of the condition. One study in the mainstream that explored the impact of changing the name of ‘schizophrenia’ found that a new name, "integration disorder," was associated with lower levels of stigma and more positive attitudes toward people with the condition (Sartorius et al., 2014). However, other research has suggested that simply changing the name of a mental health condition may not be sufficient to reduce stigma and improve attitudes toward people with the condition (Lasalvia et al., 2015; Lasalvia and Ruggeri, 2019; Gaebel and Kerst, 2019; Koike et al., 2016).

Japan was the first nation to amend the name of ‘schizophrenia.’ The name change was initiated as part of a movement to eradicate the stigma associated with the diagnosis of ‘schizophrenia.’ Following the movement and name change, there has been a decline in dismissive attitudes toward ‘schizophrenia’ (George & Klijn, 2013). In Japan, Koiske et al. (2016) looked at the long-term impact of a name change on perceptions of ‘schizophrenia’ and potential awareness and negative assumptions. The findings show that the name change effectively reduced stigma against ‘schizophrenia’ among general university students but that the long-term consequences of the name change could vary when more people think of the old and new names as distinct disorders.

Working within the psychiatric paradigm, mental illness perceptions are impossible to alter when receiving constant but unknowing help from the public and daily dialogue. Although analysing simplistic media messages and stereotypical lay audience perceptions, lumping all illnesses into one definition of "mental disease" is oversimplified, it is often helpful when examining simplistic media messages and stereotypical lay audience perceptions. It is also difficult to categorise these conditions simply because everyone's impairments are distinct. As a result, scholars must comprehend psychiatric illnesses as occurring on multiple (yet frequently related) intensity and perception spectrums.

Angermeyer, Matschinger, and Schomerus (2013) announced the results of a new demographic study that revealed shifts in attitudes toward mental health issues recognised in terms of ‘schizophrenia’, depression, and alcoholism. The authors discovered that over two decades, the biological viewpoint of ‘schizophrenia’ as a brain condition had grown, and views toward people identified with the
‘schizophrenia’ label had deteriorated; however, no such pattern was identified for depression or drug addiction (Angermeyer et al. 2013). Within the mainstream, such findings have supported advocacy for a tailored approach to anti-stigma initiatives, arguing that interventions can target attitudes toward individual diagnoses. The survey results indicate that changing people's views of psychosis takes extra effort. While many activists claim that teaching people about the biological origins of psychosis is a powerful way to alleviate the stigma, the research is conflicting, and several findings suggest that biogenetic causal theories may raise anxiety and social distance (Angermeyer & Matschinger, 2005) or be a significant cause of the stigma.

Many anti-stigma campaigns have used the biogenetic approach as a basis (Angermeyer & Matschinger, 2005). The biogenetic approach to stigma reduction employs an "illness philosophy," which uses the same biological and medical theories applicable to physical illness to mental health issues (Read, 2007). In essence, this medical approach to identifying and addressing mental health issues and behaviour considers hormones, organic brain impairments, or biology as the cause (Read, 2007). Psychosis is regarded as a "mental disease like any other illness" in this regard (Read, Haslam, Sayce, & Davies, 2006; Read & Law, 1999). This is mirrored in anti-stigma advocates' terminology; for example, mental health conditions are often referred to as diseases (Read, 2007). Since the individual's genes control the origins of mental health illnesses, this approach means that a biogenetic view of the causes would minimise the public's ability to blame people for their mental health issues (Angermeyer & Matschinger, 2005). However, when empirically assessed, the need for social isolation increased as the general acceptance of biological causes of psychosis increased (Angermeyer et al., 2005). A thorough examination of the results revealed that respondents who agreed that biological factors of psychosis exist also agreed that people with psychosis are unpredictable and risky. Finally, the authors concluded that using a biogenetic approach to stigma reduction could result in more than just a reduction in rejection (Angermeyer and Matschinger, 2005).

According to the biogenetic system, stigma is also a product of the public's mental well-being illiteracy. For example, Jorm et al. (1997) coined the word "mental health literacy" to refer to information and attitudes regarding mental illnesses that help in their identification, treatment, or avoidance (Jorm et al., 1997), and those that pursue the "mental health literacy" and "mental disease like any other condition" strategy associate understanding about mental health issues with an awareness of the illness par excellence (Read, 2007). This technique also involves educating the general population on identifying mental health conditions and attaching diagnostic marks to symptoms (Jorm, 2000).

Proselytisers of this strategy contend that the general public cannot recognise ‘disorders' or comprehend what medical language entails, resulting in misdiagnosed psychiatric conditions at the primary care level and stigma (Jorm, 2000). This perspective is closely related to the biogenetic approach to identifying the origins of mental health disorders. According to research, participants expanded their endorsement of biogenetic conditions as causal in the formation of ‘schizophrenia’ when the medical term ‘schizophrenia’ was added to a vignette, according to research (Angermeyer & Matschinger, 1996).

The main advantage of the mental literacy approach, according to Jorm (2000), is the ability to classify biogenetic causal factors by adding diagnostic marks. While others have argued for the use of mental health awareness to minimise stigma, some have doubted its efficacy (Read, Haslam, Sayce & Davies, 2006). Nineteen experiments assessing the impact of biogenetic causal models on attitudes toward mental health problems were included in a systematic review of twenty-one studies of causal models and attitudes toward mental health problems published between 1970 and 2005. (Read et al., 2006). In addition, one of the nineteen studies identified a connection between biogenetic experiences and optimistic attitudes toward mental illness (Read et al., 2006).

Angermeyer & Matschinger (2005) conducted a pattern study in Germany between 1990 and 2001 to see if the public's causal explanations of psychosis and demand for social isolation shifted. Their results showed that as societal acceptance of biogenetic causal causes for ‘schizophrenia’ grew, so did the need for social distance. Increased belief in stereotypes of lack of self-control, unpredictability, and danger was linked to increased acceptance of biogenetic causal explanations (particularly psychosis as a brain disease). “Educating people about the biological origins of ‘schizophrenia’ does not change their outlook toward people with ‘schizophrenia’,” Angermeyer and Matschinger (2005 p. 334) suggest. Moreover, the biogenetic view of biological psychiatry has been claimed to be underpinned by a kind of essentialist thought about human variation (Haslam, 2000). When it comes to individual distinctions, essentialist reasoning suggests that differences between classes are ‘natural nature' (Haslam, 2000). A separate and underlying property (such as a genetic marker) defines the distinction and brings people with differences together (everyone has this genetic marker). This fundamental property is observable and can be defined, resulting in various characteristics (such as a symptom) (Haslam, 2000). As a result, essentialist thought will widen the gap between groups by instilling in the ingroup the belief that the outgroup is radically different. Such thinking can readily lead to othering: the demonisation and denigration of others.

Essentialist ideology is linked to race and stigma (Bastian & Haslam, 2006; Haslam, Rothschild & Ernst, 2002). Biogenetic theories foster pessimism and perpetuate the stereotype that individuals with mental health illnesses are unhealthy, according to a meta-analytic analysis of the impact of biogenetic explanations on stigma (Kvaale, Haslam & Gottdiener, 2013). Second, while some campaigners advocate for a biogenetic approach to psychosis, the literature suggests that the general public does not share this perspective (Read, 2007; Read et al., 2006). A new analysis of this methodology showed that 35 of the 39 experiments examined the public's preference for biogenetic or psychosocial causal explanations for mental health illnesses, with psychosocial causal explanations showing a strong preference in 35 of the 39 studies (Read, 2007).

To summarise, while many biogenetic anti-stigma campaigns have good intentions, evidence indicates that the general population does not support this strategy. Instead, it opposes what consumers feel to be acceptable for people of colour. There is a small database for its efficacy, and evidence is growing that it could do more harm than good, raising mistrust and bias against people with psychosis.

Associated campaigning has included creative and performance-based efforts to privilege mad stories and reclaim these from perceived abuses in the mainstream (see Costa et al., 2012). Arguably by virtue of its very existence, mad studies are both a challenge and a provocation to prevailing stigma. Building upon earlier Mad Pride efforts to reclaim madness as a positive set of experiences worthy of respect, value and recognition, mad studies make a virtue out of the language of madness.

Some examples of anti-stigma campaigns and broader initiatives that have an interest in challenging stigma. compatible with a mad studies approach arguably include:

- The Hearing Voices Network: This campaign is a global movement that aims to promote an understanding of the experience of hearing voices and other unusual sensory perceptions. The campaign challenges the assumption that hearing voices is always a symptom of mental illness and encourages a more nuanced and contextual understanding of these experiences.
- The Icarus Project: This campaign is a grassroots organization that aims to provide a space for people with mental health conditions to share their experiences and perspectives. The project challenges the idea that mental illness is a fixed and static diagnosis and instead promotes a more dynamic and fluid understanding of mental health.
- The Mad Pride movement: This campaign is a global movement that celebrates the diversity and creativity of people with mental health conditions. The campaign challenges the stigma and discrimination associated with mental illness and promotes a more positive and affirming understanding of mental health.

These initiatives use a range of strategies to promote their messages, including public events (including comedy and performance art), online forums and blogs, zines[7], and peer

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[7] See the recent marvellously creative research by Helen Spandler and colleagues: Spandler, H. (2020)

support networks. More often than not, these are very local or grass-roots endeavours. They also emphasise the lived perspectives and experiences of people who identify as mad or mentally ill in their messaging and strategies, promoting a more inclusive and participatory approach to politicised mental health advocacy. While there is some evidence to suggest that anti-stigma campaigns can be effective at reducing stigma, more research is needed to determine which types of campaigns are most effective and for whom. Additionally, there is a need for more research on the impact of these alternative approaches on mental health stigma.

Anti-stigma campaigns that incorporate a mad studies approach, or ethos offers a more nuanced and contextual understanding of mental health that can be particularly beneficial for people of colour. This is because people of colour often face multiple forms of discrimination and oppression that can impact their mental health and wellbeing and that may not be adequately addressed by traditional biomedical approaches to mental illness.

Summary of the literature review

In summary, too little value is known about the interrelationships between stigma, race and help-seeking in individuals carrying a diagnosis of ‘schizophrenia.’ However, the generalisability of much-published research on this issue is problematic. Although extensive research has been conducted on stigma, mental illness and help seeking, no single study adequately and qualitatively explores people of colour’s experiences carrying the label of ‘schizophrenia’ in stigma and help-seeking experiences.

There is a need for evidence on this subject. Existing studies are primarily quantitative in nature and designed within mainstream paradigms, examining caregiver burden as measured by questionnaires and scales. However, few studies have used qualitative methodologies to delve deeply into relevant caregivers' experiences. In addition, several studies have been conducted on caregivers' experiences caring for relatives with various mental health needs. A substantial amount of psychiatric research has looked at mental illnesses, family burdens and caregiving experiences. However, not much research has given us an insight into the help-seeking experiences of family members of individuals

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Crafting psychiatric contention through single-panel cartoons. Pathographic, https://library.oapen.org/handle/20.500.12657/47038 who carry the ‘schizophrenia’ diagnosis. However, this may be because family members are obligated to support their family member with severe mental distress as there is a lack of professional mental health services available that can add support to the care. This can increase the burden and psychological distress on the family members (Alyafei et al., 2021).

Much of the stigma research done so far has used Western studies, which could be skewed by Western views of psychiatry, psychology, and culture (Corrigan, 2004). To fully understand the concept of stigma concerning diagnostic categories such as ‘schizophrenia,’ more research into the intersection of race and ‘schizophrenia/serious mental distress’ is required. The stigma associated with mental illness in various communities is unknown (Arrindell, 2003). Furthermore, most of the study has focused on adult populations (Link et al., 2004). As a result, there are differences in our awareness of stigma, particularly among young people (Jorm & Wright, 2008).

As a result, the focus of this research will be on race and extreme mental distress stigma. Both factors have significant health consequences, such as establishing appropriate anti-stigma campaigns and further recognising the construct of stigma and how mental illness is construed in various communities. Currently, no research examines the subjective experience of the effectiveness of anti-stigma campaigns in increasing help-seeking that targets all ethnic minority groups.

Moreover, there is a lack of representation of ethnically diverse individuals in anti stigma campaign measures. Furthermore, the effect of the underrepresentation of members of racial and ethnic minority groups in the media ‘schizophrenia’ on members of diverse communities is unknown (Owen, 2012). However, such underrepresentation raises an interesting question about whether the lack of non-White individuals might affect help-seeking behaviours among members of racialised groups carrying a diagnosis of ‘schizophrenia.’ Therefore, it is essential to acknowledge critical perspectives on stigma, ‘schizophrenia’ and psychiatry in general.

In conclusion, anti-stigma campaigns and mad studies offer promising approaches to addressing the stigma and discrimination associated with mental illness, including for individuals who carry the label ‘schizophrenia.’ However, more research is needed to determine which strategies are most effective and to identify the contextual and cultural factors that impact the success of these campaigns. Foregrounding the perspectives and experiences of people identifying as mad is essential to developing effective anti-stigma campaigns and advancing the field of mad studies. Mad studies absolutely refute essentialist bio-genetic psychiatric theorising and also embrace a politics of anti-racism.

Essentialising representations of madness and race come together in unwholesome constellations of eugenics and White supremacy. Grassroots, creative mad studies-inspired critical initiatives have the potential to reach and engage Black communities and simultaneously challenge and transform stigma.

Chapter conclusion

This chapter has provided literature on the existing literature on stigma and mental health in people of colour who carry the label of 'schizophrenia,' the subjective experiences of help-seeking among relatives of people who carry the label of 'schizophrenia' and the intersection of mental health stigma and racialized identities in people of colour. It is clear from the literature that stigma continues to be a major barrier to seeking mental health services or other help and support among people of colour, particularly those carrying a diagnosis of 'schizophrenia.' The research also highlights the need for more research on the subjective experiences of help-seeking among relatives of people diagnosed with 'schizophrenia' and the role of anti-stigma campaigns in reducing mental health stigma among people of colour.

Additionally, the literature suggests that the intersection of mental health stigma and racialized identities in people of colour is complex and requires a more nuanced approach to understanding and addressing the issue. The review of the literature underscores the importance of considering the unique experiences and perspectives of people of colour and the need for culturally responsive and community-approved interventions that address mental health stigma in the context of racialized identities. Overall, this literature review provides a foundation for the research questions and highlights the need for further research to address the complex issue of mental health stigma in people of colour people who carry the label of ‘schizophrenia.’

Chapter 3: Methodology

Chapter three describes the research procedure for studies one, two, three and four. This chapter addresses the many steps of the research, including selection of the participants, data collecting, and data analysis. The chapter also offers information about the theoretical framework and methodology used to undertake this research and a justification for its usage and alignment with mad studies. Interpretive Phenomenological Analysis is my chosen methodology, and I draw upon critical race theory as a critical lens through which to discuss my findings. Furthermore, this chapter discusses the researcher's role in qualitative research concerning reflexivity and positionality.

Qualitative data collection methods

Qualitative methods are research techniques that rely on collecting and analysing nonnumerical data, such as words, images, and observations, to gain insights into social and cultural phenomena. These methods are used in a wide range of fields, including sociology, anthropology, psychology, education, and marketing. Qualitative methods typically involve the collection of data through methods such as interviews, focus groups and observations. Researchers use these methods to gather rich and detailed information about people's experiences, attitudes, and behaviours. The analysis of qualitative data involves a process of coding and categorizing the data to identify themes, patterns, and relationships (Renjith et al., 2021). This process may involve the use of software programs or manual techniques such as content analysis or discourse analysis. Qualitative research often has a flexible and iterative design, allowing researchers to adjust their approach based on emerging insights and new data. The purpose of qualitative research is to create a profound knowledge of the study issue rather than obtaining statistically generalizable conclusions, as in quantitative research (Hamilton and Finlay, 2019). Ultimately, qualitative and quantitative approaches complement each other, both being suited to different kinds of research questions.

The aim of qualitative research is the development of concepts which help us to understand social phenomena in natural rather than experimental settings and which give emphasis to the meanings, experiences, and views of all the participants. Data gathered in qualitative research tends to be nonnumeric and may include interview transcripts, written texts, and less usually visual material.

Quantitative researchers have frequently criticized qualitative approaches for being unable to meet positivistic criteria such as validity and reliability, which are thought to be essential for establishing research "truth" or "proof." Qualitative methodologies, on the other hand, are not concerned with the generalizability of their findings but instead focus on the context that helps us understand the complexity of people's experiences and perspectives, examining the meaning individuals ascribe to their social experiences and lived realities. A qualitative, hermeneutical phenomenological approach is used in this study as an effective method of capturing historically unheard people's voices and subjective realities. When conducting qualitative research, there are numerous methods to select from, such as phenomenological research, grounded theory, ethnography, and case study research.

Phenomenology is the study of experience and conscious structure (Heidegger, 2005). It focuses on our relationships with others and is based on a theory of intentionality. The hermeneutic phenomenology method implies that the study's participants control their narratives and may contribute nuanced views to our knowledge of this phenomenon. Interpretative Phenomenological Analysis (IPA) is a qualitative research approach that aims to explore the subjective experiences of individuals in a particular context. Three of the underpinnings of IPA are phenomenology, hermeneutics, and idiographic, with these foundational concepts fully integrated into the construction of this relatively novel approach (Smith, 2011).

Phenomenology is a philosophical approach that seeks to understand the structures of subjective experience. It was developed by philosophers such as Edmund Husserl and Martin Heidegger in the early 20th century (Husserl and Heidegger, 2014). According to Heidegger, phenomenology is the study of being in the world, which means that our experiences are always contextualized within a broader social and cultural context. IPA draws on this approach to explore how individuals experience and interpret the world around them.

Since its inception, interest in and use of IPA has mushroomed, making it a substantially popular methodology across a number of fields, with an appreciation for its implicit adaptability and accessibility (see Pringle et al., 2011). IPA was developed within health psychology and perhaps unsurprisingly has been most taken up, and urged to be taken up, in studies of the lived experience of health problems and illness, effectively studies of how people make sense of their own experiences related to personal health (Smith, 2011) including mental health and service use (Larkin & Thompson, 2011). When the approach was developed, it was partly a reaction to a previous emphasis on quantification, psychometrics, and positivistic methods within psychology, and for many, the potential shift to embrace qualitative approaches was exciting for the discipline. Part of this appeal was the extent to which the IPA approach made its paradigmatic roots in phenomenology accessible, simplifying the possibilities of taking up these complex ideas into practically doable and meaningful research studies (Todorova, 2011).

Earlier critics of the method urged enhanced reporting of the analytic process and particularly aspects of researcher reflexivity (Cronin & Lowes, 2016). Even those researchers largely well-disposed to IPA acknowledge certain reservations or limitations. For example, Gyollai (2020) is critical of a perceived lack of fidelity to core phenomenological concepts, and Dennison (2019) notes criticisms that it ‘is unscientific, lacking a complex subjectivity and display[s] a promiscuous epistemology’ but goes on to make a virtue of mixing qualitative methods, suggesting the potential for compatibility of IPA with dialogic approaches in future research. More recent commentators continue to take a positive view of the value of IPA for health research and have teased out criteria for quality appraisal, including the following:

- Constructing a compelling, unfolding narrative.
- Developing a vigorous experiential and/or existential account.
- Close analytic reading of participants' words.
- Attending to convergence and divergence
- And fidelity to transparent accounts of the philosophical roots of the method (Nizza et al., 2021).

IPA has been used by researchers locating themselves in the mad studies field (e.g. Stothart, 2018). For a mad studies scholar, however, there are some risks with interpretive research into lived experience (Voronka, 2019). Indeed, the mad studies enterprise is absolutely concerned with the historical and contemporary misuses and co-optations of individuals’ accounts of madness and distress. Bristow (2020:3), for example, in a thesis focused on psychosis, problematises ‘the act of supplanting meaning onto individual experience and thereby co-opting these complex facets of the human condition into academic or professional frameworks’ and asks whether the ‘expression of madness can ever be analysed without necessarily re-inscribing it within such systems of knowledge, thereby committing forms of ‘epistemic violence’. So, for mad scholars like Bristow, the very act of interpretation is hazardous if it serves to reinforce pre-existing and othering narratives of madness. Alertness to these negative possibilities and commitment to reflexivity can help navigate this challenging territory. Fundamentally, the desirability for mad participants to define and speak for themselves is at the heart of such traverses and hopefully central to my research here.

This thesis focuses on examining the relationship between stigma and mental health within minority communities. To gain a deeper understanding of this topic, I consider a phenomenological research approach that emphasizes the lived experiences of individuals within their social and cultural context. As Heidegger (2005) proposed, phenomenology is a philosophical perspective that focuses on exploring how people make sense of the world around them and highlights the importance of understanding individual perspectives.

Rationale for Using Interpretative Phenomenological Analysis (IPA)

For a number of reasons, IPA was chosen for my research, which examines the relationship between mental suffering, racism, and stigma among persons of colour who have been diagnosed with ‘schizophrenia.’

Firstly, a phenomenological theoretical approach best fits the goals of my research. IPA is a data analysis method based on participant observation and interpretation of phenomena. It has its roots in phenomenology. The goal of my research is to delve deeper into the lived experiences of people of colour who encounter racism and stigma in the setting of mental health. I can convey the complex, subjective experiences of these people through the use of IPA, emphasising the individual significance they have on their interactions with mental illness and stigma.

Second, the interpretive and idiographic qualities of IPA make it ideal for comprehending personal perceptions. A thorough investigation of how individuals of colour understand and make sense of their experiences with ‘schizophrenia’ and the stigma attached to it is made possible by this methodology. A thorough examination of the larger social and cultural circumstances of these experiences is made possible by the interpretative component of IPA, which also offers rich, nuanced insights into the difficulties and coping strategies that participants faced. This is important because my research aims to identify the distinct linkages between stigma in society, mental health, and race.

Criticisms and limitations of IPA

IPA has its detractors despite its advantages. It has been argued that the idiographic character of IPA restricts generalizability because experiences are subjective and may not readily transfer to larger groups (Giorgi, 2011; Malim et al., 1992). In contrast to techniques like grounded theory, which use larger samples to support theory, the small sample sizes usually employed in IPA investigations might make it difficult to identify relevant variables (Thomson, 2011). Small samples, according to Smith et al. (2009), enable a more in-depth degree of examination. Similarities and analytical discoveries amongst IPA investigations can provide important background and support the development of theories (Cassidy et al., 2011). They can also lead to insightful conclusions with wider implications (Reid et al., 2005).

I have ensured methodological rigour by selecting a representative and varied sample, upholding reflexive practices to reduce bias, and using qualitative analysis software to address these limitations in my research. Verifying results with participants improve depth and accuracy. Although interpretations are limited by participants' capacity to communicate their experiences and the researcher's analytical skills (Brocki & Wearden, 2006), IPA's rich, in-depth individual insights can make a substantial contribution to our understanding of the intricate interactions between racism, stigma, and mental health issues in people of colour.

IPA emerges as a suitable methodology for exploring stigma, racism, and mental distress among people of colour due to its emphasis on lived experience, sensitivity to context and culture, and flexibility in data collection and analysis. By addressing potential criticisms or limitations through reflexivity, rich description, and attention to power dynamics, this research aims to provide a nuanced understanding of the intersecting challenges faced by marginalized communities.

Suitability for this research

IPA was uniquely positioned to delve deeply into the lived experiences of individuals and uncover the subjective meaning they attach to phenomena such as stigma, racism, and mental distress. This methodology prioritizes the voices of participants, allowing them to articulate their experiences in their own words. For people of colour, whose experiences are often marginalized or invalidated within dominant discourses, IPA provides a platform for reclaiming their narratives and shedding light on the complexities of their lived realities.

The experiences of stigma, racism, and mental distress cannot be divorced from the broader socio-cultural contexts in which they occur. IPA recognizes the importance of context and culture in shaping individuals' perceptions and interpretations of these phenomena. For people of color, whose experiences of stigma and racism are deeply intertwined with their cultural identities and socio-historical contexts, IPA offers a methodological framework for exploring these complexities in depth. By acknowledging and centring the cultural nuances of participants' experiences, IPA ensures that the research remains sensitive to the socio-cultural specificities of marginalized communities. One of the strengths of IPA is its flexibility in data collection and analysis methods. This flexibility allows researchers to adapt to the preferences and needs of participants, particularly when collaborating with marginalized communities whose voices may have been historically silenced or ignored. Whether through in-depth interviews, diary entries, or other forms of qualitative data, IPA enables researchers to capture the richness and complexity of participants' experiences. Additionally, IPA's iterative approach to analysis allows for a nuanced exploration of themes and patterns emerging from the data, ensuring that the research remains grounded in the voices and perspectives of participants.

Despite its strengths, IPA is not without criticisms or limitations. One common critique is its potential for researcher bias, as interpretations are inherently subjective. To mitigate this concern, rigorous reflexivity will be employed throughout the research process. This involves critically examining the researcher's own biases and assumptions and acknowledging their potential impact on data interpretation. Additionally, efforts will be made to ensure the trustworthiness of findings by providing rich, detailed descriptions of participants' experiences and contexts. Findings will be situated within broader theoretical frameworks to enhance their applicability to similar contexts.

Strengths of qualitative methods

One of the strengths of qualitative research is flexibility and relative lack of structure and rigidity constraining approaches. There is, however, a concomitant need to demonstrate rigour in the conduct of the research. For example, Sarah Tracy (2010) provides eight requirements for conducting a legitimate qualitative inquiry. The first criterion pertains to selecting a "deserving" study topic that is relevant, meaningful, engaging, or emotive. Dehumanization, invalidation, and persistent prejudice have been demonstrated to affect Black people's mental and physical health negatively. With a commitment to recognising and correcting societal injustices connected to mental health, the subject of this study truly deserves, as it is understudied and in determined need of inquiry and consciousness-raising. This also pertains to Tracy's second criterion, ensuring that the study will add to the field of study. Her third criterion is rich rigour, which refers to high-quality qualitative research characterised by abundant rich complexity. The fourth criterion, credibility, relates to the study results' trustworthiness and plausibility, while the fifth criterion, sincerity, refers to the researcher's authenticity and genuineness in being upfront and honest about beliefs, views, and commitments. The last three criteria are resonance (the researcher's ability to have a meaningful effect on the reader), ensuring the study and its results are ethical, and developing a meaningfully coherent study that accomplishes the study's objective using methods that are well-aligned with the topic and connect existing literature to current findings. These criteria are critical in executing any qualitative inquiry and will be used to lead the present study from topic identification through interpretation and to write up the findings (Tracy, 2010).

Given the goal of a qualitative phenomenological approach is to uncover the meaning of the participants' experiences by exploring their subjective perspectives, this approach is particularly useful for exploring complex and multifaceted phenomena, such as the experience of stigma and help-seeking for mental health issues. By utilizing this approach, the thesis can gain a more nuanced understanding of how individuals perceive and experience stigma and help-seeking and how these experiences have impacted their lives.

Theoretical Framework

In order to fully comprehend the experience of stigma, utilizing an intersectional approach and critical race theory as a theoretical framework is a valuable approach in this thesis.

As established by Kimberley Crenshaw (1989), intersectionality is an analytical framework for recognising and comprehending how many parts of a person's social and political identities interact to generate distinct forms of discrimination and advantage. Crenshaw alludes to the difficulties faced by women of colour; these women encounter concerns inherent in being a woman and a person of colour and additional axes of differentiation such as poverty and sexuality. Concurrently occupying several identities exposes them to challenges that White women, men of colour, and a considerable number of others do not and cannot face. Since its inception, "intersectionality" has been interpreted broadly to include all identities. Intersectionality is essential for understanding why people harbour stigma, how stigma manifests itself, and how to decrease stigma in the field of madness and mental distress successfully. While many racialised and ethnic groups adhere to similar cultural standards, this does not mean that all members have the same views. Age, gender, and economic status are just a few of the various factors that might influence an individual's perception of mental distress and stigma, as well as racial or ethnic affiliation. Due to the complexities of race and ethnicity, various factors impact an individual's understanding and perception of mental distress. As a result, research on mental illness and race and ethnicity should begin by emphasising identity, employing an intersectional approach, and combining mixed techniques.

By being alert to intersectionality, the experiences of people of colour can be explored to reveal how stigma affects help-seeking behaviours among those carrying a ‘schizophrenia’ diagnosis and how factors such as race, racism, material inequality, gender (particularly in relation to Black males and masculinity), and my own identity as a Black woman can impact these behaviours. Additionally, the idea of migration could be examined to understand potential differences between individuals who grew up in the UK and those who moved to the UK as adults from their home country.

My approach was about exploring stigma related to the ‘schizophrenia’ label, then examining how stigma experience varies among individuals according to their background. I am using a self-discovery approach for my studies (Kleining and Witt, 2001), whereby I am working on several perspectives to understand the political and personal interest in the stigma attached to ‘schizophrenia’ for people of colour: The perspectives I am using is:

- Myself as a woman of colour
- The self as an individual with a familial experience of an individual who carries the label of ‘schizophrenia.’
- The self as a researcher

Kleining and Witt (2001) proposed a "discovery-oriented" approach to qualitative research, which emphasizes the importance of allowing research participants to explore and express their experiences and perspectives in their own terms rather than imposing preconceived categories or concepts on their narratives. Of course, this is congruent with the spirit of mad studies.

In my research, a discovery-oriented approach involves:

- Conducting open-ended interviews with individuals from Black communities who have experienced mental distress or carry the ‘schizophrenia’ label and others related to them, such as families. Allowing them to speak freely about their experiences, perceptions, and beliefs related to mental health and stigma.
- Avoiding predetermined categories or concepts about mental health or stigma and allowing participants to introduce their own ideas and language to describe their experiences.
- Actively listening to participants' stories and allowing them to guide the direction of the research rather than imposing a preconceived framework or set of questions on them.
- Allowing participants to identify the factors that they believe contribute to stigma in their communities and explore these factors in more depth through follow-up questions.
- Encouraging participants to share their thoughts and ideas about potential strategies for reducing stigma related to ‘schizophrenia’ in their communities and exploring these strategies in more depth through follow-up questions.

As participants can see that I am a person of colour physically and through my name, I would anticipate some positive effect for putting participants at ease, but I am also aware that there is some evidence that individuals with shared identity fear exposure within their communities so this can be a double-edged sword. I, like the subjects in my study, am a person of colour. Concerning study 2, this is the perspective that is most significant and visible to me personally and one that is, importantly, reflexively relevant to my interpretation of the data collected by this study.

As a person of colour and with a family member who carries the label ‘schizophrenia’ and experienced stigma is another important aspect of my identity and positioning. It affords me certain insights that many do not comprehend, enabling me to empathise with and understand participants' experiences and perhaps tune in to key aspects of their narratives.

I explored how having the status of being from a different ethnicity to the majority White population can lead to tangible forms of inequality in the context of interactions within one's community. Applying this notion to my research project is a widespread belief within different ethnic groups that mental illness, especially ‘schizophrenia,’ is a 'White problem' (influenced by anti-stigma campaigns that, because of this, fail to speak clearly to Black communities). Simultaneously is the recognition of the paradoxical quality of such beliefs faced with the stark reality of Black overrepresentation in this diagnostic category. Therefore, inequalities that can arise from this are exclusion and discrimination. This research project aims to provide an understanding of the racialised context that is imbued within anti-stigma campaigns. Participants were made aware of aspects of my positioning, such as my ethnicity, which may have influenced their interactions with me throughout the research process. In addition, I was identified as a PhD researcher to the participants, and any assumptions associated with this identification may have affected several things, including their capacity to trust me with their experiences.

Critical Race Theory

My research drew upon Critical Race Theory (CRT) in adjunct to mad studies. CRT and intersectionality as a critically reflexive framework for exploring the findings of this study reinforce the necessity of a qualitative methodology and are arguably aligned to a mad studies frame. One of the tenets of CRT is to recognise people of colour's experiential knowledge using counter-storytelling by allotting a space in which those who have been silenced can express their truths and realities (Dixson & Rousseau, 2005; Matsuda, 2018). Additionally, Creswell (2013) discusses the role of the researcher, specifically how one is never able to (and should not entirely) separate themselves from their research as they bring their assumptions, values, and beliefs into the process. By combining a CRT lens with a qualitative study, I demonstrate the significance of race as a political and social construct and have analysed relevant phenomena through a social justice lens. These techniques allowed me to understand experiences through the eyes of persons of colour who carry the label ‘schizophrenia’ and their family members.

CRT is a corpus of work that aims to comprehend – and ultimately transform – the link between race, racism, and power (Garcia et al., 2018). It is critically important to consider socioecological viewpoints when researching a specific population, as is the case in my research regarding experiences of stigma and anti-stigma campaigns. This is important because cultural perceptions and values pervade all layers of influence and experience (structural/policy, interpersonal, institutional/community, and intrapersonal).

Delgado (one of the movement's founders) and Stefancic (2023) discuss several general propositions that they assert would be accepted by most critical race theorists, despite the movement's plurality. According to the authors, CRT's "fundamental tenets" include the following claims: (1) Race is a social construction, not a biological one. (2) Racism around the globe is normal, not abnormal: it is an everyday occurrence for most people of colour. (3) As a result of what critical race theorists refer to as "interest convergence" or "material determinism," legislative advancements (or setbacks) for people of colour typically benefit dominant White groups. Thus, ostensibly improved legal status for oppressed or exploited individuals may have little effect on the racial hierarchy that characterises American culture or even strengthen it.
(4) Members of minority groups are periodically subjected to "differential racialisation," or the imposition of varied sets of negative stereotypes on them, again in response to the demands or interests of Whites. (5) According to the "intersectionality" or "anti-essentialism" theory, no individual can be effectively characterised by single group membership. For example, an African American individual may also identify as a woman, a lesbian, a feminist, or a Christian. Finally, (6) the "voice of colour" thesis asserts that individuals of colour are specially equipped to speak about the forms and impacts of racism on behalf of other members of their group (or groups). This consensus has fuelled the rise of the "legal storey telling" movement, which believes that the self-expressed perspectives of victims of racism and other types of oppression give critical insight into the judicial system's character. Many of these tenets, particularly the latter, can be seen to

map onto the organising principles of mad studies, broader critical disability studies and intersectionality (Castrodale, 2017). Moreover, various mad studies scholars and activists have affinities with CRT, or mad studies have furnished an opening for new CRT contributions (Gorman & LeFrançois, 2017).

CRT has three primary goals: (1) to tell tales about discrimination from the perspective of people of colour; (2) to address other issues of dissimilarity, such as sexual orientation and class, as well as other injustices faced by groups. According to CRT, racism is a natural element of some civilizations, and the idea of contemporary racism is not always readily identifiable (Ladson-Billings, 1998). As a result, mental health professionals may unconsciously harbour implicit discriminatory attitudes about diverse communities. But, as Hyland (2005) noted, these latent racist ideas are not always obvious. Moreover, by emphasising the social, historical, and economic contexts in which racism occurs, CRT argues that race is a socially created entity (Gillborn, 2015). According to CRT, racial disparities and injustices serve a purpose for those in power and are ingrained in our culture (Gillborn, 2015). CRT is a prism through which we see how a dominant race's negative implicit racial attitudes may contribute to the health inequities experienced by individuals of minority races.

CRT is unafraid to identify instances of racism and strives to dismantle race-related assumptions while also criticising earlier research that downplays the significance of race. This is achieved by illustrating how race's social construct impacts marginalised racial groups and how White supremacist principles shape the societal norms that exclude people of colour (Ceja & Yosso, 2000; Peller, 2013; Liu et al., 2019; Costanza-Chock, 2020).

Brown (2003) presents three methods for exploring persons of colour's mental health using CRT. The first is to examine the social conditions and risk factors that may influence mental health; the second is a critique of commonly used mental health identifiers for psychiatric and psychological disorders; and the third and final is to examine the unique effects of racism on mental health among people of colour. The latter is particularly useful in the research of racial trauma. The idea of experiencing racism as trauma is palpably known to people of colour the world over, yet ironically, given the incessant expansion of the psychiatric gaze into seemingly all aspects of human experience. Thinking more broadly, recognising such trauma could support progressive forms within mainstream services, such as trauma-informed care, as a basis for a different way of thinking about mental health outside of established diagnostic categories and psychiatric taxonomy or feed into the development of a more distinct community or under-led alternative services.

The Power Threat Framework (PTF) attempts one such taxonomic alternative (Johnstone et al., 2018). The PTMF offers a non-pathological perspective on mental distress, aiming to reshape our understanding of what it labels as "emotional distress, unconventional experiences, and challenging behaviours (Morgan, 2023). This is the first step toward developing a new overarching framework to understand and identify mental distress patterns that account for people's social and relational contexts, distancing them from the disease model. However, this has been criticised for a relative lack of attention to race/ethnicity (Johnstone et al., 2019).

The argument against the use of personal narratives and stories

Critical Race Methodology is concerned with the validity and legitimacy of people of colour's lived experiences and views and the ideas, texts, and "re-telling" of those experiences (Solorzano & Yosso, 2002). This technique employs qualitative methodologies such as counter-narratives, case studies, biographies, family histories, and storytelling (Solarzano & Yosso, 2002). Conversely, several authors have argued CRT is problematic in its approach to explaining racial inequalities in Western society (Farber and Sherry, 1997; Solórzano and Villalpando, 1998; Mocombe, 2017).

Numerous critical race theorists advocate storytelling as incredibly valuable and unquestionably effective (Ross, 2020). However, personal narratives are scrutinised more than others. Given its opposition to traditional conceptions of epistemology, which examines how one obtains knowledge of reality, storytelling has become the centre of attention for illegitimacy and increased scrutiny. Stories cannot be verified or replicated, are inherently subjective, and may be atypical of real-world experiences. Furthermore, Ladson-Billings (2005) refutes these ideas by stating that while CRT is frequently viewed as problematic due to its unscientific and subjective nature, it does not present evidence of objectivity or reasoning. Rather than that, it views itself as a kind of inquiry that intertwines lived experience with racial realism (Ross, 2020). It is noteworthy that criticism of CRT fails to recognise that Eurocentrism has evolved into the prevalent mindset, directly impacting the mainstream narratives regarding race. Regardless, opinions, viewpoints, and experiences of people of colour in general, and women of colour in particular, are neglected (Thayer-Bacon et al., 2013).

A critical race methodology creates a space for conducting and presenting research informed by the experiences and expertise of people of colour. While a narrative might support the majoritarian storey, a counter-narrative or counter-story, by definition, opposes the majoritarian story or the bundle of presuppositions, perceived wisdom, and shared cultural understandings brought to the topic of race by members of the dominant race (Ross, 2020). Majoritarian narratives favour White people, men, the middle and upper classes, and heterosexuals by positioning these identities as natural or normative reference points. People of colour can also communicate majoritarianism. Similarly, misogynistic stories are frequently told by men but can be retold by women (Solorzano and Yosso, 2002). Similar dynamics are arguably at work in relation to narrations of madness and the dominating bio-psychiatry.

I am particularly interested in how the experiential knowledge of these individuals diagnosed with ‘schizophrenia’ can paint a different picture and offer a different perspective on the manifestations of race in mental health that might challenge the more traditional and liberal depictions that appear in common critical mental health discourses. As a result, my use of a critical race methodology is intended to illuminate the experiences of individuals and family members living with the ‘schizophrenia’ label, as well as to demonstrate how applying a critical race lens can encourage and empower others (researchers, healthcare professionals, and government officials) to engage actively and critically in an exploration of the multifaceted functioning of race in mental health in ways that maintain a marginalised position. Finally, CRT is increasingly used as a conceptual framework to examine the role of racism in health inequalities, and I would like to contribute to it and potentially offer evidence that can be used to inform anti-stigma campaigns.

Research process

This thesis comprises a series of four studies involving interviews held with individuals carrying a diagnosis of ‘schizophrenia’ and their relatives and an audience reception for an alternative approach to challenging stigma.

1. The first study aimed to develop a broad understanding of the lived and subjective experience of stigma and help-seeking by positioning individuals as experts on their own experience of stigma.
2. The second study aimed to explore the experiences of seeking the help of individuals having a family member who carries the label of ‘schizophrenia.’
3. The third study aimed to explore the effectiveness of anti-stigma campaigns for people of colour.
4. The fourth study - an exploration of audience reception for an alternative community-facing creative performance approach to challenging stigma[8].

Use of online interviews

Initially, the study aimed to conduct face-to-face interviews; however, interviews during lockdown were conducted online due to the global Covid-19 pandemic. Participants benefit from flexibility since they may conduct the study at their convenience (Deakin & Wakefield, 2013; Hai-Jew, 2014). Additionally, participants may feel more secure participating online from a place of their choice, most commonly their home or office. This may help individuals feel more at ease throughout the interview than in a face-to-face interview conducted at a random place. In addition, a welcoming environment for the participant may improve their desire to speak openly and honestly.

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[8] This fourth study has been published in its entirety during my doctoral studies as: Qasim, S., Kunda, C., McKeown, M., Wainwright, J. & Khan, R. (2020) Plant Fetish: a creative challenge to mental health stigma. *Genealogy*, *4*(2), 40. I am lead author and was the substantive author of the piece. Kunda is the artist who created the performance, which was investigated in the study, as such, I felt she ought to be credited as co-authors. The other co-authors are my supervisors who contributed to the paper in terms of final review and editing. They can confirm my substantive authorship. The study data has been incorporated into the aggregate analysis reported in this thesis. Some other elements of this paper appear elsewhere in the thesis.

Creswell and Creswell (2018) recommend developing an interview protocol that consists of 5-10 questions/topics to be covered. The initial interview protocol for this research was developed for a research proposal. The interview questions were then examined during my university’s transfer viva for this study by the PhD researcher and two internal examiners at the University. This initial set of interview themes can be found in Appendix A.

Bekkering and Shim (2006) describe how the “richness of a medium depends on the availability of instant feedback, the use of multiple cues (such as facial expressions, voice inflexions, and gestures), the use of natural language for conveying a broad set of concepts and ideas, and the personal focus of the medium” (p. 104). Online videoconferencing provides such a medium, simulating a rich face-to-face environment. Recent studies have even described a rapport between interviewers and interviewees over online videoconferencing (Deakin & Wakefield, 2014).

Additionally, internet interviews may give a higher amount of anonymity. Individuals concerned about the researcher and participant being seen together may opt for an online interview to minimise the possibility of the pair being seen together. Like in-person interviews, online video conferencing enables the detection of non-verbal, sensory, and emotional clues though sometimes the medium or quality of the internet connection may militate against this. Within this research, recruiting individuals was much slower as many eligible and willing participants had no access to a computer or internet to have the interview.

The rationale of the chosen participants

The makeup of the sample in a study is essential because the heterogeneity of ideas should be represented. People of colour possess unique histories and experiences with oppression and are better equipped to communicate to White individuals about matters that White people are unlikely to be familiar with or recognise. Because of this, this research has recruited people of colour to talk about their experiences as they are best placed to speak about their understandings of mental health, experiences of mental health care and anti-stigma campaigns, as experienced at the intersection of race psychiatry and community.

Gadamer (1995) emphasises the need for a degree of bracketing to be a cyclical process, as some of our preconceptions will become apparent early on in our engagement with the text, while others will become apparent later. In this regard, bracketing does not imply a need for a totality of suppression of one's own views/positioning. Rather there is a cyclical movement between reflexive alertness to one's preconceptions whilst allowing the text to talk and stimulate interpretation and direct recourse to these personally held views as part of the interpretative process (Gyollai, 2020). This has implications for this research and practising reflective and reflexive thinking was a continuous process that began during the design phase and continued throughout the research phase.

Recruitment strategy for studies one, two and three

Effective participant recruitment is a crucial aspect of conducting meaningful research, particularly in studies focusing on sensitive issues like mental health, stigma, and race. In this thesis, the strategic use of social media platforms facilitated the recruitment of diverse participants for three distinct studies. By advertising the studies on Facebook and X (formerly known as Twitter), I successfully reached and engaged with a wide range of participants who voluntarily contacted me to participate.

For studies one and two, Facebook was an invaluable tool for reaching participants through targeted advertisements and posts in relevant groups. To recruit participants, I posted advertisements in mental health support groups and general interest groups related to mental health. These posts provided information about the study's purpose, participation criteria, and contact details. The supportive environment of these groups made members more receptive to participating in a study that focused on their subjective experiences with mental health stigma. Study two also benefited from Facebook's group functionality. Advertisements were posted in groups dedicated to family/friends support for 'schizophrenia.' These groups often consist of family members seeking advice and support, making them ideal for recruiting participants who could provide insights into familial perspectives. The posts included details about the study and instructions for interested individuals to contact me directly.

Study Three required participants who were more vocal and engaged in discourse anti-stigma campaigns. X with its dynamic engagement and extensive reach, was the perfect platform to attract these participants. To recruit participants, I advertised the study on X using relevant hashtags such as #MentalHealthAwareness, #EndTheStigma, #Schizophrenia and #BlackMentalHealth. These advertisements highlighted the study's focus on evaluating anti-stigma campaigns and invited interested individuals to get in touch. X users active in these discussions, who are often advocates and highly engaged in public discourse about mental health, were likely to see these posts and respond. This approach successfully connected me with enthusiastic individuals who carry the label of 'schizophrenia,' and who provided valuable insights into the effectiveness and challenges of current anti-stigma efforts.

Effectiveness and Challenges

Using social media for recruitment presented both opportunities and challenges. The broad reach and targeted nature of advertisements on Facebook and X allowed for efficient engagement with potential participants. However, challenges included ensuring the credibility of respondents and managing the diverse range of experiences and perspectives they brought to the study. Additionally, the reliance on self-selection meant that those who chose to participate were already somewhat engaged with or interested in mental health issues, which could influence the study's findings.

Potential participants contacted the researcher through email to express their interest in the study. In addition, a purposive sampling technique was used to ensure the target population was being explored. This technique, which falls under the non-probability sampling technique, selects participants based on their knowledge, relationships, and experience regarding the focus of the research. Smith and Fieldsend (2021) suggest that sampling in IPA research must be purposeful rather than random because the nature of IPA research is to target participants who can offer their perspectives on a given topic.

The researcher sent an eligibility form for completion to meet the criteria before commencing research (see Table 1 for criteria for studies). Once completed the form, the researcher assessed the potential participant's suitability according to the criteria set. An information sheet (Appendix B) alongside a consent form (Appendix C) was sent to any participants who met the criteria. The eligible participant sent back the consent form, and then the researcher contacted the participant to arrange a time to conduct the interview through Microsoft Teams.

Criteria	Study 1	Study 2	Study 3
Inclusion criteria	Aged 18 or over. Identify themselves as person of colour. Fluent in English Diagnosed with 'schizophrenia'	Aged 18 or over. Close relative of an individual diagnosed with 'schizophrenia' Identify themselves as person of colour. Fluent in English	Aged 18 or over. Identify themselves as person of colour. Fluent in English Diagnosed with 'schizophrenia'
Exclusion criteria	Detained under the Mental Health Act (1983) Currently an inpatient at a hospital for their mental health Participated in Study 3		Detained under the Mental Health Act (1983) Currently an inpatient at a hospital for their mental health Participated in Study 1

Table 1. Inclusion and exclusion criteria for studies one, two and three

Participants from study one, which focused on individual experiences of 'schizophrenia,' were excluded from Study Three. This exclusion was necessary to avoid potential bias that could arise from their prior involvement in the research process. Additionally, fresh perspectives were sought for study three to ensure a broader and more diverse range of insights on the effectiveness and reception of anti-stigma campaigns. Initially, participants for study one and study three were kept mutually exclusive to maintain the integrity of the distinct focus areas—individual experiences versus group advocacy perspectives. Study Three was originally designed as a focus group to facilitate rich, interactive discussions. However, the onset of the COVID-19 pandemic necessitated a shift to online interviews for all studies, including Study three.

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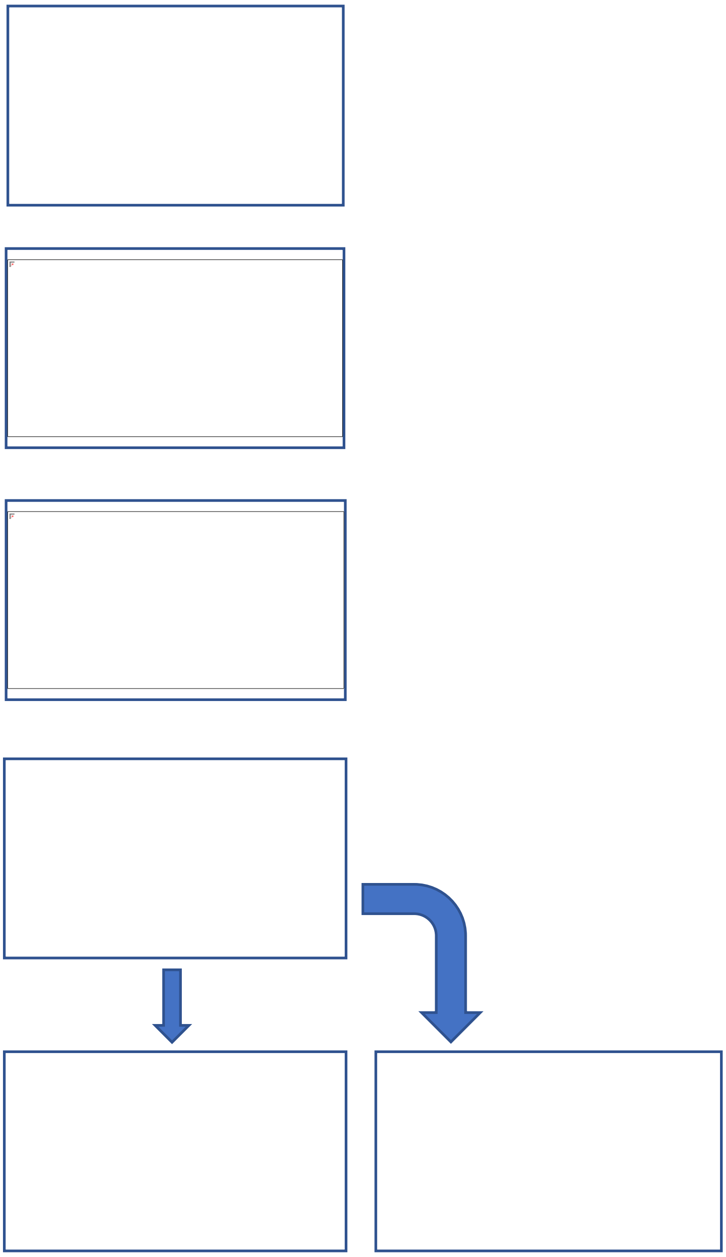

Figure 1: Schematic diagram of the recruitment process

Participants only participated in one interview at a pre-determined time that was chosen at their convenience. This allowed participants more flexibility about the time of the interview. The interview aimed to last between 45 minutes to 1 hour. Informed consent for the interview and audio recording was obtained before the interview and recording. To build the relationship between the participant and researcher, the interviews began with background questions, which Hill et al. (2005) suggest can help the participant feel comfortable and gather demographic information. All interviews were audio and video recorded. Participants were provided with a debrief sheet at the end of each interview (Appendix D).

Methods

Participants of study one

The participants were aged between twenty-five and thirty-nine. Five were males, and four were females. Table 2 shows the demographics of the participants' involvement in this study. It describes the participants' age, gender, ethnic origin, and the duration of when they first carried the label of 'schizophrenia.'

Pseudonym	Age	Gender	Ethnic origin	Duration of diagnosis in years
Rahul	32	Male	Indian	10
Asma	25	Female	Pakistani	1
Zeeshan	34	Male	Pakistani	5
Amina	29	Female	Somali	9
Laura	33	Female	Ghana	1
Zhi	39	Female	Chinese and Japanese	3
Joseph	28	Male	Congolese	7
Leon	31	Male	Nigerian	2
Koby	33	Male	Kenyan	6

Table 2. Demographic characteristics of participants for Study 1

Participants of study two

Participants were aged between twenty-one and forty-six. Out of the eight participants, five were female three were males. Table 3 shows the demographics of the participants involved in this study.

Pseudonym	Age	Gender	Ethnic origin	Relationship to family member
Jenny	33	Female	Jamaican	Niece
Tariq	35	Male	Bangladeshi	Brother
Jacob	40	Male	Kenyan	Son
Martha	35	Female	Jamaican	Daughter
Samiya	46	Female	Pakistani	Sister
Emmanuel	38	Male	Nigerian	Brother-in-law
Melissa	40	Female	Chinese	Mother
Diya	21	Female	Punjabi	Daughter
Anya	34	Female	Indian	Grand daughter

Table 3. Demographic characteristics of participants for Study 2

Participants of study three

Participants were recruited through purposive sampling online via social media and email broadcasts. Participants were aged between 21 and 46 years. Out of the nine participants, three were female, and five were male. Table 4 shows the demographics of the participants involved in this study.

Pseudonym	**Age**	**Gender**	**Ethnic origin**

Adam	**35**	**Male**	**Arab**
Nazneen	**40**	**Female**	**Ethiopian**
Karam	**27**	**Female**	**Jamaican**
Hamza	**46**	**Male**	**Pakistani**
Roy	**38**	**Male**	**Bangladeshi**
Bernie	**30**	**Female Male**	**Chinese**
Jessie	**21**	**Male**	**Jamaican**
Derick	**34**		**Ghanian**

Table 4. Demographic characteristics of participants for Study 3

Methodology for study four[9]

This qualitative case study focused on the Plant Fetish show, a comedic performance piece. I analysed interview data from the artist, Chanje Kunda, and audience reception data collected in the course of a post-show discussion facilitated by myself and other invited panel members (Qasim et al 2020). This study aimed to enhance understanding of how creative arts can raise awareness of the stigma associated with mental distress and explore the potential by which racialised or other marginalised communities might engage with knowledge and discourse that shift understandings of mental health and stigma out of the mainstream orthodoxies.

Case Study Interview

A semi-structured interview was conducted with Chanje to explore her experiences with Complex PTSD and her artistic process related to Plant Fetish. The interview lasted 104 minutes in a private setting and was audio-recorded and transcribed verbatim. I adopted a reflexive, participatory approach, allowing for co-creation and provisional analysis with the artist, who was also included as a co-author on the published paper due to her integral role in the study. As an artist/ writer, Chanje was clear she wished to own her own views and her artistic work and be named in the study, rather than hide her identity under a pseudonym.

Audience Reception: Post-Show Discussion

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[9] A version of this element of my thesis has been published in a peer reviewed journal; full citation: Qasim, S., Kunda, C., McKeown, M., Wainwright, J. & Khan, R. (2020) Plant Fetish: a creative challenge to mental health stigma. Genealogy, 4(2), 40 https://doi.org/10.3390/genealogy4020040. All elements of this published paper that appear in this thesis are my own work.

A post-show discussion was held at HOME in Manchester, with around 130 attendees from diverse backgrounds. The discussion aimed to create a space for participants to share their experiences and views, facilitated by a panel that included the artist, myself and one of my supervisors (MM). This session was video recorded and transcribed.

Data analysis

Data analysis is a critical component of any research study. It involves transforming raw data into meaningful information that can be used to address research questions. The process of data analysis typically begins with organizing and cleaning the data, followed by exploring patterns, relationships, and trends within the data. This can be achieved through statistical methods, visualizations, and other analytical techniques, but here proceeded via cyclical reading and re-reading of text. The results of data analysis can then be used to draw conclusions, make predictions, and inform further research. The importance of data analysis cannot be overstated, as it is the foundation upon which research findings and conclusions are based. As part of this process, I utilized NVivo, a software tool that supports qualitative data analysis, to help organise, analyse, and code my data. Additionally, the programme was used to do keyword searches and compare them to manually coded categories and themes. NVivo was advantageous for data storage and data sorting (Bryant & Charmaz, 2010). NVivo was not employed as the primary source of coding and was simply used to consolidate data analysis.

Transcription is a part of the organisation and management of the data. It is the production of a written record of the interview. For all three phases of the research, transcriptions were aided by the automatic transcription offered by Microsoft Teams. This provided speed when it came to transcribing an extended interview. Once the transcription was conducted automatically, the researcher correlated the audio with the transcription as some sentences were not picked up to ensure the interview audio matched the transcript and that full transcription was achieved. All the participants' names were changed on the transcripts.

Trustworthiness

Before findings are presented, the criteria for evaluating the analysis are explored. Trustworthiness is a critical multi-faceted component in ensuring the quality of qualitative research findings. It comprises dimensions of credibility, dependability, confirmability, and transferability.

In this context, trustworthiness is an indicator of rigour in the research process. It is indirectly a product of a range of research practices, including the relational efforts necessary to engage participants, put them at their ease, and facilitate the telling of their stories. In this sense, the trustworthiness of the findings is, to some extent, a consequence of building trust with research participants, but conceptually these are two semantically similar but different notions.

That said, it is important that the researcher must establish a favourable and trusting rapport with the subjects. This building trust with participants lays good foundations for enhancing the trustworthiness of data analysis but is important in its own right in relation to maintaining high ethical standards. If participants did not feel respected or trusted, they could be guarded and hesitant to provide relevant and sensitive information, undermining the study's aim. If they had given material in a limited, guarded, or defensive manner, the research would have been invalid. This is especially critical considering the study's population's marginalisation and oppression. I was well aware that a sizable portion of this group, including their family members, had undoubtedly faced prejudice or hardship due to their skin colour or the label they were carrying. Critical race theory maintains that our society is racialised and unequal and mad studies point to other intersectional disadvantages. As I began to hear about participants’ experiences, this became clear. Transparency of methodology supports the reader's evaluation of the actions of the researcher. I reflexively revisited preconceptions and biases throughout the research process. I also discussed my noted reactions from the interviews with my supervisory team.

Numerous approaches were employed to verify the study's credibility. First, the researcher's experiences and perceptions of prior experiences have been explicitly bracketed, recognised, and named as part of the study process. This has aided in ensuring that no prior assumptions about the phenomenon influenced either the participants or the analysis during the study's course. All interviews were videotaped and transcribed to ensure accuracy and keep the analysis focused on participant replies. Member checking, also known as a participant or respondent validation (Birt et al., 2016), was used to validate interpretations and was included throughout the interview process, with regular checks for comprehension, clarity, and confirmation that the researcher interpreted the experience correctly. In addition, participants received a complete transcript before analysis to ensure their discussion with the researcher was captured accurately. Following analysis, participants were contacted and invited to see and discuss the findings.

Ethical considerations

Ethical approval was received from the University ethics committee (STEMH 1088). It is crucial to think about any potential ethical issues that may arise when conducting qualitative research (Dowling, 2005; Ryen, 2011; Hammersley & Traianou, 2012). Confidentiality, informed consent, anonymity, data security, and the potential effects of the particular research on an individual are some of these ethical concerns (Orb, 2001). Under no circumstances should either the researcher or the participant be put at risk physically, mentally, or psychologically. This may have an effect on the research results and render it unethical (Wa-Mbaleka, 2019).

There were several reasons why it was crucial to consider potential ethical issues. First, because of the flexible nature of qualitative research design, it was impossible to anticipate the reaction individuals could have to the exploration of issues at stake in the interviews. Given the nature of this inquiry, a wellbeing protocol was implemented to safeguard the participants' welfare during the research interview process, ensuring that those experiencing distress were provided with appropriate support and care. I have personal and professional experience dealing with mental distress. I completed safeguarding training to support individuals if needed. I advised the participants at the beginning of the interviews that I have no medical position and cannot provide medical support or therapy for the participants, but I am able to offer informal support and can signpost to relevant organisations that will be able to support them should the interviews precipitate distress.

A small number of participants became slightly distressed when responding to questions involving family and their mental health. However, they did not want to be referred for help and support. In these cases, I briefly paused the interview and asked questions such as “do you feel ok?” and what are you feeling right now.” Depending on their answers, I allowed participants to determine whether to end the interview or whether they would prefer to take a break but then resume the interview. However, some participants also ended the interview abruptly by logging off. A follow-up email was sent to ensure their well-being. They all responded to reassure that they were well. In two instances, interviews were paused to enable the participant to gather their thoughts, and when they were ready, the interview resumed.

It is critical to comprehend the subjective understanding that results from comprehending and appropriately expressing ideas and thoughts (Hammersley & Traianou, 2012). At times, participants disclosed personal information about family hardships or showed grief, and it was critical to recognise and validate the emotional component inherent in qualitative research while remaining empathic and suitably responsive but, to some extent, detached from the individual's experience. Maintaining some level of emotional detachment helps researchers maintain objectivity and avoid bias in data collection, analysis, and interpretation.

Issues with access

In the context of academic research, it is widely acknowledged that recruiting individuals from diverse racial and ethnic backgrounds, particularly people of colour, can be a challenging endeavour (Farooqi et al., 2022). The underrepresentation of diverse populations in research studies has significant implications for the generalizability and applicability of findings.

Farooqi et al. (2022) identified four themes as barriers to recruiting people of colour in research.

- Language use and ability - English speaking capacity of participants, translation and interpretation problems, and illiteracy.

- Socio-cultural variables that might determine how a problem is related to an individual's ethnic identification are challenging.
- Participants' ignorance of research, mistrust of researchers and health professionals, and the stigma attached to specific health problems.
- Practical concerns include the financial consequences of study involvement and individuals' conflicting agendas.

Some of these themes became evident in my research. For example, a participant frequently felt that they could not describe their experiences in fluent English; however, I always asked them to discuss their experiences in their own words. In addition, due to the global pandemic, it was challenging to reach potential participants.

Researcher positionality

A factor to consider within research is the firsthand experiences of the researcher. Creswell and Poth (2016) contend that the success of qualitative studies depends primarily on the interpersonal skills of the researcher building trust, maintaining good relations, and respecting norms are critical. Over time, my ability to develop strong, trusting relationships with adults and family members by working within mental health services has been demonstrated over several years. Along with external sources of information, my own experience as a family member of a person diagnosed with ‘schizophrenia’ gave insight into the problems and obstacles that individuals of colour frequently confront while seeking support in mental health. However, I took great care to regard this prior knowledge and other personal positioning as a mixed blessing for my research; being careful to be alert to the hazards and potential benefits of the intrusion of my own viewpoints and experiences, being able to be open to disconfirming data as well as holding the possibility of clarifying insights into shared experiences. Using a reflective journal helped me in this regard. Shame thrives in hidden quiet corners. Stigma in mental health was very openly discussed within my community. Anyone who was seen to have some form of mental distress could be immediately outcasted or gossiped about. I have family members who struggle day in and out with severe mental distress, but seeking help can be seen in this community as a weakness or an embarrassment. However, I do not hold these stigmatising views.

These firsthand experiences, on the researcher's part, developed a level of sensitivity and understanding that would not have existed without this prior experience. Thus, before the interviews and after each interview, I used a journal to write about my reflections, thoughts, and personal feelings. This contributes to a process of bracketing or epoch as understood within developments of phenomenology. This allowed me, as the researcher, to put aside my own experiences and biases and to "gain clarity from [my] own pre-conceptions at key points in the interpretive cycle, but also to benefit from my own lived experience at other moments in this cycle (Marshall & Rossman, 2006, p. 148). In a very real sense, complete bracketing of prior views and experiences is an illusion and undesirable; influential phenomenologists such as Gadamer (2004) make this clear and suggest key moments of interpretation can be highly intuitive or indicate unconscious insights into the data.

For all of these reasons, maintaining conscious reflexivity is emphasised. My positioning has greatly impacted my research journey. In line with the hermeneutic cycle, participants, and I co-constructed meaning together in a reflexive process. My interpretation of their accounts was guided by my experience of ethnicity in mental health and my cultural beliefs about this phenomenon. As an early career researcher, one of the things that I noticed was that there is no immediate outlet for you to discuss your concerns on some aspects of your research, especially in matters of race and racism. Supervisors can only support me by providing guidance and signposting me to relevant support, learning or well-being services. It is worth noting that several of the supervisors have demonstrated a profound interest in matters pertaining to race and racism. Acknowledging this aspect could potentially enhance the research process and its relevance, particularly in addressing issues of racial equity and social justice. Conducting the research has opened me up to issues that need to be considered and incorporated into the research process within academia, especially with early career researchers from an ethnic minority background.

A certain belief was envisioned at the beginning of my thesis. However, as with many things in life, there is the element of surprise. Hence why, in this research, contrary to my beliefs on what would be found, contrasting experiences were discovered. It was more than just the stigma of seeking help. As I talked to participants, I began to think about my own experiences as a person of colour working within the public sector and academia. I experienced racism and did not even think twice about it.

Being a (person of colour) researcher: A reflection

At the start of my PhD journey, I was informed of the loneliness that doctoral students can go through when conducting their research. I was advised on multiple occasions by my supervisors that it was up to me to become an expert in my field. I was motivated and intrigued by the element of independent research. First-year of my PhD programme was very easy. I completed all my milestones on time and was on track to publish my first research paper. Before COVID-19, I would use the university's research facilities to work on my studies. I was a doctoral student in that setting, confident in my abilities and able to complete the tasks I had planned. I had my own space to work and focus on my research.

The significant transition began in the second year. The Covid-19 pandemic. I was personally impacted. With me, a lot of significant life changes happened. Multiple bereavements within my family due to the global pandemic caused my mental health to be affected, and I lost interest in continuing my PhD. There were months when I was completely idle with my research. I was a frontline worker in my public sector job, whereby I experienced first-hand the effects of the global pandemic on vulnerable individuals. I became a friend and sometimes the only person they saw for months due to the lockdown. Personal Protective Equipment (PPE) shortages, contracting Covid, social distancing, and the emotional turmoil of supporting vulnerable people with an infectious illness that we had no information about affected the momentum of my research.

Before designing and implementing my research, my beliefs regarding stigma and ‘schizophrenia’ may have been affected by studying the stigma literature conducted as part of my studies. As mentioned before, a pre-study assumption based on prior research is that stigma is a danger to self-identity (Major & O'Brien, 2005). Additionally, pre-study perceptions regarding the impact of stigma on well-being may have been affected by a literature review examining connections between internalised stigma, which suggested that internalised stigma can result in various adverse consequences, including decreased self-esteem.

In the course of my studies and becoming exposed to mad studies perspectives, I am in the course of both unlearning some previously taken-for-granted understandings of ‘mental health’ and associated mainstream terminology and developing a more critical appreciation of the relationships between madness, society, services and stigma. This has been particularly evident in my struggles to articulate the basis of my research in language that does not begin to appear problematic, reinforce patterns of disadvantage or simply fail to escape the mainstream paradigm of which I am now critical. In this regard, I console myself that the vocabulary of madness and mental health is possibly amongst the most loaded of any scholarly or welfare territory, and alternative semantics are yet to be wholly or satisfactorily worked out; the ‘mad’ language of mad studies itself remains a hugely pejorative terminology for many who might eventually benefit from this powerful critical discourse.

Throughout the research process, I knew that I had to be incredibly careful to avoid unintentionally influencing the data or misrepresenting someone else's story. To keep track of my reactions or potential biases, I kept a research journal and made sure to reflect on my perceptions of participant responses after conducting, transcribing, and coding every interview. Additionally, I consulted with my supervisory team about any interviews where I found myself having a strong positive or negative reaction to participant responses or having difficulty identifying codes that felt true to the raw data and participant experience. While I do not believe in remaining completely objective in research, my use of a supervisory team, journaling, and self-awareness allowed me to control threats to the trustworthiness of my research that could have negatively skewed the data collection, analysis, and interpretation process. I was also open to including disconfirming data, data that contradicted my prior beliefs.

In light of promoting transparency and declaring my positionality, I would like to provide insight into my own ethnicity and identity. As an individual, I identify as a Black, Arab, and Muslim female. This aspect of my identity shapes my perspective and influences the lens through which I approach research, particularly concerning issues related to race, ethnicity, and social justice. By sharing this information, I aim to offer readers of my thesis a better understanding of the researcher behind this work and how my personal background might inform the content that follows.

An unexpected – yet somehow expected - development during the participant interviews was that the participants tended to say, “You’re Black, you understand me,” or “You know what I am talking about.” Some participants unintentionally thought that I was from the same heritage as them (South Asian in particular).

Although I politely corrected them so as not to mislead them into thinking I am from the same background, I represented somebody who mirrored them in terms of experiences and knowledge. As a result, people of colour share specific attributes and characteristics in common such as family, community, and sense of self. This shared heritage is our shared experience of racial oppression in the United Kingdom. Due to this shared history and experience of oppression, my participants, like all people of colour, have a unique perspective on race and racism that is far too often ignored in mental health discourses.

However, my positionality did pose complexity when trying to identify with participants completely. This was important when interviewing individuals who carry the label as I do not have first-hand knowledge of what the participants have experienced. However, a degree of unfamiliarity and detachment can let me capture aspects of the participant’s experience that an insider might overlook (Olokuton et al., 2021).

Methodological and epistemological reflexivity

One of the core questions one of my supervisors continuously asked me was what methodological stance I was taking to approach my research. My main concern was ‘how do I capture voices like mine’? Experiences from participants became almost synonymous with what I have experienced. Not just the stigma of mental health but also trauma and racism. I deliberately chose a qualitative research approach drawing upon critical race and mad studies theorising for my study, as it is motivated by social, political, and personal concerns. Being a Black feminist woman, I am deeply concerned about the marginalization experienced by people of colour and how they are typically represented in research literature. I view qualitative research as a means of empowerment for these communities, as it provides a platform for the voices of the marginalized to be heard, recognized, and validated. I aimed to perform this research with sensitivity to cultural differences. To accomplish this, I developed a forum for contemplating, doing, and evaluating research from a particular standpoint of colour by adopting a critical race perspective and similarly took a mad studies lens to mental health stigma. In addition, this methodology in the round allows me to prioritise the cultural views of my participants — people of colour and mad people who live with the political, economic, and social consequences of unequal power relations – above the presumptive knowledge of those unfamiliar with their experiences.

I cannot deny my experiences, ethnicity, culture, or being a person of colour who has experienced mental distress. Throughout this research, I was required to be aware of my biases as well as my positive reflexive potential. The disparities faced by people of colour and mad people in the United Kingdom and across the globe are heartbreaking. I was required to consider my capacity to bracket and the repercussions if I was unable to bracket effectively and without affecting the research. My experiences and interpretations of those events are produced individually and personally. Consequently, the reflective practise has some bias or subjectivity. By examining my positionality, I have been aware of the areas in my study where I may be biased and have accounted for them at the same time as being able to celebrate insightful and facilitative turns in the research process that are predicated on my positionality. Moreover, the potential impact of my work is also bound up with my positionality, and my interest in its social justice potential is, in this way, strengthened. For mad studies scholars, critical reflexivity is essential and a positive characteristic of mad scholarship. For Sweeney (2016), this allows for movement beyond who I am to explore the radical potential of interconnections and interrogations with others' storied experiences amid extant levels of understanding; the institutional, social, and theoretical:

'We, researchers, and scholars don't seek evidence of our own truths, views, or experiences reflected in the lives of others, but instead move reflexively between a critical understanding of our own experiences, the points of intersection and departure with others, and the interconnections and implications at broader levels. Thus, accusations of bias relating to the conscious shifts between I and We are simplistic and misleading' (Sweeney, 2016: p39).

Analysing the data from the four studies

I initially considered analysing data separately, taking each study in turn. After receiving feedback, I changed approach and undertook a process of analysis of the qualitative data aggregated across all four studies together. This was felt to offer the best potential for offering a rich set of answers to my research question, and has enabled me to present my findings thematically, illustrated with direct quotations from participants. Anonymised participant quotes indicate minimal identifiers such that the respective study they participated in is clear.

Chapter conclusion

This chapter outlined IPA as a qualitative research approach. I have focused on my positionality, which was initially presented in chapter one to include the potential function of my subjectivity and its influence on the research process, and then explained my research study procedures. This chapter also included recommendations for participant selection, data collection, and analysis for investigating the help seeking experiences of persons of colour carrying a ‘schizophrenia’ diagnosis and their families.

Chapter 4: Personal and Cultural identity conflicts

In the intricate landscape of cultural identity struggles, individuals often find themselves entangled in the web of internalized stigma, grappling with the pervasive influence of societal stereotypes and expectations on their sense of self-worth and belonging. This chapter embarks on a deep exploration of the theme of Personal and Cultural identity conflicts, phenomenon that lies at the intersection of identity and mental health. Central to the inquiry is the analysis of how individuals navigate the complex terrain of internalized stigma, disentangling themselves from the bonds of self-doubt and shame perpetuated by societal norms and expectations.

The first overarching theme identified in the analysis of the research was personal and cultural identity conflicts. This theme delves into the complex interplay between an individual's sense of self and the cultural expectations and stigmas they encounter. This theme explores how internalized stigma can undermine self-worth and create internal turmoil as individuals struggle to reconcile their personal identities with societal and cultural pressures. It highlights the challenges faced by those navigating dual or conflicting cultural identities.

Negotiating their place and identity

The data has shown concepts such as the ‘Coconut’ conundrum (Letshufi, 2016), where individuals may feel alienated from both their cultural heritage and the dominant culture.

“My family call me a coconut. I was really struggling, not the greatest thing so why do I need to be White to ask for help?”

Joseph, Congolese

At the outset of the interviews, many participants denied feeling stigmatized or labelled due to their mental health experiences and instead identified external sources of stigma from broader society and social networks. However, as the interviews progressed, a number of participants began to recognize patterns of internalized stigma, contradicting their earlier denials of self-stigma. This may be due to participants reflecting more deeply on their experiences. They may become more aware of the impact of internalized stigma and begin to recognize patterns of self-stigmatising thoughts and behaviours. This could be due to increased self-awareness or a better understanding of mental health and stigma through the interview process. CRT addresses the complexities of racial identity and the pressures of conforming to dominant cultural norms. The ‘Coconut’ conundrum, where individuals are perceived as betraying their ethnic heritage, reflects the internal and external conflicts arising from systemic racism and cultural assimilation pressures.

Amina referenced that individuals from her community ethnicity and culture associate seeking support for ‘schizophrenia’ as a “White issue” and families from her heritage believe that only White individuals seek support.

“My mum calls me ‘Cadaan[10]*.’ Anytime I tell her that I’m going to therapy she says that I’m just like them the people. Makes me feel like I am not worth it ….Because like I’m treating myself? Why can’t she just accept it like all the other White parents?”*

Amina, Somali

Being referred to as White for seeking help has made participants feel alienated from their ethnicity, culture, and local community. It can also imply a sense of disapproval or criticism towards the behaviour as if it is seen as not aligning with the speaker's own cultural or racial identity. However, it is important to note that such generalizations and stereotypes can be harmful, as they homogenise specific ethnicities and cultures. Within this context it is important to have a critical and reflexive lens when considering participants’ experiences concerning their community and culture that they identify with.

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[10] Cadaan" is a Somali word that is often used to refer to people from a White heritage.

"It feels like…you know… I don't belong to my own people just because I have a mental illness."

Leon, Nigerian

Self-denial and stigma

This pattern of initial denial and subsequent recognition of self-stigma highlights the complexity of how individuals experience and internalize stigma and the need for nuanced approaches to understanding and addressing stigma in mental health. It also underscores the importance of creating safe spaces for individuals to reflect on and explore their experiences of mental distress and stigma and to challenge the internalized beliefs and attitudes that may be hindering their ability to seek help and access appropriate care. This theme has important implications for mental health professionals and organizations. It highlights the need for mental health providers to be aware of the potential for internalized stigma among their patients and to create safe and supportive environments for individuals to explore and challenge these beliefs. It also emphasizes the need for broader societal and cultural changes that address the root causes of stigma and promote more inclusive attitudes towards mental health.

Rahul, who is of Indian heritage, spoke about his feelings on the stigmatisation of the 'schizophrenia' diagnosis. He described how he felt normal with the diagnosis but was uncertain and worried about his family members' beliefs.

"I don't necessarily feel ashamed...I don't feel embarrassed that I have it ['schizophrenia']. It's normal to have something going on in the brain, I'd be surprised if I met anyone who never felt some kind way up there… I don't know what my siblings or parents think of me. When I broke down, and I told them it was because of my mental health, they just…like… fake smiled and nodded. I have no idea what they think of me."

Rahul, Indian

From an IPA standpoint, Rahul's assertion that he does not feel ashamed or embarrassed about his condition offers a glimpse into his internalization of societal attitudes towards mental health. His belief that experiencing mental health issues is 'normal' suggests a level of normalization or acceptance of his condition, which may serve as a coping mechanism to mitigate the stigma associated with ‘schizophrenia.’ However, the uncertainty Rahul expresses regarding his family's response reveals the discord between his own acceptance of his condition and the potential lack of understanding or acceptance from his social support network. This discrepancy underscores the relational aspect of stigma and the impact of social interactions on an individual's mental health journey.

From an IPA perspective, Rahul's description of his family's reaction as 'fake smiling and nodding' illuminates the nuanced interpersonal dynamics at play. This perceived lack of genuine understanding or acceptance from family members may exacerbate feelings of isolation and alienation, compounding the already significant challenges associated with managing a mental health condition.

Zeeshan, a participant of Pakistani heritage, initially asserted that he did not experience self-stigma associated with his mental health condition. However, his narrative unfolds to reveal a more nuanced understanding of his internalized feelings and societal perceptions.

“I don’t have no self-stigma, but I think the community [general population] does. I think the way I have been treated with services… there has been stigma… no doubt, especially being heavily medicated…what can I do about that. There is a lot of shame and guilt [for me]. I feel in denial.”

Zeeshan, Pakistani

Zeeshan's initial denial of self-stigma reflects a defensive mechanism to protect his sense of self from perceived societal judgment and stigma. His statement, 'I don’t have no self-stigma,' suggests an attempt to maintain a positive self-image despite the challenges posed by his mental health diagnosis. Upon further exploration during the interview, Zeeshan gradually discloses his true feelings, indicating a shift from his initial denial. This progression highlights the dynamic nature of self-stigma and the complexity of individuals' internalized perceptions. Furthermore, Zeeshan's narrative highlights the intersectionality of cultural identity and 'mad identity,' as his experiences of self-stigma are shaped by both his Pakistani heritage and societal attitudes towards mental health.

Zeeshan's acknowledgment of experiencing stigma from others, particularly within the context of accessing mental health services and being heavily medicated, sheds light on the external pressures and societal attitudes that contribute to his internalized feelings of shame, guilt, and denial. From an IPA perspective, this internalization of societal stigma manifests as self-stigma, wherein individuals internalize negative societal beliefs and begin to perceive themselves through a stigmatized lens.

Zeeshan's resistance to the notion of 'self-stigma' initially may be understood as a reflection of the broader discourse surrounding mad identity, wherein individuals may resist internalizing societal stigma and instead attribute negative perceptions to external forces. This resistance underscores the agency of individuals in constructing their identities in the face of societal oppression and stigma. In essence, Zeeshan's narrative offers a poignant illustration of the intricate interplay between self perception, societal stigma, and cultural identity. By applying an IPA lens, we gain deeper insights into the subjective experiences and meaning-making processes underlying Zeeshan's narrative, illuminating the complex dynamics of self-stigma within the context of cultural heritage and societal attitudes towards mental health.

This quote highlights the complex interplay between self-stigma and societal stigma related to mental health conditions. Zeeshan is saying that they do not have any self-stigma, which means that they do not feel ashamed or guilty about having a mental health condition. However, they believe that the community at large does have a stigma towards individuals with mental health conditions, which affects the way they are treated with mental health services. Zeeshan also notes that they feel a sense of shame and guilt, which may be related to their mental health condition or how they have been treated.

Interestingly, Joseph also changed their perception of self in the interview. He expressed how disappointed he was in himself when he received the diagnosis of ‘schizophrenia.’ He blames himself for the diagnosis and feels unable to seek support from family members, embarrassed to disclose to his family as he is disparaging himself.

"I asked myself so many times, where did I go wrong? Why am I schizophrenic?
How can the doctor tell me I'm schizophrenic? How can I tell my family this?
The feeling is just horrible, it's like having shame about something that is a part of you. I'm like this because I deserve it. I have done things in the past and God is punishing me. I don't want anyone's help. When people sometimes ask me like what happened that day, the day I had the psychotic episode, I just tell them I was on drugs."

Joseph, Congolese

Disclosing diagnostic label

The act of disclosing a diagnosis can be a complex process and may pose various challenges in different situations. In the case of Leon, an individual of African heritage, he found it easy and reassuring to disclose his diagnosis to his employer. However, this freedom to disclose was not without difficulties, as he faced challenges when disclosing his diagnosis to his father. This could be informed by Leon's ethnicity as it raises a relevant point regarding the potential influence of cultural heritage on the subject matter. It also highlights the connection to Nigerian or African heritage, suggesting potential similarities with Joseph's experiences. This observation prompts an exploration into the role of ethnicity and heritage in shaping the themes that emerge in our study.

"I told my manager in case I have an episode. I felt really comfortable. I was surprised with myself how I could just easily tell her because it is my life and I need people to know what I am going through…. Conversations with my dad and everyone else? No, I'll pass I know what they'll say.... I'm going to be the joke of the house."

Leon, Nigerian

Interestingly, this participant is willing to disclose to his employer and says, "I need people to know," but the 'people' do not include his family members. The participant also expressed the support from a relationship outside the family whereas not being able to disclose the diagnosis in fear of ridicule and shame.

"My girlfriend has been so supportive when I told her. It just came out because I didn't feel the need to hide. She always tells me tell my family but that is a death sentence. I haven't even told my parents about my diagnosis. I can be me around her but my family will not understand. I'm afraid they will just call me all sorts of names or make me feel like I'm some loser. I don't have a problem with myself. I am not ashamed of carrying the diagnosis I just know they won't take it well and what they think of me is important right now until I figure out a way to make them accept me."

Rahul, Indian

The participant's disclosure of their mental health diagnosis to their girlfriend represents an act of resistance against societal norms that seek to silence and marginalize individuals with mental health conditions. By sharing their experiences with someone close to them, the participant challenges the stigma and secrecy that often shroud discussions of mental health. However, the participant's reluctance to disclose their diagnosis to their family highlights the pervasive impact of familial stigma and the fear of rejection or discrimination. Mad Studies emphasizes the importance of recognizing and addressing the systemic factors that contribute to the marginalization of individuals with mental health conditions, including familial attitudes and societal stigma. The participant's fear of being labelled or ostracized by their family reflects broader societal attitudes towards mental health and underscores the need for structural changes to promote acceptance and inclusivity.

Moreover, the participant's assertion of self-acceptance despite external pressures aligns with the principles of Mad Studies, which emphasize the importance of reclaiming agency and self-determination in the face of oppressive systems. By asserting that 'I don't have a problem with myself,' the participant challenges the pathologizing discourses that often characterize discussions of mental health and asserts their right to define their own identity on their own terms. Interestingly, two participants felt some degree of self-stigma in relation to their diagnosis. One participant felt that there was a denial in their diagnosis label in other terms, they believed the diagnosis label 'schizophrenia' was given incorrectly. Koby expressed their concern on what others will think, and most importantly what he believes.

"Look at me. Imagine going up to the doctor saying to them that I want help. I can't be somebody with 'schizophrenia,' it's just… I didn't want to be seen as weak. I didn't want to look like those guys who are weak and unstable."

Koby, Kenyan

This suggests a belief that the 'schizophrenia' label indicates some sort of individual weakness. This seems to be a powerful component of stigma experienced by this participant. This also might relate to the complex relationship between a societal privileging of notions of the individual and diagnosis stemming from individualising bio-psychiatry.

When prompted to explain why he feels like this, his ideas stemmed from past experiences of having an individual in his life being treated unfavourably by his community due to their diagnosis of bipolar illness, another severe mental illness diagnosis.

"My cousin was cut off from everybody because he had that Bipolar. He kept switching up on people and they just had enough. I can't be like this in front of everyone. They will definitely tell everyone to cut me out too."

Koby, Kenyan

Participants have been embroiled in a fight over who should learn about their diagnosis. 'Schizophrenia' itself is the vector of stigma. The term is freighted with stigma, and participants are aware of this. The self-stigma is then revealed in their acknowledgement of not wishing to disclose the diagnosis to the family. While some participants indicated that they felt no stigma, others gained the confidence to assess and express their feelings throughout the interview. Others felt more apprehensive about disclosing their condition to others outside their familial network for fear of stigma. Families are the primary source of stigma for these people when disclosing the illness.

Language plays a crucial role in shaping how participants define and claim their mental health experiences. The language used to describe mental distress can significantly impact an individual's ability to seek help and receive appropriate care. For example, if a person has only ever heard negative or stigmatizing terms used to describe mental illness, they may be hesitant to seek help or disclose their struggles for fear of being judged or misunderstood. On the other hand, if a person has been exposed to more positive, empowering language around mental health, they may be more likely to seek help and feel validated in their experiences.

The three most often mentioned terms by participants in relation to their ethnicity were “mad,” "weakness," and "crazy." Another participant claimed that terms used in his culture were not as subtle as he had hoped that terms such as mad is damaging to the individual.

“They’re not using appropriate terminology in the community because I don’t think they understand. The words they come out with is like…are you.. like there is a word called in the south Asian culture it’s called Pagal….is a person mad? So, I don’t think that’s very supportive, to support people with…if they are already suffering with illness are able to support it. When I was in a primary care setting, the Imam came, my family came…they said to pick myself up. There isn’t a problem. But I was so unwell, I just couldn’t do it.”

Zeeshan, Pakistani

It seems like the Zeeshan is expressing their frustration with the lack of appropriate and supportive language around mental illness within their community. They believe that some individuals in their community may not fully understand mental health issues and use inappropriate terms, such as "pagal" [11] which can be stigmatizing and unhelpful. Zeeshan also describes an experience where their family and religious leader suggested that they simply "pick themselves up" when they were struggling with their mental health, which they found unhelpful and dismissive of their condition. This highlights a need for more education and understanding around mental health within the speaker's community, and for more supportive and compassionate language and attitudes towards those who are

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[11] In Urdu, "pagal" means "crazy" or "mad." It is a term used to describe someone who carries a label of mental illness or behaves in an irrational manner.

struggling with mental illness. This was also similar for another Muslim participant who described her family's attempt to cure her.

"I came home, and I went straight to my room. I didn't want to deal with my parents alone. I wanted to move out, but it's not accepted in my culture to do this as the eldest. My mum came over and just started splashing Zamzam water (holy Islamic water) at me to try and heal me. I just froze and let her do it because I know if I reacted in some way, she would think something is up again and keep being at it."

Amina, Somali

Asma resonates a similar experience. The quote appears to be describing the Amina's experience with a mental health condition that they believe was misdiagnosed and treated with religious rituals, such as exorcisms and Quran recitations, before they were able to find the support they needed online. Asma indicates that they initially did not accept the diagnosis of 'schizophrenia,' but after connecting with a supportive online community, they were encouraged to seek professional help. This suggests that the Asma found validation and understanding within the online group, which helped them to come to terms with their condition and seek appropriate treatment. Asma also notes that they are still experiencing trauma from their past experiences with misdiagnosis and ineffective treatments.

"*After 3 exorcisms, and men coming to the house to read the Quran on me, they just left me to it alone because it didn't work. So, I googled my symptoms, and came across a Facebook group. They were supportive to say it honestly. They encouraged me to seek help. I just knew deep down that it was 'schizophrenia,' but I just didn't accept it before. Now I do and I wish I had help sooner. I'm still traumatised with it."*

Asma, Pakistani

A participant, of Chinese and Japanese heritage also noted the term "crazy" and elaborated by citing an experience spoke involving herself and the GP:

“The stigma with ‘schizophrenia’ is like it means you’re mad. You’re crazy right? That’s the way it is. I told my GP you must be thinking I’m mad. Because that’s what we say back home.”

Zhi, Chinese and Japanese

The quote suggests that there is a stigma associated with the diagnosis of ‘schizophrenia,’ with the participant stating that the term is often associated with being "mad" or "crazy". This stigma may be influenced by cultural beliefs and attitudes towards mental illness, which may be different in the participants’ native country compared to the country of residence. Zhi expresses concern that their GP may also hold negative perceptions about ‘schizophrenia’ due to the stigma associated with the term. Zhi also remarked,

“Saying you are crazy in contrast to the phrase stressed… since crazy just makes you think of the worst thing. I just say to my family I am stressed. And so, this entire negative stigma that calls individuals crazy in my culture is not right. Just say how it is. No big deal.”

Zhi, Chinese and Japanese

The quote highlights the negative stigma and stereotypes associated with the term "crazy" in some cultures. This stigma can make it difficult for individuals to seek help for mental health issues or to discuss their experiences with others.

Using alternative language such as "stressed" was a way for Zhi to talk about her experiences without facing the negative stigma associated with mental distress. However, it is important to recognize that these terms may not fully capture the complexity of someone's experience and may not accurately reflect their mental health needs. In the context of Mad Studies, the goal is not necessarily to replace terms like "crazy" with other terms, but rather to challenge the negative stereotypes and stigma associated with mental illness and to promote a more accepting and inclusive society. This involves recognizing the diversity of experiences within the "mad" community and advocating for greater social acceptance and support for people with mental health conditions.

Additionally, being a member of a South Asian community, mental illness would be considered non-existent. If such a thing exists, the community will label individuals with derogatory terms.

"In our culture, there just isn't anything such as a mental illness. And people still use like a lot of words like crazy or like nuts that are the words our culture describe people who are probably not usual."

Rahul, Indian

Speaking to White professionals instead of an ethnic minority professional

Another observation of importance was that when participants were questioned about their ethnic, cultural and community identity they felt most at ease to discuss outside of the family, they all responded "White."

"It's easier to speak to a White person because they are more knowledgeable on 'schizophrenia.' It is definitely better in our community to talk about mental health. But not there yet, with 'schizophrenia' or any sort of serious mental health illnesses like bipolar and others. It is not the same because they just accepted that we can be stressed and depressed."

Laura, Nigerian

Furthermore, another participant believes the healthcare professionals who are White stigmatised their mental health less. But, upon further exploration, it became evident that the participant had not encountered a person of colour who works in the mental health field. The participant's experience of only having mental health care provided by White professionals indicates a central problem of a lack of diversity in mental health services.

"Better to talk to a White person because they get it and its more common. I feel like talking to a Black doctor about is hard. I don't want them to know. They're going to think the same as my family, right?"

Amina, Somali

However, this was not always the case for others. Joseph felt that it was a preference for him to talk to a White person as it gave him reassurance.

"I prefer to talk to White people. I don't know…it's just that time when I went to the GP to tell him about what I was going through, he was [of] Pakistani [heritage]. He was very closed up and didn't really strike me as somebody who is okay with mental health. The first thing he said was okay, I can refer to counselling and give you some medications. He acted really weird. Made me feel super uncomfortable, but when I had my admission, the psychiatrist was easy to talk. She was White. I talked to her. I think talking and opening up is better."

Joseph, Congolese

This also, suggests that for this participant and for some people of Black and South Asian heritage who experience the mental health system, they are reticent to discuss their mental health with a professional of similar heritage because they may feel they are being judged and/ or responded to in a negative way.

When a person of colour prefers a White doctor over a doctor who looks like them in a mental health setting, it can reflect a complex interplay of factors, including perceived competence, trust, internalized stigma, and experiences with systemic racism. This preference may arise from a perception that White doctors are more competent or better trained, a view that can be reinforced by societal biases and systemic inequalities that often place White professionals in positions of authority and expertise (Kendall, 2012; Collins, 2018). Internalized racism may also lead individuals to devalue professionals from their own racial or ethnic group, believing that White doctors are superior due to societal messages that favour White standards. Additionally, previous negative experiences with doctors from their own racial or ethnic group or with the healthcare system in general could influence this preference, as individuals may assume they will receive better or more impartial treatment from a White doctor. CRT posits that racism is deeply embedded in society, affecting perceptions and behaviors. Internalized racism, where individuals devalue professionals from their own racial or ethnic group, can be seen because of societal messages that uphold White superiority. This devaluation reflects broader systemic issues that reinforce White standards as the norm.

Furthermore, cultural mistrust can play a role, where individuals might fear that professionals from their own community could judge them or disclose their issues within the community, compromising their confidentiality. Some may seek objectivity, believing that a doctor from their own racial or ethnic group might not provide a neutral perspective. Systemic racism within the healthcare system itself can also reinforce these preferences by subtly favouring White doctors through better resources, support, or prestigious roles, influencing patients' perceptions.

Additionally, the intersection of various aspects of a person’s identity, such as race, gender, and socioeconomic status, can shape their preferences, especially if they have faced significant discrimination from members of their own racial group. To address these preferences, it is crucial for the healthcare system to ensure cultural competence, break down systemic biases, provide training on the impacts of racism and internalized stigma, foster an inclusive environment, and work actively to build trust within communities of colour. Having a mental professional of a similar ethnic heritage for some participants may feel like there is lack of professional distance and boundaries, and that the cultural expectations and norms of that professional, however inadvertent, may detrimentally inform the experience that they participants have, however unintended. Amina also believes there should be more diversity in the mental healthcare services as it can aid in talking therapies.

“Do we need more Black people in mental health? 100 percent.”

Amina, Somali

Participants in this study also spoke about the term weakness as another common stigma associated with ‘schizophrenia.’ More specifically, when discussing the term “weakness” the male participants spoke about it in terms of feeling responsible for their families. For example, in discussing “weakness.” Koby discussed how there is that perception that if you go to seek help it means your weak. This participant further elaborated by saying:

“Imagine going up to the doctor saying to them that I want help. I can't be seen as somebody with a mental illness, it’s just I didn’t want to be seen as weak.”

Koby, Kenyan

“I believe it’s a cultural thing. Not acceptable for us to be mentally unwell. Even though we go home after a mental health awareness course, we don’t have these conversations as a young child. These White kids go home and are able to speak freely to their mums and dads… I think parents don’t want their kids to be weak.”

Leon, Nigerian

For instance, this participant suggested viewing weakness as the number one stigma and spoke about how Congolese men, are viewed as the head of the family, and cannot associate mental illness, especially ‘schizophrenia’ with themselves.

Joseph noted:

“I started getting help for my symptoms…quite a while back… it was because I just at the time had a psychotic episode, but I didn’t know what was going on and my friends took me to the hospital. That’s when I knew that thing got out of hand, and I needed to relax and set my ego aside and go through with it.”

Joseph, Congolese

The same participant also spoke about how this stigma also affects Somali women and that idea that women – especially from an African heritage are made to feel that it is frowned upon to seek support. This is informed by a stereotype that Black women need to be strong in the face of adversity. This negative stereotype suggests that women, in particular, Black women should suffer in silence and be uncomplaining (Jefferies, 2022).

"The fact I as a Black woman need to be a strong woman. I need to get over my problems and not allow my diagnosis to affect me. I can't be the strong Black woman at the moment. I can't pretend to be something I am not. Seeking help, it was just a self-crushing experience because I felt so little. This is too much for me. I wanted to tell my sister, because I felt had to keep up the ideal image of who I am supposed to be."

Amina, Somali

Individuals described a range of settings in which they encountered perceived and enacted courtesy stigma, both inside and beyond the group. Courtesy stigma, referred to as experiencing stigma through having a relationship with the person who had experienced mental distress. While the majority of participants in this study indicated that their close family members knew what was happening in certain situations, they were hesitant to discuss it openly with others outside the family.

"…they [neighbours] don't know what we are going through. People should just know that they need to be understanding and not be so mean to us…giving us weird looks…"

Melissa, Chinese

"When we went to my grandad's birthday party, they [grandparents] ask us not to mention that he [participant's brother-in-law] has 'schizophrenia.' Almost like it's an embarrassment. I'm sure that hurt my brother-in-law."

Emmanuel, Nigerian

Furthermore, keeping their experiences a secret owing to perceived shame was mirrored by this daughter who expressed it a societal context.

"It's like a hidden secret… I mean, you go to a party, and everybody is coming up to you, you know, 'is your grandad okay, we heard what happened, why does everyone know

about it?' Somebody was giving me a lecture that I should have kept it a secret and then the next thing you know they start talking about it around me. That's the stigma you know…. They all think of mental health as something that should be a secret and kept in the family."

Anya, Indian

However, other participants have not experienced stigma in relation to their family member diagnosed with 'schizophrenia.'

"I haven't experienced anything from anybody. We [family] don't also make her feel some kind of way – she was scared we would say or do something but never judged her or make her feel ashamed. Everyone was really supportive too – like our aunties used to make us dinner when she was hospitalised just to show that she cares."

Martha, Jamaican

A participant recounts his experiences when his brother first was experiencing symptoms. Stigma was not a factor but rather there was a sense of helplessness for the family to support his brother.

"I think we just didn't know what to do. we felt powerless…We didn't know what to do. It's not about we felt guilty. No, we didn't care about image, and I mean we just ignored it because we didn't know what to do. It's not because we felt ashamed by him or embarrassed by the situation. You know, we've been through other stuff as a family, so this… was nothing basically. So, we just thought, yeah. We just don't know what to do. We just don't know what this is."

Tariq, Bangladeshi

There were some suggestions, however, that the stigma may be present, but some participants had chosen to ignore it which meant it would not be experienced.

“Never felt anything from anyone – I don’t really care because at the end of the day, this is my mum. I love her lots and if anybody feels some kind a way about it, I honestly couldn’t care less.”

Diya, Punjabi

This could be due to a conscious decision not to notice what people are saying. It's almost as if the family member has turned a blind eye.

“My father pretends that she is not well. When I try to tell him about it, it’s… hard. He doesn’t want to accept it. He doesn’t want to believe that his daughter, my sister is you know, she has ‘schizophrenia’. Do you understand? Like, it gives me a difficult time as well because I need him to support us. We need our dad to be on board, but he does not. He just ignores it and says that it does not exist.”

Samiya, Pakistani

When prompted to elaborate on what the participant meant by that, she suggested that her father does not believe it exist:

“He generally does not believe mental illness in general does not exist. That my sister needs to snap out of it and get on with it and stop attention seeking.”

Samiya, Pakistani

There was a consensus that family members place importance on the image the family present. Participants stated that they felt more alienated from others as a result of their family member being diagnosed with ‘schizophrenia.’ This effectively prevented them from addressing it freely with those who were close to the individual. As one family member described, she did not want to talk about her niece because she believed they will stigmatise her niece through insults and discrimination.

“I have not told my friends about it because they will definitely talk about her and say really nasty things about her. They will spread gossip. They know something is up, but I

just brush it off. It is important to me that the image of my family is upheld – I just don't want people to make up things that are not true about her."

Melissa, Chinese

A general sense of not being an equal member of the community, or of being frowned upon, was a recurring theme among participants. Some of the participants felt that with their family member being diagnosed with 'schizophrenia,' this has caused the community to actively show disapproval. This was particularly prevalent in the South Asian community.

"It just felt like we were generally frowned upon a lot of the time, like we were in some kind of cult or something."

Samiya, Pakistani

Similarly, a participant from a Black community felt that there was a sense of alienation from their own communities when the label of 'schizophrenia' is imposed on their family member.

"I feel like…. feel like you do not have anything in common with everyone else [Black community in the area] … As an example, if your neighbours do not share your what you are going through, you will have nothing in common with them."

Martha, Jamaican

Some respondents became protective and angry as a result of the behaviour exhibited by the community. One respondent reflected on an incident that occurred while conversing with another Pakistani family member:

"We were not invited to somebody's wedding because they didn't want him to 'act out'. I flipped. Made me so angry how they could treat us like that." They do not really say anything front of us, but you can get it from the way they act around us."

Samiya, Pakistani

Some participants felt that the when the topic of mental illness comes up in family discussions, the family members would discuss it in a negative light. The associated family member of the individual diagnosed with 'schizophrenia' who are present during these discussions would agree unanimously.

"I really do not get it – like you're here helping my grandad but when people start talking about just general mental health issues you agree with them. It was like she was trying to impress them. We cannot be sending mixed messages you know – she tells him that we are not embarrassed of him but when the time comes to speak up for him, it's not there."

Anya, Indian

"I remember we were watching the movie Split and one of my uncles said – That guy is schizo – crazy. We just stay quiet because of our auntie. We just do not want people thinking stuff about us and that's why we didn't challenge it. Our auntie seriously hates the fact that my dad had help you know, and he has medication for 'schizophrenia'".

Jacob, Kenyan

Another way that individuals try to educate family members when stigma was happening, there were instances where they glorified symptoms of 'schizophrenia' just so they could be more accepting and avoid stigmatising behaviour.

"I said to my cousin once – you know my mum, she sees amazing things and can tell what you are thinking. I just wanted my cousin to stop saying these things about my mum. Then again, he was like 11 so if he believed me, I do not know."

Diya, Punjabi

"I would say that my family – Beyonce had mental illness too. I would try and list all the celebrities who had mental illness especially those who were Black you know."

Martha, Jamaican

This method, however, was linked to emotional distress and ambivalence because it created the possibility of stigmatisation:

"When I talk about my mum and the things, she goes through…it makes me feel good about it at some point. You know start conversations - conversations in the Indian community, but then I feel like I am also closing the door. What if me actually speaking about it makes things worse for my mum?"

Anya, Indian

"I am quite vocal about 'schizophrenia' and my mum so when I start talking about it to others they just start like huffing and walking away you know. They refuse to listen to me. It is like they had something against my mum and me too. They rejected my mum and now they are rejecting me."

Martha, Jamaican

This theme captured the experiences on seeking help for their family member diagnosed with 'schizophrenia.' In their accounts of the events associated with seeking help, there was a mutual understanding that family members felt powerless when it came to seeking support. This was mostly due to a lack of knowledge on the appropriate course of action.

Participants reflected upon their background and its effect on courtesy stigma. Some participants felt their ethnicity was brought up quite frequently. A participant discussed the notion that the family are no longer acting 'Black' because the individual was hospitalised.

"When my papa was hospitalised, we regularly seeing him at [name of hospital]. People [extended family members] around us said we were acting White too like my dad who sought help. So, you are saying, I'm not Black because my dad is acting White for what being hospitalised?"

Jacob, Kenyan

When asked to elaborate this participant explained that the family believed his illness was attributed to demonic possession and should seek help through the church. Once challenged, it became known that the family seeking support had become involved in a dispute that centred on identity, ethnicity, and implicit racism. Some of the family members had suggested that by engaging with mental health services that they perceived as White their father had lost his sense of and African identity and had acquiesced to the predominantly Eurocentric cultures and values.

"My family, God, they are something else. We had many family gatherings to discuss my father's illness. Meetings after meetings, as if it is a marriage proposal. You get me right?... My papa's brother asked for an exorcism, but we argued about how that is inappropriate as our papa was super religious. The one of our aunties said "oh, so you're going to take him to the White people and be like them, and what get medication and see those people called psychologists." She did not even know what they [psychologists] were called we had to correct her."

Jacob, Kenyan

Language and diagnostic labels

The language Joseph used to describe the diagnosis had negative implications. There is a clash between a scientific (psychiatry) and supernatural (ethnicity/cultural) understanding of his condition. But this may not be an apparent contradiction as both understandings and explanations can be accommodated in a Eurocentric and Africanist context. An important commonality is self-blame in a context within these broader frameworks. Both afford both an individualistic and social context. Arguably, both explanatory frameworks are impervious to complexity, and people generally desire simple explanations for things. Even though an illness diagnosis need not be associated with self-blame (and for some people, illness operates to deflect self-blame – it is not me, it is the illness), the privileging of individualism allows this to inform their understanding of their condition. The corollary belief in religion as punishment of sin/sinners also relies on individualism (people in a personal relationship to their God). Thus, it fills some of the explanatory space not covered by illness acknowledgement (psychiatry is not as good at explaining why this may happened to him). In this sense, the interaction of psychiatry and religious frames, relying on individualism, reinforces a sense of self-blame. Interestingly, drug use is also stigmatised, especially in some communities. Yet, the stigma of ‘schizophrenia’ appears to be more imposing on the participant’s feeling of diminished self-worth and this makes it more important to avoid than that of drug use.

However, the same participant later in the interview suggested that he feels no self-stigma and has accepted his diagnosis, which indicates contradictory and ambivalent feelings regarding this label and elicits something about the semantics of stigma and shame.

*“I think myself personally. I’m normal. I am fine. Sometimes I do not even feel like I have ‘schizophrenia.’ I’m just okay, you know. I’m not a schizo freak as people say online. But why does it? Why do people think of that? Why do people think we’re like these people who need to be locked up and are out of control? I never lost control. I am fine. These people who feel that we are not should just f*** off.”*

Joseph, Congolese

Joseph is expressing frustration and anger at the negative stereotypes and stigmatization surrounding ‘schizophrenia’ and those who live with it. Joseph is asserting his own normalcy with mental health, even though they have been labelled as a "schizo freak" by others online. Joseph is questioning why people hold these negative views of those with ‘schizophrenia,’ as they have not experienced the loss of control or other negative symptoms commonly associated with the condition. The use of profanity indicates the intensity of the speaker's emotions and frustration with the situation.

The participant's narrative reflects the internalized stigma and societal perceptions surrounding mental health conditions, particularly ‘schizophrenia.’ From a Mad Studies perspective, the participant's reluctance to accept the label of 'schizophrenia' underscores the pervasive impact of stigma and pathologizing discourses within society. By rejecting the diagnosis, the participant challenges the dominant narratives that equate mental health conditions with weakness and instability, highlighting the oppressive nature of these societal constructions. Mad Studies emphasizes the importance of challenging ableist assumptions and reclaiming agency over one's identity. The participant's refusal to be labelled as 'weak and unstable' reflects a form of resistance against the stigmatizing discourses that marginalize individuals with mental health conditions. By asserting their desire for help without wanting to be categorized as 'somebody living with ‘schizophrenia,’ the participant seeks to reclaim autonomy and challenge the power dynamics inherent in diagnostic labelling.

By examining the processes of identity, this theme underscores the journey toward self-acceptance and empowerment. While some participants initially denied experiencing self-stigma, further exploration suggested a complex interplay between external and internal sources of stigma.

Jacob argues that ‘schizophrenia’ is not a real illness, but mental illness is generally spoken about.

“Well, ‘schizophrenia’ is what you see in movies and what others [White individuals] experience. I get people are mentally unwell, I mean we talk about mental health in our family. But I don’t think it’s [‘schizophrenia’] real. I don’t think he has that.”

Jacob, Kenyan

Some individuals started to question the existence of ‘schizophrenia’ in general due to the lack of treatment that was helping them. This in turn led them to believe that ‘schizophrenia’ does not exist. By ‘home,’ the participant meant to discuss alternative arrangements from families abroad in their country of birth.

“I don’t believe he has ‘schizophrenia’, whatever this illness or whatever is happening. It’s definitely not ‘schizophrenia’. We have given him drugs; therapy and we are on the waiting list for a psychotherapist. None of the medication are helping. He still has according to the GP ‘schizophrenia’ symptoms. If the drugs are not helping… then what is it? It makes no sense. We are considering taking him home for other treatment options.”

Jacob, Kenyan

Psychological diagnosis is essential to proper mental healthcare and no treatment is provided if it is not labelled in society. For some participants, the notion that ‘schizophrenia’ was just a label to begin treatment.

“I don’t know if this is even legal but when my partner and I brought it up and questioned our doctor… we said that we don’t think he has ‘schizophrenia’, and the doctor then said well he does have all the symptoms and we believe it is. Okay, but we don’t think that… then he said it still haunts me, if you don’t think he has it, we can stop treating him for it but then we can’t help him.”

Anya, Indian

Another individual said:

“Either they don’t know what they are doing or they just like to call my mum schizophrenic”.

Martha, Jamaican

The statement reflects a perspective commonly found in traditional psychiatric discourse, where psychological diagnosis is viewed as essential for accessing mental healthcare and treatment. However, it's important to critically analyse this assertion from various perspectives, including those of Mad Studies and critical psychiatry.

The most common symptoms of ‘schizophrenia’ – hallucinations were attributed to possession and drugs in this participant’s family:

“Oh, we thought at first he was faking it. I thought it was him not wanting to go to work because he hated it. But things were getting worse. Maybe he was possessed, my parents thought the hallucinations was because he was on drugs.”

Jacob, Kenyan

From a Mad Studies perspective, there is a recognition of the limitations and potential harm associated with diagnostic labelling. Mad Studies critiques the hegemony of psychiatric diagnosis, questioning the power dynamics inherent in labelling individuals with mental health conditions. This perspective emphasizes the importance of considering social, cultural, and environmental factors in understanding mental distress, rather than solely relying on diagnostic categories. Additionally, critical psychiatry raises concerns about the over-reliance on diagnosis and the medicalization of mental distress. It highlights how diagnostic labels can pathologize normal variations in human experience and contribute to stigma and discrimination. Critical psychiatry advocates for a more comprehensive approach to mental healthcare that prioritizes the individual's subjective experience and social context over diagnostic categories.

Chapter 5: Generational and Systemic Barriers

The theme of help-seeking experiences in connection to migration, generational divides, and stigma highlights the challenges faced by second-generation persons of colour in seeking help for mental health issues. The participants in the study shared their experiences of feeling stigmatized by first-generation individuals, particularly their parents, who often held cultural beliefs and attitudes towards mental health that were different from those of their children.

Some participants expressed that they found it difficult to discuss mental health with their parents, preferring instead to confide in peers their age, such as friends and siblings. This was attributed to the generational differences in attitudes towards mental health and seeking professional help. They suggested that first-generation individuals tended to view mental health issues as a personal weakness, something to be kept hidden, and often relied on religious and cultural practices to address them. On the other hand, second-generation individuals were more open to discussing mental health and sought professional help when needed. However, this was not always easy due to the stigma associated with mental health in their community, and some participants felt that seeking help would make them appear weak or mentally unwell.

Lack of knowledge of 'schizophrenia within families

Another participant expressed frustration with the lack of understanding that exists in the Pakistani communities when it comes to discussing her diagnosis label of 'schizophrenia.'

"My own friends, we don't speak about it. It's the backwards thinking in the Pakistani culture. We're in 2020. I'm not possessed. I have 'schizophrenia' Religion can't help me get rid of my voices. I'm genuinely annoyed that Pakistanis well from my side at least think I should just read the Qur'an and become more religious. My father once said my 'Iman' [Islamic faith] was low. I had low faith."

Asma, Pakistani

Contrary to this, a participant explained that it may not be due to lack of understanding but the motivation behind trying to understand for some in the community is low.

"I'm not saying that the South Asian community is not supportive or doesn't want to help but they just don't want to understand, and I think in that community it is a taboo an area of concern when nobody seems to be talking about this."

Zeeshan, Pakistani

This was also prevalent for a participant from a Chinese and Japanese heritage. She explains that there is a lot to expect from individuals from this heritage and seeking support for mental illness was not received well by many within this culture from this community.

"There was a lot of conflict and tension after trying…. They saw it as
I'm making a big drama out of nothing. Being from Asian family, they have very high expectations for like I needed to go to college, university, I need to do very well in my exams, because of my mental health I had to drop out a lot. It's not their expectation of where they want me to be. That's not their expectation. They still don't think that a mental health is a justifiable thing of like losing school and taking breaks."

Zhi, Chinese and Japanese

Furthermore, another participant emphasised the importance of starting conversations. This quote highlights the importance of starting conversations about mental health within communities of people of colour who are living with mental health diagnoses. The participant expresses frustration with the lack of support from family members and the feeling of being on their own in dealing with their mental health struggles.

They believe that starting a conversation about mental health in general within their communities would help reduce the stigma surrounding it. The participant also points out that mental health issues are often invisible, which contributes to the lack of understanding and support within their community. By ‘we,’ the participant refers to the people of colour who are carrying mental health diagnoses such as ‘schizophrenia.’

“Our families aren't there for us. We're on our own in this situation. It would be much more comfortable if the discussion of mental health in general takes place in our homes. People in our communities have difficulty dealing with it because it's not visible. If it is not visible to them, it does not exist.”

Laura, Nigerian

Another participant further elaborates*:*

“It's difficult to accept if you aren't exposed to anything in a younger age. For such a long time you have... really prudent values and this idea of mental health and going counselling... This is a new concept that many older people have just not embraced in the older age.”

Rahul, Indian

Commenting on the lack of understanding of the label ‘schizophrenia’ within first generation families, one of the participants said:

“I got called all sorts of names from my mum’s side of the family. This is another reason why my parents and grandparents would not be willingly and easily say ‘oh I’m depressed’ or ‘I have anxiety’. Our generation have been told that its normal to be mentally ill. Especially due to our environments. The environment that we grow up in.”

Asma also feels it may be because her parents have not experienced or encountered it in their lives. Second generation Asians, with UK education experiences, were perceived to have a different understanding than their parents.

“It was very hard for them to understand what was going on because of what I was experiencing, they weren’t experiencing that. They keep telling me what I was saying was

not true. That was actually very distressing for me for me because for me at the time what I was seeing, and hearing was real."

Asma, Pakistani

Religious/spiritual beliefs of mental distress

This quote highlights the belief system of the elders in the participant's family, who attribute any illness or mental health condition to the influence of supernatural beings such as 'jinn' and' Black magic.' This belief system can create stigma and misunderstandings around mental health, leading to resistance or reluctance to seek appropriate care or treatment.

"In our culture it's just that 'schizophrenia'....we just strive to be happy you know, anything related to being mentally ill is just a no-no. Just pray and keep yourself closer to God and you will be fine. I grew up in Nigeria and we have been told to basically pray anything related to the mind away. Our brother just doesn't anymore that is why he is the way he is. He needs to pray."

Emmanuel, Nigerian

The participant's family's belief system also illustrates the influence of cultural beliefs on attitudes.

"The elders were brought up to believe any illness is the cause of the unknown power of the jinn. So, when it became known in my family that I had 'schizophrenia,' they believe it's either evil eye, jinn possession and Black magic."

Zeeshan, Pakistani

Some participants suggested that migrating from their country of birth to a European country, with a healthcare system, such as the UK has contributed to individuals gain the appropriate the right support for their mental health needs. Participants' experiences in their countries of birth concerning their mental health made them reluctant to seek support in the UK, but once they had they were relieved to have done so.

"You know what the funny thing is? Because here mental health is talked about, it is just great. If you go back years ago, I moved here from Saudi when I was about 15. Back before, when I was feeling a bit off, I would not say anything at all. It was a… just something to ignore or else it would be a huge issue. Coming here, and everyone just casually saying, oh I am depressed, and I have anxiety attacks, I felt like okay this could be a place to talk about what I was going through. So, I went to the doctor after years of suffering and just blurted out, I hear voices. And she just knew what I was talking about, asked the right questions, and made me feel somewhat normal? Like this happens to everyone. It felt amazing…"

Amina, Somali

When this participant explained to his family that he was sectioned and hospitalised, the family took a while to understand. In this quote, the speaker is expressing their frustration with their family's lack of understanding and acceptance of mental illness, particularly 'schizophrenia'.

"'Schizophrenia' is misunderstood craziness. They just never seen mental illness as common here than in India. It is hard to go to them (family)."

Rahul, Indian

This may because of the length of time they were in the UK as the participant explained they only migrated here in 2017. In contrast, another participant who migrated to the UK with her family over 15 years ago said:

"We [second generation], know how important mental health is for us. We look after each other. It did not take long to convince my dad that mental health issues were a thing but now he is my number 1 supporter."

Laura, Nigerian

When asked or prompted to discuss the impact of the label of ‘schizophrenia’ on family relationships, the participants were unanimous in the view that religious practices were used to show views of ‘schizophrenia’ was common among the family members of the individuals who carry the label of ‘schizophrenia.’

“My dad says my Iman (faith in God) is weak. I need to read more Quran, [Islamic Holy book] they did plenty of Ruqiya (exorcism) on me. When people come over, it’s just a silent rule that I should just stay in my room. My auntie thinks I’m making it up, my mum *sister. It’s the older generation who don’t understand that mental health is real. They act that it doesn’t exist. They need to educate themselves, but I don’t know why they won’t do it for me.”*

Asma, Pakistani

Talking about this issue an Zeeshan said:

“Getting help is nothing to be ashamed off. Unfortunately, that is nothing in my case in my community. We do not say ‘schizophrenia.’ We just say he has got the evil eye on him.”

Zeeshan, Pakistani

This quote suggests that there has been a generational shift in attitudes towards mental health within some communities. Laura, who is a member of the second generation, indicates that they as second generations are aware of the importance of mental health and support each other in this regard. They also mention that their father, who may belong to the first generation, was initially sceptical about the existence of mental health issues but has since become their primary source of support. The quote may indicate that younger generations are more open and accepting of mental health issues, and that they may be playing a role in changing the attitudes of older generations.

Some participants were received well from their direct family members such as parents and siblings. However, extended family members were not as forthcoming in their support when they found out about the individual’s diagnosis. The same participant expressed how her grandparents from her hometown was not supported and experienced discrimination.

"I told you did not I that my dad is now my number 1 supporter, but my grandparents and aunt and uncles… they are horrible when it comes my diagnosis. They called me the devil one time. I just do not get it. You would think they'd be more supportive."

Laura, Nigeria

Asma was excluded from social events due to her diagnosis because of a fear that the older generation would ridicule the family. Even though, her mother was supportive and understanding there was still elements of fear of stigma from the first-generation family members.

"My mum she keeps me out weddings and when people come over, she asks me to keep away from the guests. It is not that she doesn't like me. She is accepting. She just does not want other family members to see me and start thinking about me negatively because they don't understand."

Asma, Pakistani

From a different generation

The generational differences in attitudes towards mental health were further complicated by the experience of migration, which often resulted in cultural dislocation and a sense of not belonging. This further exacerbated the challenges of seeking help for mental health issues, as participants felt they had to navigate the expectations of their culture and their new home.

Amina notes:

“….my older siblings and mum, I could not talk about it, maybe my little brother, he’s kind of with it you know…mum and sisters… no could never discuss. I keep it on the low because they would make me feel like I am crazy all the time. They would just call an Imam [religious leader] and make my situation worse.”

Amina, Pakistani

Amina is discussing their difficulty in discussing their mental health experiences with their family members, specifically their older siblings and mother. They express that they feel like they cannot discuss their experiences with them because they would be made to feel crazy, and their family would call an Imam to deal with the situation. However, she notes that she may not be able to talk about it with their younger brother, who is more understanding. This quote highlights the challenges individuals may face in seeking support from their families due to cultural/ religious beliefs and the stigma surrounding mental health in some communities.

Similarly, to the previous participant, another interviewee expressed difficulty discussing their mental health with family members due to a perceived lack of support and understanding. Instead, they found more acceptance and validation from friends, who were more willing to take their struggles seriously. The participant noted that their family would often push the issue aside and tell them to "fix yourself up," whereas their friends were more supportive and less dismissive.

“I suppose because they [family] sometimes push it aside. They keep it on the hush hush. And they will say things like, fix yourself up. But when it comes to my friends, they take me more seriously.”

Rahul, Indian

The challenges faced by second-generation persons of colour in seeking help for mental health issues can be understood through the critical lens of Mad Studies, which highlights the impact of cultural and generational divides on perceptions of mental health. The reluctance of first-generation individuals to discuss mental health issues, viewing them as personal weaknesses and preferring religious or cultural practices, contrasts with the more open attitudes of second-generation individuals who seek professional help. This divide underscores the need for mental health frameworks that are inclusive of diverse cultural beliefs and practices, as advocated by Mad Studies. Additionally, the stigma associated with seeking professional help within these communities reflects broader societal stigmatization of mental distress, which Mad Studies seeks to challenge and transform.

Participants face a complex set of challenges where stigma mediates access to support. A number of positives and negatives were revealed as influential concerning help-seeking, associated with ethnicity and sense of community. Intersections between race(ism), ethnicity and gender contribute to the challenges for participants navigating their way to securing help and support, and at least one insidious racist stereotype was remarked upon as constituting a barrier to formal services.

Following an examination of participants' attitudes toward ‘schizophrenia’ and their feelings of self-stigma, they were asked to identify the stigmas associated with ‘schizophrenia’ within their own ethnically defined communities.

Leon mentioned how mindsets, cultural beliefs and religion from the Nigerian community could have an influence on seeking support for symptoms related to the ‘schizophrenia’ diagnosis.

“The Nigerian mindset… there is a big stigma in mental health in general anyway. It comes from our religion. If I ask for help or talk about how I am feeling they tell me to snap out of it and pray more.”

Leon, Nigerian

Shame and disclosure

A participant felt that it would cause the family to break if he discloses his illness with the rest of his family due to the stigma associated with mental illness in general.

This quote highlights the fear and shame associated with mental health issues within some families and communities. Koby expresses concern that if they were to seek treatment or support for their own mental health issues, they would be treated differently and potentially disowned by their family. Koby also shares a personal experience of their father leaving the family after their mother had a nervous breakdown, citing embarrassment as the reason. This quote underscores the significant impact that societal and cultural attitudes towards mental health can have on individuals and families, often leading to feelings of isolation, stigma, and abandonment.

*"Treat me differently? They will disown me. I am done. *laughs* I am done. Its- I cannot even stress it. You know right. My own father left us because my mum had a nervous breakdown when my sister was 7. He left us. He was too embarrassed to be a part of us because his family would say so many things about us."*

Koby, Kenyan

The reasons for this generational difference may stem from lack of open communication to discuss feelings in general. For example, a participant said:

"It is hard to ask. For example, my grandmother was part of the Windrush experience. She just would not be open about it or talk how it was like. She just denies it – I see her struggle with her mental health."

Leon, Nigerian

This quote highlights the difficulty of intergenerational communication and how it can impact mental health. The speaker mentions their grandmother's experience as a part of the Windrush generation, a term used to describe people who migrated from Caribbean countries to the UK after World War II. Leon suggests that their grandmother is not open about her experience and denies talking about it, which may be contributing to her struggles with mental health.

"I could never. I could never my mum sees me as her eldest somebody on a high status. It will crush her. She will never understand. I tried to even joke and hint it to her. Just to see her reaction. She flat out told me to not to joke about these kinds of things."

Koby, Kenyan

Asma mentioned that she sought support from her college counsellor, but this became a negative experience when the counsellor had written a referral to CAMHS, and the referral letter was sent to her home from the school.

"I talked to my high school counsellor first because I had to because my friends told me that it was not normal. I told the counsellor I was hearing voices. He explained to me that I will need to be referred to CAMHS. He sent a letter to the house. It was the worst experience. My mum read the letter and just gave me the letter to try and explain something. I lied and told her that I had a headache and the counsellor misunderstood me. I put the letter in the bin and did not see the counsellor again. At least tell me you are telling my family. That way they do not find out by others. But now I understand why she did it, but it would have been easier for me to tell my family first. But it got progressively worse, the hallucinations, I could not take it, so I just ignored my mum and carried on with the referral."

Asma, Pakistani

For Chanje (from the Plant Fetish study), there was a familial constraint not to willingly speak about her Complex PTSD experiences:

"So, part of my complex PTSD means that . . . one of my symptoms is that I have suicidal thoughts, so if I speak to my mum about having suicidal thoughts, she says oh don't think like that. You're so young . . . and it's like, don't think like that. I don't want to think like that. That's just what's happening and don't think like that is not useful advice. It puts a distance between you because they don't understand how you think or what, what your experience of the world is and there is no way to assimilate with any of their experiences."

Chanje

Her mother not fully understanding or legitimising Chanje's experiences has had a negative impact on their relationship. Avoiding difficult conversations or seeming to downplay the severity of a person's mental distress may be a highly adjustable and normative approach within the context of stigma. However, it may not always be the responsibility of the family to address the causes of mental distress but rather support the person through their recovery.

This theme conceptualises the experiences and feelings towards mental health services. The theme articulates the participants' participants views on what they believe prevents individuals from their community race to seek support. One of the key aspects of this theme is centred around racial trauma, and the fear of believing that they may face racism when accessing services. This treatment in turn, according to some participants, created a mistrust of the system and a concern for how people of colour would be treated if they were to access services. Another aspect was family influence whereby individuals cannot speak up due to the expectations of the family household. Among barriers of seeking help were those related to race, including racism and a perception that the mental health services could not accommodate them due to cultural differences.

A participant expressed her concern that service providers were racist in terms of level of care was provided compared to the individuals who are White counterparts.

"I met a girl in my support group a while back who also had schizophrenia.' We talked about our first time, and she told me how she went to the doctor and who referred her to a psychologist within two weeks. I asked her what she said to the doctor for her to be referred so quick. It was similar to what I said, and I was referred to a psychologist after 7 months of going to the doctor with the same thing. But he just prescribed me medication and told me it was temporary. Because she is White, she gets the psychologist whilst I get drowned in medication which does not even seem to work."

Asma, Pakistani

Similarly, another participant claimed believed that services were failing her due to her ethnicity and culture.

"I remember when my mental health was deteriorating, I was calling my case worker, but she would not get back to me. There was no communication at all about my treatment plan. It took me 5 weeks to meet a social worker another couple of months to start therapy. Cannot imagine how it will be now. Sometimes I feel like is it because I am Black? Why is it taking weeks to get a phone call."

Laura, Nigerian

These delays may have little to do with racism, they are endemic in an under resourced system damaged by politics of austerity. Racist discrimination could overlay this. The important matter for this participant the sense that it is racism that caused the delays for adequate mental health support.

Additional stigmas alluded to the overarching theme of fear. In other words, there is a fear of being diagnosed, a fear of being labelled and fear of being hospitalised. This quote describes the fear that some individuals from Black communities may have when seeking help for mental health issues. The participant states that they were afraid that if they sought help, they may be locked up due to the stereotype of mental illness being associated with violence. This fear was particularly acute for the participant as they were a 6ft Black man and were worried that they would be treated with suspicion and hostility. Additionally, the participant expresses a general mistrust of the UK healthcare system due to its historical mistreatment of Black people, which further exacerbates their anxiety about seeking help.

"Luckily, I never had a violent episode in association with my diagnosis. The only thing that used to stopped me from going to seek help was that what if they lock me up? Hear me out, I am 6ft Black man who is hearing voices linked to a well-known mental health illness that has tendency for violence. So, I was just waiting and making sure it is getting handled well. The U.K have a reputation of causing harm to Black people."

Koby, Kenyan

"We [gestured to herself] are already seen as violent and aggressive, they do not look at us as person."

Laura, Nigerian

Chanje specifically called attention to White privilege in the context of being denied an opportunity to organise a particular arts-based initiative within services, where she believed her experiences and expertise were overlooked on discriminatory grounds:

"Now . . . they said no to that project and I am a Black woman and they said yes to a White man who wanted to run a project for White people. They look at me . . . a Black woman with dreads… they look at the White man who is paranoid schizophrenic and they're like, yeah, go for it. I think your idea is great. I don't mind him getting the money. Let's both get some."

Chanje

The subjective experience of racism also can intersect with gender discrimination and, for Chanje, realising this in the context of her own experiences provoked an angry response:

"It is because Black women are unimportant and in expendable and they don't give a damn about what I think, what I feel, and they don't have any value for what I can contribute towards my community."

Chanje

Seeking support for mental illness could mean that it can have detrimental consequences for those associated with the individual seeking support. A participant explains her anxiety of labelling as follows:

"…if I am suffering, everyone else in the family suffers because they can have problems in the future because of me. People will say things like oh they have a crazy sister in the family so they would be crazy too."

Amina, Somali

Another person expands on this further in the following, using the following example to explain this situation:

"When I had my first psychotic episode, that was it for my family. Anything little that is out of the ordinary for my family is now seen as weird or suspicious. They are tiptoeing around me and making me feel like I am walking on eggshells. When I do have a moment, they just shout at me and say things like 'act normal! People are going to know."

Asma, Pakistani

Participants also explained the lack of knowledge of 'schizophrenia' prior to seeking help contributing to delayed help-seeking. Knowledge about mental health has been highlighted as a barrier to seeking support and in stereotype formation. In addition, some participants felt because of the lack of awareness in the community, the symptoms they were experiencing were associated with other less severe mental illness.

"I did not know what it was because we don't talk about these things in our family. I just thought that hey you are seeing things you're too stressed out and need to sleep. I started doing stress reducing techniques, it kind of worked but after a week, I saw things again and yes then I panicked."

Zhi, Chinese and Japanese

"At first, I just thought 'schizophrenia' was somebody with multiple personalities and that I probably am just depressed…. If everyone around me does not know, why would it mean that I did?"

Koby, Kenyan

A participant expressed that her auntie also had 'schizophrenia' but was treated as if they had no idea what was happening to her.

“My auntie who lives up north, she has ‘schizophrenia.’ I hear stories about how she would be walking around the streets shouting, making stuff up about family members and one time she did attempt suicide. So, I asked my sisters, why is nobody doing anything about it? My mum said that it is just your auntie being crazy. With the way we are raised, and how we just ignore what is happening, were just not going to seek out help for like support.”

Asma, Pakistani

The participant further elaborates:

“So, when I was diagnosed with ‘schizophrenia,’ it was strange because everyone in the family started wondering if they had it too. Like it was contagious or something.”

Asma, Pakistani

Another barrier to seeking help was the concept of keeping mental health issues within the family and this theme was prevalent across most participants. Participants said that the families would keep it within the family, and it was seen as a breach of trust to seek support from outside.

“My family – we are close. We make sure we talk about things together. But when I had my episode, my family made something up about my illness. Claiming it be the evil eye just so others outside cannot know the truth. “

Zeeshan, Pakistani

This view was echoed by another participant who said that nothing goes out of the family.

“It was like a huge thing. My parents felt ashamed and betrayed that I sought support. I tried to avoid it because you know we grew up with the fact that what happens at home stays at home.”

Amina, Somali

In this theme, participants discussed the factors that played a role in the barriers of seeking help for their diagnosis which included knowledge, familial influence, and racism in mental health services.

"I renew my medication at the GP that is about it. I hardly speak to my support worker when she comes over. They just ask me questions that I do not think is necessary. I am having breakfast, why are you asking me if I am hearing voices?"

Koby, Kenyan

The theme explores the perspectives of participants on the effectiveness of anti-stigma campaigns related to mental illness, specifically regarding 'schizophrenia'. Many participants who had a perspective that contributed to this theme expressed that they believed these campaigns were not effective in reducing stigma because they were performative, meaning that they were focused on creating a superficial appearance of progress rather than addressing the root causes of stigma and discrimination.

Participants felt that these campaigns were often driven by a desire to appear socially responsible or politically correct rather than a genuine commitment to addressing the issue of mental illness stigma. They felt that these campaigns tended to focus on raising awareness and changing attitudes towards mental illness rather than addressing the structural inequalities and discrimination that underlie the stigma associated with conditions like 'schizophrenia'.

Participants felt that anti-stigma campaigns often missed the bigger picture by failing to address the social, economic, and political factors that contribute to stigma and discrimination. For example, many participants highlighted the role of poverty, racism, and other forms of social exclusion in perpetuating stigma and discrimination towards people with mental illness. They felt that anti-stigma campaigns needed to be more holistic and address these broader issues in order to have a real impact on reducing stigma and discrimination.

A participant claims that the policy makers involved in the anti-stigma campaigns are merely pretending to be 'allies' in reducing stigma surrounding mental illness but are actually making things worse – inducing stigma.

“Those responsible for making these campaigns, why do they think that we can just oh it is okay to be mentally unwell, it's normal. Okay but why when I go to the doctors or talk about it like it is 'normal' then people still treat me weirdly.”

Roy, Bangladeshi

This quote reflects the sentiment that simply promoting the message of "it's okay to be mentally unwell" through anti-stigma campaigns is not enough to change the way individuals with mental illness are perceived and treated by society. The speaker questions the effectiveness of these campaigns and suggests that there is a disconnect between the messaging and the reality of how people with mental illness are treated in everyday life. In other words, the anti-stigma campaigns may be performative, but they do not address the deeper issue of discrimination and prejudice towards those with mental illness.

“Anti-stigma campaigns….needs to like when you see them yes, on the TV talking about it’s good to talk. How can I talk about it? To whom do I talk? My family? My friends? Who? It annoys me so much.”

Karam, Jamaican

This participant is expressing frustration with the lack of practical support that is offered to individuals with mental illness. The participant is questioning the effectiveness of anti-stigma campaigns because they do not provide clear guidance on how to actually seek help or talk about mental health issues. They feel that simply promoting the idea that it is "good to talk" is not enough, and that more needs to be done to provide resources and support for those who are struggling with mental illness. The participant's frustration highlights the need for more concrete action and practical solutions to help those with mental illness, rather than just surface-level awareness campaigns.

Regardless of any intention to reach the wider public, participants could feel that the key messages in these campaigns put the onus on themselves as individuals to make change happen. This quote is referring to the idea that some participants felt that anti stigma campaigns placed the responsibility for change solely on the individuals affected by mental illness, rather than on society as a whole. The campaigns may have been intended to raise awareness and reduce stigma, but some participants felt that the messages were not effective because they did not address the systemic issues that contribute to stigma and discrimination. Instead, the campaigns seemed to suggest that individuals simply needed to "talk about it" or "be open" about their experiences, without acknowledging the many barriers that can make it difficult for people to do so. In this way, participants felt that the campaigns reinforced the idea that people with mental illness are responsible for their own recovery and for changing societal attitudes, rather than acknowledging the role that society and institutions play in perpetuating stigma and discrimination.

“Why is it my responsibility to get people to get me?”

Jessie, Caribbean

Some participants expressed the view that anti-stigma campaigns are not useful in decreasing stigma, and that focusing solely on stigma is not enough to address the issues faced by people of colour when seeking mental health support. These systemic issues include racism, discrimination, and bias within mental health services, which make it difficult for people of colour to trust these services and feel comfortable seeking help. The participants believed that instead of focusing solely on stigma, anti stigma campaigns should be part of a broader approach that addresses systemic issues and barriers, including cultural competency training for mental health professionals, better representation of people of colour within the mental health workforce, and more accessible mental health services.

“Stigma is not what stops people seeking help. Lack of access, racist mental health services. When these campaigns frame it in that way, it is just a lie…
Stigma affects people, totally get it, but what I’m saying it’s not the main reason. The ones experiencing it, it is just, the whole purpose of is it just way off.”

Hamza, Pakistani

In conclusion, this study highlights the urgent need for comprehensive mental health education and awareness campaigns to address stigma and promote empathy within communities. Encouraging open conversations about mental health and overcoming cultural barriers can create a more compassionate and inclusive environment. Culturally competent mental health services are essential to provide appropriate support and care, reducing stigmatization and improving the well-being of individuals with 'schizophrenia' and their families. Ultimately, combating stigma and promoting understanding will contribute to a more inclusive and supportive society for all individuals affected by mental health conditions.

In developing themes, I also observed patterns of expressions and feelings shared by all participants, i.e., "condensations" and "generalisations" that may be discovered and analysed without disregarding the specific life circumstances or distinctive social environment of each participant (Falmagne, 2006).

In the next chapter, I will analyse and discuss how anti-stigma campaigns is effective to support help-seeking intentions for people of colour through participant narratives on their thoughts and views of current anti-stigma campaigns.

Chapter 6: Community support and Anti-stigma campaigns

Systemic racism and institutional barriers significantly hinder access to mental health care for minority groups. However, community-driven approaches and a focus on radical kindness can foster understanding and support, facilitating better mental health outcomes. Community initiatives that directly address the stigma surrounding conditions like schizophrenia are crucial for creating inclusive and supportive environments.

Community disconnect

These thematic findings provide a comprehensive overview of the key issues related to stigma, cultural identity, and systemic barriers, as well as potential pathways for improvement through community engagement and systemic change.

"My family, they, say that they find it weird that I talk to them about it. I like to encourage a dialogue in the Punjabi community. It is not a White problem only. I received some positivity from my community. After my grandfather's diagnosis, I had to put myself forward…because who else will?"

Diya, Punjabi

The following participant, from a Jamaican background, tells us that her uncle experiences bullying associated it with his diagnosis. Due to her kindness, the family now do not inflict mistreatment.

"My experience with stigma… my uncle used to get bullied quite a lot because of his condition. I have made sure I am always kind to him where I know that he can feel himself. It is hard for him. I feel responsible to make sure he feels okay because I'm the only one who gets mental health. Me showing up for him made my family realise that he's not all bad and now he's accepted."

Jenny, Jamaican

Asma noted that professionals are less likely to stigmatise than family members.

"To be really honest, the only person I have actually spoken so openly about this is my support worker. She knows about this stuff so it's easier. I don't think she is [support worker] judging me and I feel like she judges me."

Asma, Pakistani

Particularly revealing is how Asma described her relationship with her support worker. Although there is a degree of freedom with disclosing, feelings of being 'judged' are still present, bringing a sense of ambivalence.

"I feel sorry for my family to put up with me. They just make me feel so embarrassed about myself."

Asma, Pakistani

Another participant attempts to influence how her family think and feels, rather than about her own self-stigma. She feels that educating her family are what enables her to maintain her own resilience to stigma which closes down her family as a source of stigma.

"I have benefited from therapy; I always talk about how important it is in my family because the house itself is where stigma originates from. Me talking about it, my family accepting it, has helped me so much in my recovery. That's what important. My little sister talks to me now when she is feeling anxious about the situation with Covid impacting her grades to go to university. That's a win for me."

Laura, Nigerian

Radical kindness

Another participant also noted that individuals from the Bangladeshi community and society in general need to practice kindness for individuals with a diagnosis. It gives an example of perceived congruence between religious teachings and support.

"But what they could do? Yeah, they could be kind, I think. Be kind and practice human values. Practice their religion. I mean, I don't think it's anything that's they need to have something complex…. I realise actually no, they are actually worse, some of them and actually it doesn't matter about clothes and beards, and you know heads, carts and stuff is actually. Human kindness and you know that kind of stuff is much more. What's the word carries more value. You know that they believe in value."

Tariq, Bangladeshi

Kindness is linked to compassion and understanding. Understanding mental distress will give individuals more room to be compassionate. Emmanuel explains this.

"It's like they don't want to understand, they don't want to get it. I just know that if they understand more, they will treat him better, be more patient… The problem is that they don't want to understand which means that they choose to be mean, in my own opinion."

Emmanuel, Nigerian

But this can also be contradicted by the idea that we should be kind nevertheless regardless of lack of understanding. Emmanuel said:

"Just because you don't get it, why do they have to be mean about it. I think if they were just nice to him, we would feel better about it [the 'schizophrenia' label]."

Emmanuel, Nigerian

This is an important finding. It interlinks with the previous theme - courtesy stigma. When family members or the support system feel that others do not exert compassion and understanding surrounding the ‘schizophrenia’ label, they seek approval from others to accept the label. Understanding that individuals diagnosed with ‘schizophrenia’ must be understood is important from the standpoint of Pakistani family members. Acceptance from those around them is required for them to grasp the diagnosis label.

“They need to come terms with it. The fact that she is ill …she's seriously ill…we [Pakistani community] got to make sure they [parents] understand that she can't do anything. It is difficult and they understand now there's something wrong and they can't really exactly say that. It's not within her control and we can't do anything. We just need to be understanding.”

Samiya, Pakistani

Understanding is crucial for kindness to support individuals to experience less stigma from others. For this individual, he focuses on raising understanding in the Black community to ensure that they are given support and not feel stigmatised.

“People are always like… we need to talk about it more in the Black community but why is nobody doing it? We still have a long way to go. But in the process, we need to suffer the lack of support, everyone constantly making comments. It makes us feel so bad about ourselves. Ok, you don’t understand mental health, or you don’t believe it in it but have some decency.”

Jacob, Kenyan

*“You can see their faces and the little comments, it’s so f****** annoying.”*

Emmanuel, Nigerian

“It’s horrible what we actually get from others. Its ruthless. They are rude, mean, they just, God, I can’t even say some of the things they said because it makes me cry. It’s not nice at all.”

Jenny, Jamaican

Participants experience hostility and aggressions from their family and feel upset by it. However, there were positive experiences when some were shown kindness from family members. Although some experienced negative and others received positive, it was quite clear that family support was, again, central to the decrease of stigmatisation.

"I was actually surprised by what we got from family. My daughter was very popular in our network. When she got sick, you know psychosis, it was at the family brunch to celebrate my niece new-born. A couple of weeks later, we had visits from everyone, bringing family. I could tell that they wanted to know what happened, you know how we Asians are so nosy. But they were supportive, they were kind and sweet. I know they didn't mean no harm when asking quite intrusive questions. My father-in-law was the sweetest, when we told him she has 'schizophrenia,' he said to have faith and it will be alright. Makes us feel supported and better when it comes to the challenges with our daughter."

Diya, Punjabi

Furthermore, another participant says that those around them were supportive and compassionate, which surprised him as he believes the Bangladeshi community is not kind. There was also a reference to the generational mindsets in terms of believing it. There is a shift in how family members perceive mental distress, in particular 'schizophrenia.'

"His cousins were the sweetest, my brother's girls. They always checked up on him. He was quite close with them. I think that helped him be more confident and feel better with himself. It was quite weird; I did not expect it. But then again, these girls are from this generation. They are more in tune with what's happening and are more informed, if that makes sense."

Tariq, Bangladeshi

This was similar in the family of a Jamaican heritage. This participant says:

“Just growing up in the Jamaican community, mental health was not taken seriously at all. There was no like oh my god are you okay, you have this, we should get you help. It was more like you get up move on. So that was how I grew up. Now, it’s different. I am educated by own child on what is what on mental health. I am the only one in the family with a child with ‘schizophrenia.’ Some have children with depression, or anxiety, or stress. So, it’s not a big deal, but with my child is different. So, I was afraid to tell everyone that I have a child with ‘schizophrenia.’ I explained later to my family…its serious.”

Educating the community

The lack of information about 'schizophrenia' also affected participants' ability to understand their own symptoms and behaviours. They often expressed feelings of confusion, fear, and isolation, as they struggled to make sense of their experiences without a clear understanding of what was happening to them. For some participants, ‘schizophrenia’ was a known diagnostic label but there was limited known information about ‘schizophrenia’ prior to receiving the diagnosis.

“Getting the diagnosis wasn't very easy… because we were thinking it can't be ‘schizophrenia’, we thinking it’s not in the family we are all fine no issues. How come she's had some issues? But now it makes sense slowly. I think it's probably genetic. I think. I don't know if it is. We all got bit mixed up, well… anxiety we've got anxiety in the family but not as bad as my sister has.”

Samiya, Pakistani

The same participant also said the reason why they did not understand it is because they did not want to know about it due to a sense of denial that it was happening to a family member.

“Yeah, because we didn't understand it or want to know about it. Because it's not something we come across before.”

Samiya, Pakistani

This participant suggests that exhibiting mental distress was often associated as normal behaviour in Black communities.

"How she used to behave, she would go so, like snap sometimes, and become so aggressive and we would be like why your throwing things, and then everything is fine like…. Growing up Black, you see that as normal you know? Until my other family member became very concerned and called the police. She was sectioned and been told that she has 'schizophrenia'".

Martha, Jamaican

A few participants describe their experiences of receiving information on 'schizophrenia' and how they felt that their family member did not fit right into the label as they are unsure about what it means to carry the diagnosis of 'schizophrenia.

"When we first went through the hospital, we weren't quite sure about when they have told us about 'schizophrenia', we had to Google it. But our previous understanding was that 'schizophrenia' was split personality, going on crazy rampage. But for our father, it's different, he was just experiencing weird feelings like feeling on edge or like everything is going to fall. He never experienced a split personality.
Until now we don't know what it means. So we just talking to family members on the Facebook group".

Emmanuel, Nigerian

"It would be nice like to have an information session for families like us. It's easier to talk about depression, you know, the aunties know what that is by now… but 'schizophrenia', see I can't even say it properly… it's easier to talk about it if they know. So knowing about it, can help reduce stigma."

Diya, Punjabi

"It kind of helps the fact that we kind of know and are aware. I know some of my friends who say to me, what do you mean family is okay with it? And then I ask them well… do you know what it actually is?"

Samiya, Pakistani

The experiences of participants who had limited knowledge and awareness of 'schizophrenia' before receiving the diagnosis for their family member. For some, the diagnostic label was known, but they lacked detailed information about the condition. This lack of understanding led to confusion and denial, making it challenging to accept the diagnosis initially. Participants mentioned that 'schizophrenia' was often perceived as something they had seen in movies or related to others, not their own family. In some cases, family members attributed the symptoms of 'schizophrenia' to possession, drug use, or loss of spirituality, reflecting the stigma associated with mental illness in certain cultural contexts. Others questioned the validity of 'schizophrenia' as a real illness, leading them to believe that the diagnosis was incorrect or misapplied. Participants described the struggle to find appropriate treatment and the need for proper labelling to access mental healthcare services.

The lack of knowledge and understanding about 'schizophrenia' hindered participants from discussing the condition openly, and they expressed the need for information sessions and education to reduce stigma and increase awareness within their communities.

Missing the bigger picture

The theme "missing the bigger picture" explores the perspectives of individuals on the effectiveness of anti-stigma campaigns in relation to 'schizophrenia' and mental illness. Participants expressed that anti-stigma campaigns are not effective in reducing stigma due to performativity and not addressing the root causes of stigma, such as lack of access and racist mental health services. Additionally, some participants believed that these campaigns put the onus on individuals to make change happen, which is unfair. The focus should be on getting people to trust the government and mental health services. There were also opinions that anti-stigma campaigns overlook the broader context of its purpose and should instead focus on addressing the impact on the community, particularly those who have had negative experiences and have been treated unfairly. Overall, participants felt that these campaigns are ineffective and not addressing the root causes of stigma.

The participants are saying that stigma is not the main reason that prevents people of colour from seeking help. Rather, it is the lack of access to mental health services and racist mental health services that hinder them. The participant believes that anti stigma campaigns that frame stigma as the main obstacle to seeking help are missing the bigger picture. The participant argues that the purpose of these campaigns is misplaced and that it fails to address the actual barriers that prevent people of colour from accessing mental health care.

Another participant emphasised the purpose of anti-stigma campaigns should be focusing targeting communities who have distrust in the mental health system.

“We need people to engage with the politicians, people to help us directly, we as Black people do not trust the government, the NHS, doctors whatever, you know, so come to us. Get us to trust that if we come to you, if we speak up, if we speak up you will help us. Because we will not come talk to you. Oh no, we will not.”

Nazneen, Ethiopian

This quote highlights the issue of trust within mental health services and institutions among people of colour, particularly Black individuals. Nazneen suggests that anti stigma campaigns are not effective in building trust or encouraging individuals to seek help. Instead, they suggest that there needs to be a focus on building trust through direct engagement with individuals and communities. This may involve engaging with politicians and other decision-makers to address systemic issues, as well as developing relationships with individuals to demonstrate that they can be trusted to provide appropriate support. Nazneen comments reflect the broader issue of trust in healthcare, which is crucial in ensuring that individuals feel comfortable seeking help when they need it.

Another participant claims that the anti-stigma campaigns are:

"…missing the bigger picture. It is useless. It does not work, end of story. End of discussion. It is the…most…it is just not helpful. If anything, it is like a laugh in our faces, like…ha-ha we can go and talk and that it is normal… whatever that means."

Bernie, Chinese

This quote seems to express a strong opinion that anti-stigma campaigns are not effective and that they ignore the structural barriers faced by people of colour regarding their mental health. The participant is suggesting that the campaigns are useless and not helpful and that they can even come across as a mockery to people who face real barriers to accessing mental health services. The idea of talking about mental illness as "normal" may not resonate with individuals who have experienced discrimination and a lack of resources when seeking help.

Some participants believe that the stigma campaigns are not tailored to 'schizophrenia' or severe mental illness in general. Anti-stigma programmes are thought to have a greater impact if severe mental illness like 'schizophrenia' or the symptoms of these illnesses are targeted rather than more broad phrases like "mental illness."

"Everyone just talks about depression, and stress and anxiety, if 'schizophrenia' apparently so life limiting, and help is available why not talk about it more? They [anti-stigma campaigns] are still making people believe that 'schizophrenia' is a scary thing, but it is not. 'schizophrenia' is not like any regular mental illness. But that is not in campaigns."

Derick, Ghanian

Due to the lack of representation and understanding of 'schizophrenia,' individuals developed an idea of 'schizophrenia' prior to their diagnosis and felt anti-stigma campaigns were responsible for their understanding on 'schizophrenia.'

"It is too vague to be honest. I feel like the campaigns we see on the T.V or little snippets online its always about stress. When I first learnt about my diagnosis, first thing I thought

about was a guy wearing a scary mask and looking all evil. Looking back it is maybe because that's all I ever known because I haven't seen it being talked about on T.V."

Adam, Arab

A further participant blames the generation who are not willing to accept the anti stigma campaigns and believe it is not stigma that anti-stigma campaigns should be focusing on.

"Most reasonable people agree that stigma comes from negative experiences with people who have had issues with people with 'schizophrenia.' I do not think at this point, stigma is not there… This generation, people don't really give a crap about what you say. When you start causing issues in society, then they will take it as an actual issue. I don't support any anti-stigma campaigns. It doesn't really because it doesn't do the actual raising awareness or whatever they are trying to do."

Hamza, Pakistani

Hamza suggests that stigma towards people with 'schizophrenia' is still present but doesn't think that anti-stigma campaigns are effective in reducing it. He argues that people only care about mental health issues when it starts to impact society and their own lives. Therefore, Hamza does not support anti-stigma campaigns because they do not effectively raise awareness.

"If anti-stigma campaigns just go, then that's great. The money the government could put it in… instead having these campaigns just focus on the impact it has in the community of individuals who are having psychotic episodes or whatever… then get arrested and treated unfairly. When you do that, people are more understanding and empathic if that's the word… to those with 'schizophrenia."

Bernie, Chinese

Bernie suggests that instead of investing in anti-stigma campaigns, the government should focus on addressing the negative impacts of psychosis in the community, such as unjust treatment by authorities. He believes that if people understand the impact of psychotic episodes and unfair treatment, they will be more empathetic towards those with ‘schizophrenia.’

“It does not get to the root cause of, these anti-stigma campaigns. We need to focus on why us as BME people are getting the worst end of it….the worst end of getting.”

Derick, Ghanian

Derick argues that anti-stigma campaigns do not address the root cause of stigma towards BME people. He believes that the focus should be on why BME individuals are disproportionately affected by stigma and how this can be addressed.

“It’s a slap in the face…an empty gesture , empty promises…”

Jessie, Caribbean

Jessie thinks that anti-stigma campaigns are of little or no value that do not deliver on their promises. She feels that these campaigns do not address the root causes of stigma towards mental illness and that they are not helpful in reducing stigma.

“These campaigns do nothing but make us to swallow our diagnosis, I don’t think this is the right way to get rid of the stigma, and to be honest, I don’t even think these campaigns get it, with us the stigma is within our families, our communities, our own selves…They’re shooting at the wrong target.”

Hamza, Pakistani

Hamza suggests that anti-stigma campaigns do not effectively address the stigma within families, communities, and oneself. He believes that these campaigns are targeting the wrong issue and are not helpful in reducing stigma towards mental illness.

“I think they are effective; I think they are because….it’s getting around people.

But it's not so popular with Black people because it doesn't show the Black talking or doesn't show that it's an okay thing to talk about."

Nazneen, Ethiopian

Nazneen believes that anti-stigma campaigns are effective in raising awareness and reducing stigma. However, she suggests that these campaigns may not be popular with Black people because they do not talk to the culture, identity and experiences of the Black community and do not show that it is acceptable for them to talk about mental illness.

Bernie also highlights the need for anti-stigma campaigns to engage with specific communities and understand their unique cultural beliefs and attitudes towards mental health. Failing to do so can result in campaigns that miss the mark and do not effectively reduce stigma. The participant suggests that anti-stigma campaigns should start by addressing the fundamental belief that mental illness does not exist in their community before moving onto more specific issues. This approach acknowledges the broader cultural context and avoids oversimplifying the problem of stigma.

"For us [the Chinese individuals diagnosed with 'schizophrenia'] we need to be met in the middle. To reduce stigma, they [anti-stigma campaigns] have to come to us to where the problem is…so for example we [Chinese community] don't think mental illness exist right. So why not start talking about that hey mental illness is a thing. Then carry on from there."

Bernie, Chinese

Similarly, a participant from the Caribbean, has the same perspective. She was adamant that it was the most essential aspect in shaping how her community and culture viewed mental illness.

"Get to the root problem! That's one thing I would do if I was in charge of anti stigma campaigns. I would have somebody coming around knocking on doors and say that mental health is not a sign of weakness."

Karam, Jamaican

Participants thought that anti-stigma initiatives are ineffective at encouraging people to seek assistance for ‘schizophrenia’-related symptoms because the public still have a strong negative and discriminatory attitude towards ‘schizophrenia.’ If the public stigma is reduced, it will be as difficult for individuals to acknowledge and inform others that they have experienced mental distress without feeling vulnerable, criticised or embarrassed.

“I think anti-stigma campaigns are not doing us a favour. It’s not changing the perception of ‘schizophrenia’ or any other illness like bipolar or OCD. So it’s useless…. useless because they’re going about it the wrong way.”

Karam, Jamaican

“We see people on the tv talking about how bad they have it, to try and normalise mental illness. We [those diagnosed with ‘schizophrenia’] understand, we know that but the biggest thing is trying to get others around me to understand they are doing us more harm than good.”

Adam, Arab

The notion of illness like any other illness was frequently mentioned in the interviews. The participants were prompted to consider the validity of the ‘illness like any other illness’ approach and its usefulness in destigmatizing mental health.

“It’s ‘schizophrenia’ though…not like stress. I wish it was because it would be easier then to just talk to my mates about it. But it’s not.”

Derick, Ghanian

A participant from a Caribbean heritage, said that:

"If you look at it this way, what people think right now…would you prefer saying hey I'm psychotic or hey I'm depressed? Hey, I got a broken bone? Definitely would say those things because it's more acceptable, you get me. It's not even funny because they say things should talk about it like it's any other health condition, okay can you make us feel like that then? Like we can just casually talk to you? No, don't think so. They're [anti-stigma campaigns] useless."

Jessie, Caribbean

Another interesting finding was that some participants have not heard or seen any anti-stigma campaigns but when as the researcher, I suggested examples, one participant from an Arab background, recognised it and called it mental health advertisements.

"Aren't they just ads?"

Adam, Arab

This is an interesting finding for a few reasons. First, it suggests that some anti stigma campaigns may not be reaching their intended audience effectively. If participants have not heard or seen any anti-stigma campaigns, it could indicate a lack of visibility or promotion for these campaigns within certain communities.

Second, the fact that one participant recognised the anti-stigma campaign as "mental health advertisements" highlights the importance of clear and effective messaging in these campaigns. If the language or terminology used in the campaign is not relatable or understandable to the target audience, it may not have the desired impact.

It is not so much that mental health is comparable to other ailments as it is that people must realise that mental health issues are 'real,' inescapable, and inherent to the human condition. A participant of Chinese ancestry contributed to the notion that mental health issues are real but may have a biological cause for it.

"I hate to say this. But I think my illness ['schizophrenia'] is biological, it's not the same for sure as others, but there should be a common understanding that….it exists."

Bernie, Chinese

The theme explores the perspectives of individuals on the effectiveness of anti-stigma campaigns in relation to ‘schizophrenia’ and mental illness. Participants expressed that anti-stigma campaigns are not effective in reducing stigma due to performativity and not addressing the root causes of stigma, such as lack of access and racist mental health services. Additionally, some participants believed that these campaigns put the onus on individuals to make change happen, which is unfair. The focus should be on getting people to trust the government and mental health services. There were also opinions that anti-stigma campaigns overlook the broader context of its purpose and should instead focus on addressing the impact on the community, particularly those who have had negative experiences and have been treated unfairly. Overall, participants felt that these campaigns are ineffective and not addressing the root causes of stigma.

Anti-stigma campaigns solutions

Some participants expressed alternative forms of reducing stigma and ways to raise awareness surrounding ‘schizophrenia’ drawing upon available community and cultural resources. Participants from communities with a religious attachment to mental illness have suggested other op on how the community could raise awareness surrounding mental illness. This participant from an Arab background believes that incorporating mental health awareness informational session could help eradicate the myths surrounding symptoms related to ‘schizophrenia.’

“I don’t see them on T.V or whatever, maybe do some school plays or have people come into colleges or Uni to tell them that. Who watches TV anyway?”

Jessie, Jamaican

“Every Friday, the Imam does like, Khutbah12, you know what I mean, he could talk a bit more about mental health and teach everyone that it’s not related to Jinn [spiritual entity]. With ‘schizophrenia’ especially. Hearing voices is not related to Jinn possession.”

Hamza, Pakistani

Similarly, another participant from an Ethiopian background suggested,

“…the church could hold information sessions about ‘schizophrenia,’ talking about where it comes from, that people have it, that it exists, and prayer is not always the answer…to actually seek help…promote mental health services…direct people to professional.”

Nazneen, Ethiopian

These participants provided strategies to promote awareness in the form of community participatory events by the South Asian community.

“We always have these events that are happening at [name of location] so it would be really good if people came over and talked to us about mental health and not just depression and anxiety but everything including psychosis.”

Hamza, Pakistani

Participants from the South Asian communities feel that community members would be more receptive to awareness efforts in the form of social activities.

We love to go to events, Asians in general like going to the social events. So anti-stigma campaigns can be embedded in the events.

Roy, Bangladeshi

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[12] In the Islamic tradition, the khutbah is the major ceremonial occasion for public preaching. On Fridays, the Islamic tradition is formally observed during the Dhuhr (noon) communal prayer.

The statement underscores nuanced perceptions within South Asian communities regarding strategies for raising awareness about mental health issues. Here, the focus on utilizing social activities as a platform for awareness efforts suggests a multifaceted approach shaped by cultural values and community dynamics. Cultural nuances within South Asian communities, such as the importance of communal gatherings and social interactions, are reflected in the preference for awareness initiatives framed within familiar social contexts. This preference implies a recognition of the need to integrate mental health discussions seamlessly into existing community structures rather than adopting approaches perceived as external or intrusive. Additionally, the emphasis on social activities as a vehicle for awareness underscores an understanding of the role of social bonds and interpersonal relationships in fostering trust and receptivity to sensitive topics like mental health. Such insights are crucial for developing culturally responsive interventions that resonate with the lived experiences and social realities of South Asian communities, promoting more inclusive and effective mental health advocacy efforts.

This highlights the crucial role of education and awareness in improving understanding and acceptance of 'schizophrenia' and mental health conditions within families and communities. The statement exposes the entrenched racial disparities in access to education and healthcare, which perpetuate ignorance and misunderstanding surrounding ‘schizophrenia’ within marginalized communities. It highlights how racialized stereotypes and discrimination compound the stigma already associated with mental health conditions, effectively silencing discussions on the topic. From a critical race perspective, this reflects a broader system of oppression that marginalizes and disempowers racial minorities, hindering their ability to engage openly with issues of mental health. The call for information sessions and education thus emerges as a means of challenging this systemic injustice, aiming to disrupt dominant narratives and empower marginalized individuals to reclaim their voices and narratives regarding ‘schizophrenia.’

The following theme explores the views of participants regarding the delivery of anti-stigma campaigns. Participants expressed that anti-stigma campaigns were not tailored to people of colour, even though there were some individuals that they could relate to it still was not enough. This theme explores how anti-stigma campaigns can be promoted within diverse communities.

Images of people of colour within anti-stigma campaigns was a regularly raised as an issue and discussed among participants. Some questioned whether the use of people of colour would raise awareness of mental illness in general however this may also do more harm than good.

"We need more people like us to represent these anti-stigma campaigns. It is just White people. It is not going to like to help us raise awareness in the Black community."

Karam, Jamaican

Interestingly to note, the same participant has noticed a trend whereby anti-stigma campaigns use people of colour to discuss severe mental illness.

"If you noticed, there is only Black people or ethnic minorities who are talking about 'schizophrenia' or bipolar. Are they trying to tell us that only we get it? I understand that it defeats the purpose of what I said earlier about having more BAME individuals in the campaigns but at least do it right?"

Karam, Jamaican

This participant's observation suggests concern about the representation of mental health conditions such as 'schizophrenia and bipolar illness among Black people or ethnic minorities. The participant notices that these conditions are often portrayed or discussed primarily by individuals from these ethnic and cultural backgrounds. They question whether this representation implies that these conditions exclusively affect Black people or ethnic minorities.

The participant's statement also highlights a potential contradiction or tension in their perspective. On the one hand, they express the desire for more diverse representation in mental health campaigns, acknowledging the importance of including individuals from diverse backgrounds. On the other hand, they express frustration about the way mental health conditions are portrayed within these campaigns, suggesting that it may perpetuate stereotypes or reinforce the notion that certain conditions are specific to certain ethnic and/or cultural groups.

This individual believes that there is a new wave of people of colour who are advocates for mental health and reducing stigma.

"For so long, the stigma of seeking help for our mental health was there…it is sad you know we always were like don't put your business on the streets. People will know, you need to keep it a secret. But it has changed now, and I am here for it. I love it. I love the fact people are now so open. The pandemic really has helped a lot of young people come out and talk about mental health. The best way for these anti-stigma campaigns is to include our voices, the ones that had to be silenced and the ones that are different than a typical White person, no offense but it's the truth. We have to be more diverse. Best way to go about it."

Adam, Arab

Some participants have expressed that anti-stigma campaigns should be accessible to those whose English is not their first language. This point was mentioned regularly amongst participants when asked how anti-stigma campaigns can be tailored more to people of colour.

"I think we need them [anti-stigma campaigns] to have others speak in Urdu for example. Talk about it. Or even have well known That can help my people [South Asian community]."

Hamza, Pakistani

"My parents barely understand English, how can my African parents understand what these people are saying about mental illness and stigma? If I ask my family about reducing stigma they don't know what I am talking about."

Nazneen, Ethiopian

This theme delves into the challenges and considerations regarding promoting anti stigma campaigns within diverse ethnic communities. Participants voiced their concerns about how such campaigns were not tailored to people of colour, and the need for such campaigns to come to them. They also highlighted the importance of representation of Black and (south) Asian communities in anti-stigma campaigns, and the use of images and individuals from diverse ethnic backgrounds. However, participants also recognized the potential complexities that can emerge from diversifying anti-stigma campaigns, including the risk of reinforcing some negative stereotypes or over-representing certain mental illnesses within particular ethnic communities. For example, pathologizing Black (African/Caribbean) men as being more likely to become mentally unwell. Participants also highlighted the need for campaigns to be accessible to those whose first language may not be English, as a way of increasing engagement with such campaigns within these communities. The theme emphasizes the importance of involving diverse ethnic voices in anti-stigma campaigns, in order to create greater awareness and understanding of mental health within communities that have often been marginalized or excluded from these conversations.

Another participant suggested to hide the true purpose of the events to ensure the communities are caught off guard.

"Don't make it bait because they won't come. They just don't want to come to these kinds of events, so sneaking it in would be better."

Hamza, Pakistani

Hamza's suggestion to avoid making events overtly about mental health to increase attendance stresses the challenges of engaging certain communities in discussions about mental health. Concealing the purpose of events to catch communities off guard has profound implications for stigma, ethnic minority groups, and individuals experiencing severe mental distress. By promoting secrecy and deception, this approach perpetuates stigma surrounding mental illness, reinforcing harmful stereotypes, and discouraging help-seeking behaviours. Within ethnic minority communities, already burdened by cultural stigma and limited access to culturally competent care, this tactic erodes trust and creates barriers to meaningful engagement with mental health issues. For individuals experiencing severe mental distress, such as 'schizophrenia,' concealing the purpose of events deepens feelings of shame and isolation, exacerbating their distress and hindering their ability to seek support. In addition, suggesting hiding the true purpose of events to catch communities off guard does not align with the principles of Mad Studies. Mad Studies emphasizes empowerment, agency, and the importance of reclaiming narratives surrounding mental health experiences. This approach contradicts the values of transparency, respect, and collaboration that underpin efforts to challenge stigma and promote mental health awareness within Mad Studies.

To further illustrate the previous point, this participant explains that hosting awareness campaigns as social events makes it easier to bring up the subject of mental health rather than hosting an event solely focused on mental health, which she assumes community members would not attend due to the community's perceived lack of mental health literacy.

One participant discussed the importance of getting community leaders on board talking more about mental health issues and incorporating it more into their lectures.

"Everyone has like a favourite speaker or a favourite lecturer…if you get more high-profile people on board, it really helps."

Hamza, Pakistani

"If we have more people in our own communities providing talking about mental health because… they understand us, and the aunties will too…"

Adam, Arab

Both of these participants discussed the importance of involving community members, specifically leaders, in raising mental health awareness in the community, presumably because community leaders have a stronger rapport with the community and a better understanding of the community's developmental needs.

"The most important thing is to bring the dialogue…"

Roy, Bangladeshi

Another participant suggested that: -

"Individuals who are aware they have 'schizophrenia' should attempt to speak up, even if it is difficult. So, they can assist those who are unable to do so."

Derick, Ghanian

For the Arabic community, the participants feel that initiating a discussion about 'schizophrenia' is an important strategy to engage the community. One participant stated that when Arab members are: -

"…told that these things are happening, especially coming from Arabs, then they would take it more seriously…you know..." There is no way we can break the stigma with campaigns. The White thing won't work on us [Arabs]. We need people like us to talk about it. Got no clue who would step up. Also, we Have really bad views about depression, and that's minor. 'schizophrenia'…. not for the next five years or so…"

Adam, Arab

From a Mad Studies perspective, discussions about 'schizophrenia' within Arab communities represent a nuanced exploration of Mad identity within cultural contexts where mental health discussions are often taboo. Reclaiming narratives and asserting agency over one's Mad identity becomes an act of resistance against prevailing stigma and societal norms. Openly addressing 'schizophrenia' challenges stereotypes and misconceptions, advocating for greater acceptance, and understanding of Mad identities within Arab cultural frameworks. Importantly, such discussions necessitate an intersectional analysis that considers the complex interplay of culture, religion, and societal expectations, highlighting the need for nuanced approaches that respect diverse Mad identities within Arab communities.

The discussion with audience members from the Plant Fetish study highlighted the audience's ability to disclose their personal mental health journeys and views of Chanje's outlook on how to reflect on the challenges faced in her journey. In some ways associated with these critical views about medication, one audience member decried the extent to which the psychiatric system has focused attention on a very individualised notion of pathology, rather than seeing mental distress in, arguably less stigmatising, community terms. This was linked with the performance context by a suggestion to think about different modalities for challenging stigma or promoting well-being, such as forum theatre; a participatory, emancipatory approach to working in communities:

"*. . . allowing them, the community, to step, literally step into the story and change the course of the play. And it's meant to help you feel empowered and understand that you can have control of your narrative when you can . . . and negotiating a community response for that and include the community in care and response rather than putting the individuals at the heart of the problem. But also, I think is an interesting tool for the individual as a way of safely like re-enacting and control their traumatic situations."*

Audience member (AM) 13

One audience member movingly disclosed his own childhood trauma, and another revealed his own experiences of Complex PTSD. Both spoke in different ways about the experience of not having recourse to a vocabulary that could adequately explain their own pain or articulate their feelings. An extension of this contribution was to commend the performance for doing just this sort of articulation, setting it in a context of healing, and accomplishing this by way of entertainment.

The process of making sense of mental distress is key to notions of recovery. Making sense of one's mental health crisis has an important impact on how individuals understand and define their own recovery and help place it in a social context. Plant Fetish's comedy was thus central to the show, allowing engagement with profound and serious concerns, whilst intending not to trigger further untoward upset. In this regard, alertness to the potential for further trauma constituted a reflexive process between the artist and the audience, with regard to mutual sensitivities:

“So, when I was talking about suicidal ideation, I was talking about failed relationships and talking about having emotional flashbacks. I had to dress it in a humorous way, and it made it easy for me to talk about it. It also made it easy for audience to listen to and easy to open up a discussion about it.”

Chanje

Hence, Chanje humorously adorned her experiences to make it easier for her to discuss and the audience to listen. This comedic representation of mental distress could, and did, work to encourage the audience to begin conversations about mental illness. However, humour in a broader context or in the wrong hands might also risk having a negative effect, perhaps reinforcing negative stereotypes of individuals with mental distress, such as “making a fool of themselves” (Coe 2018). Similarly, there may be a risk that humour may adversely affect the seriousness of the message behind anti-stigma campaigns.

More than one audience member remarked upon the aspect of the show that dealt with notions of beauty in imperfections. This was a reaction to the imagery and symbolism of a broken pot, mended with gold so that the cracks in the ceramic became the best part, and how this worked as a profound metaphor for human repair and recovery from trauma. This led to a longer discussion of the use of poetics and metaphor, both in the script and the set design. One audience member highlighted certain dramatic aspects of the performance, contrasting the authentic voice of a traumatised person in this show with other writings where such authenticity may be more questionable.

For this person, authors may be better at times writing about other people’s trauma and less prepared to face up to their own. From this perspective, it was “thrilling” to hear Chanje’s voice in this performance. Other audience members showed their affinity for the use and visibility of plants, and how these may be implicitly or explicitly nurturing or therapeutic in everyday life. One person linked her own role as a horticulturist in a psychiatric unit with a question about democracy within such roles and wider services and how such alternatives may be more cooperative and respectful.

In writing the Plant Fetish show, an interplay between wider social stigma and the internalised impact was something Chanje was mindful of:

"I think when I was making this show, I was trying to eliminate the internal stigma that I had about my diagnosis and so . . . I feel like that was my primary purpose, but it also had some peripheral awareness that I'm not the only person with this diagnosis or that experienced and I do think that there needs to be more visibility around people with mental disabilities and not trust negative things about people with mental health conditions, but some kind of positivity and celebration of it."

Chanje

When asked about how Plant Fetish aligns with current anti-stigma campaigns, Chanje compared her performance to the current, at the time, Heads Together campaign, which features the involvement of members of the British Royal Family:

"I am not offering any stupid advice . . . I'm talking about the real-life experience and I'm making it beautiful and I'm making it funny. And I am not some person from the Royal Family who thinks that they are doing a good thing by telling you to talk to somebody next to you for a minute."

Chanje

Chanje also called into question some perceived shortcomings of established anti-stigma campaigns, particularly how they apply to aspects of severity. This, the act of beginning a conversation regarding mentally distressing experiences, a key message in the mainstream, though useful for some, can be frightening or lead to detrimental consequences, especially within ethnic minority communities in the UK.

"The anti-stigma campaigns have got absolutely nothing to do with anybody with a serious mental health condition at all . . . I had a friend who was seeing bats and thought she was being chased by a vampire. That's not something you can drop in a conversation. "It's good to talk." Because she was going to get sectioned and obviously being sectioned is frightening and that creates its own stigma."

Chanje

Chapter 7: Discussion

Chapter overview

This chapter explores key findings across my four studies and positions them within the context of broader literature and research**.** Returning to my critical lens of mad studies, allied to critical race theory, I offer a commentary on the key findings, which firstly reinforce the desirability of alternative, creative, situated spaces for consciousness-raising and challenging stigma for people of colour and Black communities. Secondly, a mad studies perspective allows for a critical reading of the qualitative findings of people's experiences within my first three studies. In many regards, the participants here, even those who were critical of aspects of mainstream services and the shortcomings of psychiatric labelling, struggled to evade recourse to a bio-psychiatric framing of their experiences, including the terminology that goes with this. That is, alternatives could be difficult to conceive of and participants more often than not reproduced psychiatric language while telling their own stories, albeit often narratives of dissatisfaction and disadvantage. Arguably, this state of affairs makes a case for the mission of unlearning proposed by mad studies evangelists to escape psychiatric hegemony.

The overarching goal of this thesis was to comprehensively analyse and explain help seeking experiences, with a specific focus on the influence of stigma among persons of colour carrying a diagnosis of 'schizophrenia.' By adopting a nuanced perspective, I aimed to shed light on the subjective nature of help-seeking experiences, including among relatives of individuals diagnosed with 'schizophrenia.' Additionally, I sought to explore the unique experiences of people of colour concerning anti-stigma campaigns and how people experienced an alternative, creative approach to consciousness-raising and defeating stigma.' In the subsequent sections of this chapter, I delve into the findings and insights derived from the research, addressing each research question in detail.

The study findings reveal the complex intersectional experiences of individuals from ethnically diverse backgrounds who face mental distress. Participants described the compounded effects of racial discrimination and mental health stigma, highlighting the need to understand and address the unique challenges such marginalised communities face. The research underscores the systemic nature of racism and its impact on mental distress and well-being. Participants' experiences shed light on how structural inequities, such as limited access to quality mental health services and cultural insensitivity within the mainstream healthcare system, contribute to disparities in mental health service usage and outcomes among people of colour. The study findings highlight the role of trauma in exacerbating mental distress among individuals of colour. Participants shared their experiences of racial discrimination and its distressing effects on their mental health. There is also a complexity to the reporting of help-seeking behaviour that goes beyond previous research tethered to a mainstream framing of the assumed desirability of help-seeking. From within such a frame, early help-seeking is to be encouraged as this is assumed to be the best way of receiving the most timely and appropriate help and avoiding the unhelpful delays that result in deterioration of ‘illness’ and then necessitate amplifications of coercive and compulsory entry and processing through services.

Furthermore, if only Black communities could be helped to appreciate these advantages, then the endemic mistrust of services prevailing in Black communities, predicated in part upon stigma, could be dismantled to mutual advantage. As my findings and more comprehensive literature show, there is more to it than this: mainstream anti-stigma campaigns typically fail to address the concerns of Black communities, and taking for granted the positive virtue of mainstream psychiatric services is part of a complex set of problems for people of colour, not simply a Pollyanna viewpoint to be urged upon them under mantras such as ‘illness like any other’. Viewed through a more critical lens, the idea of ‘help-seeking’ begs the question of what sort of help and support is desirable, who provides it, and how it is offered and delivered.

This connection underscores the need for trauma-informed approaches in mental health interventions and support services in the mainstream or the provision of entirely alternative forms of help and supports organised by and for Black communities. There is some history of the latter formations within the UK, but these initiatives have not managed to survive intact as distinct alternatives because of well-meaning (and understandable concerning funding arrangements and constraints), but perhaps misguided, engagement with the mainstream (Bhui et al., 2012; Fernando, 2010; Thomas, 2014). More informal enactments of mutual aid and support are less well understood and, in turn, operate in a context where inclusionary and supportive tendencies within Black communities continue to sit in tension with exclusionary, stigmatising community relations. The research offers counter-stories that challenge stereotypes and misconceptions about mental health and race. By amplifying the voices of marginalized individuals, the findings contribute to a more nuanced understanding of the experiences of people of colour with mental distress and combating stigma.

By emphasizing these connections, the analysis demonstrates the interplay between race, mental distress, and systemic factors, providing a detailed understanding of the issues and their implications for anti-stigma campaigns and mental health advocacy. By incorporating the experiences of individuals from ethnically diverse backgrounds in the research findings, we can contribute to understanding racism as a determinant of mental distress and underscore its role in perpetuating stigma and discrimination.

Intersections of Race and Mental Distress

Critical Race Theory (CRT) underscores the significance of examining the intersectionality of race and mental distress. Integrating CRT into the analysis deepens the understanding of mental distress within racial contexts, informing alternative anti-stigma campaigns or facilitating targeted interventions to address mental health disparities and combat stigma among ethnically diverse populations.

Participants disclosed their experiences from personal, social, and environmental perspectives. An important set of disclosures revealed the difficulties arising primarily from being diagnosed with ‘schizophrenia,’ which could lead to stress, frustration, and perceived racism. Such experiences link with previous scholarship on the adverse impacts of labelling.

Although it was not extensively addressed, fear is strongly associated with stigma. Most participants feared being diagnosed and, as a result, labelled, which ultimately led to hospitalisation. Seeking assistance for mental distress may also have negative implications for people close to the person seeking assistance. For example, a participant discusses her fear of labelling and how anytime she suffers, her family suffer as well. This is because when her family assist her in resolving an issue, they are later connected with her being ‘crazy’ and thus also become subject to stigma, resulting in isolation in the community.

Despite the appeal of mad studies for me as a researcher attempting to make sense of participants' reported experiences, mad politics was not part of their accounts. Indeed, even those participants with cause to be critical of psychiatric labels often found themselves recycling the vocabulary and terminology of psychiatry in their narratives, seemingly because they did not possess alternatives. The term 'mad' was typically seen negatively. From these findings, it is a short step to assume that these ethnically diverse participants may not be ready to accept a 'Mad identity' as a politicized disability identity in line with Mad politics. Despite none of the participants expressing satisfaction with the diagnosis label and experiencing shortcomings in their relations with mainstream services, this did not translate into any expressed desire, or indeed knowledge of, mad pride as an alternative standpoint.

These findings draw our attention to the importance of considering race in Mad studies. LeFrançois and Gorman (2018) believe that Mad Studies has always possessed a global, critical racial, and postcolonial perspective. They contend that Mad Studies should advance Black psychiatric history that is racialized and colonised, although the Mad Studies movement has been criticised for lack of a clear anti-racism strategy. Rachel Gorman (2013), Louise Tam (2013) and others have called attention to the Whiteness of Mad Studies in Canada.

Interestingly, participants' accounts of the notion of internalised, or self, stigma point to some nuance in this regard and hold the promise of creating conceptually uncertain circumstances whereby alternative framings, such as mad studies or precursor ideas, such as mad pride, might gain traction. Some participants admitted to experiencing self-stigma or being in denial of distressing experiences likely to be identified by services as psychiatric symptoms. This, in turn, discouraged them from seeking help within the mainstream. This aligns with Topkaya's (2014) and Shepherd and Rickard's (2011) findings, who claimed that self-stigma significantly predicts attitudes toward help-seeking. In contrast, there is little evidence of participants in my research relating an internalisation of stigma; familial and community stigma were common reasons for not seeking early help from mainstream services. Aligned with negative views of psychiatric labels and the support provided within mainstream services, there is a potential, as yet incompletely realised, for participants to wish for alternative service provision, less stigma from within Black communities and families, and, perhaps, that these are grounded in a more politically aware framing of mental distress and race. The establishment of alternative Black mental health support in places like Brixton, Manchester and Liverpool in the 1980s was a consequence of such thinking through of alternatives, and this small piece of place-based history was forged by community activists who combined insightful critique of the racialised failings of mainstream services with a politics of race and civil rights. For example, in Liverpool, one such alternative service emerged within a complex local politics of perceived inadequacies of psychiatric services and layered activism against racism in the city on a global (anti-apartheid) and local scale (post-riots and racist policing and employment practices) (Wainwright & McKeown, 2019).

The potential for the participants in this research to feel a sense of pride when discussing their mental distress may not be a too extravagant leap of imagination. Moreover, this may be further potentiated in the possibilities for creative community responses and interactions such as those enacted in study four’s performance piece. At this historical juncture, we are living through tumultuous times where various fascistic, racist, and White supremacist ideologies and tropes have achieved an unwholesome and regrettable prominence across social media, public discourse and even government rhetoric and policy. One only has to look at the narratives espoused concerning immigration legislation and the so-called small boats issue in UK politics or the Trump and MAGA contributions in the US to see that racist demonisation and denigration of Black otherness is alive and kicking in contemporary times. This is not comforting for the collective psyches of people of colour. Nevertheless, there is always resistance, and the prideful mobilisations under the banner of Black Lives Matter offers a dynamic and assertive counter-narrative. A politics of mental health that thoroughly engages with insights from critical race theory and mad studies could inject the sort of pride hitherto absent from ant-stigma campaigns and the accounts of participants in this study but enticingly within reach if we collectively formulate alternatives.

Whatever Mad Studies may or may not include, it falls into a long tradition of popular psychiatric critiques and more general attempts to redefine what we understand by terms like crazy, 'psychosis,' or ‘schizophrenia.’ In the lineage of critical perspectives, older and newer forms of anti-psychiatry, including abolitionist demands, exist alongside looser theoretical, political, and practice-based critiques, sometimes collectively known as critical psychiatry but also involving critical wings of other professional psy-disciplines. Mad Studies exists within this ideological terrain but is distinct in privileging survivor, service user or service refuser voices. Earlier, Mad Pride activists represented something of a rupture: amongst other things reclaiming the language of madness for positive movement ends, in turn, posing a direct challenge to stigma, especially perhaps the stigma attendant upon being a psychiatrist and using services. These various narratives illustrate activists' refusal to uncritically self-identify with processes of psychiatric classification and their resistance to and co-optation of confessional practices. Because it is due to the influence of anti-stigma campaigns grounded in biomedical models of mental illness that constrain these sorts of mould-breaking counter-narratives, I concur with opening the standpoint of being anti-anti-stigma. While laudable in their goals, current mainstream tactics to target the stigma associated with mental illnesses function to inhibit other forms of experiencing and engaging and understanding madness. When these are enacted in a hegemonic terrain of psychiatric orthodoxy, it becomes difficult for people excluded from power and subject to oppression within the system to imagine ways out from under oppressive forces or even to speak of alternatives without recourse to the language that carries the oppression. Whilst such hegemonies pose, by definition, a substantial challenge to resistance, they are not omnipotent and critical spaces can be found from within which alternative thinking and potential practices can emerge. Situated, creatively inspired challenges to stigma and psychiatric power can form one such set of spaces, and mad studies activists have drawn attention to such potential (e.g. Castrodale, 2019; Reid, 2019; Reid et al., 2019).

Latterly, scholars with affinities for mad studies activism have cautioned against performing a critique that collapses into binary arguments and also notes that a too simplistic critique can play into the hands of neoliberal policy makers, for whom a politics of austerity will close services, that however much they are far from ideal, will be missed if they are cut without provision of any meaningful alternative (Spandler, 2017; Spandler & Poursanidou, 2019). Such commentary can help to explain some of the seeming contradictions voiced in this research whereby participants could express critical views of services alongside dissatisfaction at having to wait sometimes to receive a diagnosis (perhaps as a route into receiving support) or could only conceive of help-seeking concerning that which was known to be available – services in the mainstream –

however much these were viewed as inadequate, culturally insensitive, or bedevilled with racisms. Of course, this is how hegemony works: the oppressed within a hegemonic system become complicit in their disadvantage and struggle to mobilise ideas and even vocabulary outside of accepted mainstream orthodoxy.

According to Mulhbaur's 2002 study, stigma was experienced sequentially in private and public domains, including internalised, family-centred, direct personalised, and indirect institutionalised. This means that, despite recognising intergenerational patterns and beliefs about mental distress, little is known about how this process occurs and what role family stories may play in influencing the experience. Socioeconomic and cultural discourses shape intergenerational narratives about mental distress, including that which is diagnosed as an illness, and given the prevalence of mental health stigma, most families are likely to have some stigmatising attitudes and beliefs in this context. These will affect families' experiences living alongside their relatives with mental distress. A considerable part of this can be ascribed to what some participants discussed, as most of their testimonies indicate a lack of information about ‘schizophrenia’ before seeking help. Within the mainstream, so-called mental health literacy has been identified as a barrier to seeking help and establishing stereotypes. Additionally, from within a psychiatric frame, some participants thought that the symptoms they were experiencing were similar to those of other, less severe mental illnesses due to the community's lack of knowledge.

Furthermore, one of the participants stated that her auntie had ‘schizophrenia’ but was managed as unaware of her condition. The currency of mental health literacy depends on an uncritical acceptance of a psychiatric worldview and does not allow for the possibility that people may legitimately choose to avoid services or seek help and support outside of the mainstream. From a mental health literacy perspective, such behaviour is confused or mistakenly motivated and is eligible for correction, for example, by endorsing proper knowledge and behaviour within mainstream anti-stigma campaigns.

As a result of the discussion above, it is clear that individuals are influenced by various circumstances while requesting assistance. Self-stigma on an individual level was less widespread amongst participants, but the public stigma was more prominent. People of all ethnicities have varying perspectives on mental distress, with variability as likely to be found within as between different ethnic groups. There are, however, certain popular tropes: ‘schizophrenia’ might be understood by individuals from an African heritage in terms of personal weakness compared with certain South Asian cultures view as a spiritual affliction, both variously associated with shame. Maintaining a family reputation could be even more critical. For example, many migrants families or people of migrant heritage hold high expectations for their children's success, reflecting a sought-after good impression of the family, which could be spoilt by the stigmatised detriment associated with a family member in mental distress and engaged with the psychiatric system (Sheikh & Furnham, 2000).

Similarly, within certain cultures seeking aid outside the family unit was looked down upon. The participants sought aid only when events spiralled out of control and they found themselves without a choice. Participants reported a mixture of helpful and unhelpful responses from families and communities in this context.

The participants described numerous instances in which they encountered, saw, and exercised politeness stigma within and outside society. While most respondents indicated that their relatives were aware of specific events, they hesitated to share them with others outside the household. In addition, family members remarked how the individual carrying a diagnosis of ‘schizophrenia’ was a source of embarrassment for the affected and the respondents, corroborating Goffman's (1963) assertion that the taint of stigma spreads through social networks.

What was evident across studies was the similarities and differences in values, experiences and beliefs surrounding the label ‘schizophrenia’ and help-seeking among people of colour from different ethnic communities. It is important to reiterate that people of colour are incredibly diverse and heterogeneous, representing various cultures, ethnicities, and histories. Acknowledging and respecting this diversity is crucial to avoid oversimplification and stereotypes. Within communities of people of African heritage, there are significant differences between individuals born in the UK and those born in Africa.

For instance, people of African heritage born in the UK may encounter unique challenges as they navigate their identity in a multicultural society. They often experience a dual sense of belonging, connecting to their African heritage while influenced by UK culture. On the other hand, African-born individuals who later immigrated to the UK may face acculturation and adaptation challenges as they integrate into a new social and cultural environment.

Similarly, among people of (South) Asian heritage, there are notable distinctions between those born in the UK and those born in the sub-continent (South Asia). British born Asians may embrace a fusion of cultural influences, blending aspects of their ancestral heritage with British norms. In contrast, individuals from South Asia who migrate to the UK may encounter cultural adaptation struggles as they strive to preserve their traditions while embracing aspects of British culture.

Furthermore, it is essential to recognize the distinctions between people of African heritage and those of South Asian heritage. These differences include cultural practices, religious beliefs, spoken languages, and historical experiences. Each community has unique strengths, challenges, and contributions to British society.

By acknowledging the diversity within communities of people of colour, policymakers, service providers, and society can adopt a more nuanced and culturally sensitive approach to address the needs and experiences of individuals within these communities. Embracing diversity and understanding the various perspectives and histories can lead to more inclusive and effective policies and services that empower and uplift all members of people of colour communities.

According to some participants in my research, reported culturally specific norms around mental health are more prevalent among their parents, first-generation immigrants who brought these ideas from their countries of origin. From within the mainstream, adherence to such cultural ideas is viewed as connected to a general lack of mental health education or mental health literacy due to a lack of access to such education and related resources. Such assumed deficits also extended to friends and communities. Moreover, because the second generation is deemed to have a higher level of Western acculturation and increased knowledge and exposure to mental health and related challenges, they are considered to have a higher level of mental health literacy than their parents.

Similarly, Han and Pong (2015) found that second-generation Asian Americans were more likely to seek mental health care than first-generation. This is comparable to Lawton et al. (2017) finding that younger family members acculturate more quickly than senior family members, resulting in a generational divide. Increased acculturation in the second generation frequently increases the chance of utilising mental health services (Arora et al., 2016; Han & Pong, 2015; Islam, Khanlou, & Tamim, 2014; Nguyen, 2011; Tonsing, 2014). Williams et al. (2011) document a poor concordance rate between parents and children regarding assistance-seeking within the mainstream. Han and Pong (2015) also hypothesised that Asians with a more substantial commitment to Asian cultural values are less likely to seek help, as doing so "may be viewed as bringing disgrace to themselves and their families" (p.3). In contrast, those viewed as more acculturated to Western norms and values held significantly fewer stigmatising beliefs.

From a mad studies perspective, such views are hugely over-simplistic, and the very ideas of acculturation and mental health literacy require a thorough critical interrogation and transformation in unlearning the shibboleths of the psychiatric orthodoxy. If we layer in an appreciation for critical race theory, the assumption that all correct knowledge belongs to Western knowledge systems, such as psychiatry, can be seen as the Eurocentrism that is, in turn, founded on racially dubious colonial stereotypes of superiority.

Regardless of how we understand it, the stigma of mental distress is associated with various negative experiences for individuals, families, and communities, valid across cultures. Community members believe this stigma generates a variety of negative attitudes and behaviours, including avoidance, rejection, isolation, fear of retaliation, and humiliation. For instance, one participant described how his brother, who had been diagnosed with mental health difficulties, was kept concealed from other family members by his parents, who steadfastly denied that anything was wrong. His parents assumed that any 'problems' would ultimately resolve themselves. Another participant expressed that persons experiencing mental distress are viewed as passing through a phase; their problems are unhelpfully disregarded as insignificant. Similarly, Han and Pong (2015) highlighted in their study of mental health help-seeking behaviours among Asian community college students that mental health is frequently ignored in Asian communities despite the prevalence of mental health problems.

Another view expressed by a few individuals is that mental health problems indicate supernatural possession. Findings from a study on mental health help-seeking behaviours among Asian Americans and another on mental health stigma in ethnic minority communities (Knifton et al., 2010), some individuals of Asian heritage, particularly South Asians, believe possession by demons, spirits, and other such entities cause mental illnesses. As one participant in my study stated, disclosing the existence of mental health difficulties would imply that an asterisk would be placed next to his name—he would be permanently branded. This labelling creates an atmosphere of shame, which is believed to influence the entire individual family with mental health difficulties. Similarly, Han and Pong (2015) address the concept of face and status loss in the context of mental health stigma'. Within the mainstream, the concept that stigma associated with mental distress becomes attributed to an individual's entire family is also described by Larson et al. (2010) and further defined as 'courtesy stigma' by Corrigan et al. (2014), in which family members are victimised as a result of their association with an individual who has mental health issues. Thus, concealment and seclusion have been the cultural norm to avoid being stigmatised or linked with being made in certain circumstances. This finding has also been reported in the extant literature as the tendency for Asian Americans to use problem avoidance and social withdrawal as primary coping mechanisms, as opposed to seeking professional help, which is frequently viewed as a source of shame and disgrace (Han & Pong, 2015; Kovandi et al., 2011; Roberts, Mann, & Montgomery, 2015). Indeed, Ciftci (2013) noted that in certain situations, "fathers would blame moms for giving birth to a kid with mental illness" (p.22).

According to individuals from a Chinese background in this study, this propensity to avoid/deny mental health problems may be connected to a view of personal failures, such as an inability to achieve in school. This is similar to Abdullah and Brown's (2011) study on the connection between mental illness stigma and cultural views, which concluded that "an unwillingness to recognise family accomplishments may also result in stigmatisation" (p.941). Concealment was favoured over seeming weak in public.

The data in my research indicate that participants had a stronger sense of their identity as members of a larger group than the individualism prevalent in the West. Nonetheless, it must be acknowledged that problems associated with mental diagnoses are not necessarily due to cross-cultural disparities. For example, if a significant stigma is associated with mental illness in a person's culture, the individual may feel uncomfortable disclosing his feelings to a psychiatrist or professional from within one's own cultural group. In this case, consulting with a psychiatrist from a different cultural background may be beneficial.

Papadopoulos et al. (2013) argue that persons from more individualist cultures are less stigmatising of mental health disorders. They contend that this is because individualistic cultures are fragmented and thus more tolerant of diversity, in contrast to collectivistic cultures, which are less fragmented, and anything out of the ordinary is quickly pointed out, motivating families to conceal the existence of mental health problems and thus avoid accessing mental health services. However, this argument is insufficient to account for the mental health stigma in the UK, a Western country known for its individualism, exemplified by the widespread practice of 'othering' people with mental health problems, both in the community and the healthcare system. This unsatisfactory explanation may be due to the tendency in the literature to dichotomize individualism and collectivism (Tse & Ng, 2014). Thus, while being mainly individualistic, Western societies can also exhibit specific collectivistic values that could contribute to the prevalence of mental health stigma or, indeed, the felt stigma is inextricably bound up with the available mainstream service model. In relation to this lack of prioritisation and associated cultural norms, participants in my study acknowledged that their parents frequently offered what were felt to be ineffective solutions for resolving mental health issues, such as simply sleeping earlier, studying harder, stopping watching television, and praying more frequently.

Participants of African heritage felt that most believe African men should handle their problems, fearing guilt or being a burden to others. These findings align with various studies conducted in the mainstream. For example, Watkins and Neighbors (2007) argued that discomfort is experienced among African men, which prevents them from talking about their mental health, as well as the findings from Genuchi and Valdez (2015), argued that men that experience depression may express symptoms in ways that are highly influenced by traditional masculinity ideology and norms. My research revealed that the experiences of the participants varied. Participants expressed that it is a misconception that they can always navigate and handle problems without the assistance of informal support through family and friends or formal support through mental health professionals. The study conducted by Hammer and Good (2010) argued that researchers had found ways in which society feels men should act and attitudes they should hold without showing weakness, which also confirmed my research findings.

The findings from Study 2 offer valuable insights into the intersectionality of race, family dynamics, and mental health, highlighting the relevance of Critical Race Theory. The study illuminates the significant role of the family in shaping the experiences of individuals from racially diverse backgrounds concerning mental health stigma. Through participants' narratives, the study uncovers the complex interplay between cultural beliefs, racial identity, and mental health support within families. These findings provide evidence of how systemic racism permeates family structures and influences the help-seeking behaviours of individuals from marginalized communities.

When considering alternatives to mainstream psychiatry, or reforms within the mainstream, various relational practices have been urged as more desirable than psychiatry's coercive and compulsory character. It has also been remarked that the hyper-atomised individualism of Western cultures, typified by a privileging of autonomous independence, can be contrasted with the more interconnected interdependence of various ethnic minority cultures; and that the latter might be a more propitious basis for transacting psychosocial support or mutual assistance for mental distress.

Aspects of prejudices, racism or seemingly unconscious biases are linked to stigmatising or exclusionary behaviours. Alternatively, various positive social/relational dispositions might have opposite effects. Empathy is the capacity to place oneself in the shoes of another person in such a way that the other person's experiences may be comprehended, felt, and articulated. Empathy and moral reasoning are shown to be inversely linked with prejudice or stigma, but authoritarianism and social dominance correlate with prejudice (McFarland, 2010). When clinicians' empathy exceeds their sympathy, client experiences tend to be more pleasant, and objectivity in clinical decision-making is maintained. Additionally, increased empathy can help reduce professional burnout.

Interconnectedness may also help reduce stigma by encouraging compassion, an interpersonal attribute associated with the Buddhist faith. Compassion originates with the Four Immeasurable: loving kindness, friendship, empathetic joy, and tranquillity (Buddhaghosa, 1991). These four components are primarily concerned with self-and other benefits, with compassion emphasising the desire to relieve the pain of oneself and other sentient animals. In Western psychology, compassion is an awareness of another's suffering and a desire to alleviate that suffering (Goetz et al., 2010). It is usually cultivated through contemplative practices such as loving-kindness or compassion meditation (Hofmann et al., 2011). Compassion may also develop from an understanding of the interconnectedness of all beings (Hanh, 1998). Those who are connected may have a better understanding of their connection to the suffering of individuals with mental illness and their potential contribution to that suffering. People with this information are more likely to act compassionately to alleviate this pain. One barrier to obtaining help is the belief that most participants expressed that mental health concerns should be addressed within the family. According to participants, families would keep things within the family, and seeking outside assistance was viewed as a breach of trust. Some of this may be explained by the fact that research indicates that family members of people with severe mental illness are aware of prevailing negative attitudes toward them and have defined several unpleasant experiences, including being gossiped about in the community, being blamed for their family member's illness, being devalued, and receiving insufficient support (Shamsaei et al. 2013; Rezayet et al., 2018).

Others in my research have not experienced significant stigma due to a family member's ‘schizophrenia’ diagnosis. Nonetheless, some believed the stigma existed but refused to admit it, implying they were unaware. This could result from a conscious decision to disregard what others are saying. It is almost as if the family member has turned a deaf ear toward it. One of the most often mentioned themes among interviewees was a sense of not belonging to the group on an equal footing or being looked down upon. Some believed that the community had exhibited open contempt for them after a family member was diagnosed with ‘schizophrenia.’ This was particularly prevalent in South Asian communities, as indicated by one respondent's experience, in which multiple respondents became protective and offended in response to the society's behaviour. For example, one respondent recalled an instance during a conversation with another Pakistani family member where they were not invited to a wedding to prevent her sister from misbehaving, which aligns with research published in 2017 by Koschorke et al. on how mental illness can affect how a family member is stigmatised.

According to the reports of a participant of Jamaican ancestry, her uncle was bullied following his diagnosis of mental illness, but due to her generosity, the family no longer abuse him. Additionally, one of the participants observed that members of the Bangladeshi community and society must demonstrate kindness for persons with a diagnosis. Through a Mad Studies lens, the reports of the participant of Jamaican ancestry and the observation regarding the Bangladeshi community highlight the intersectionality of mental health stigma and the potential for transformative change through community support and understanding.

The participant's account of her uncle being bullied following his mental health diagnosis illustrates the harmful impact of societal stigma on individuals with mental health conditions, especially within communities of colour. This situation is emblematic of how people with mental health challenges often face discrimination, isolation, and mistreatment due to prevailing societal attitudes and misconceptions surrounding mental illness. A Mad Studies perspective would emphasize the need to challenge and dismantle these stigmatizing beliefs by advocating for a more inclusive and empathetic society that values the diverse experiences of individuals with mental health conditions.

The participant's generosity, which led to the family no longer bullying her uncle, demonstrates the potential for transformative change through individual and collective agency. In Mad Studies, the agency takes centre stage as individuals with lived experience challenge oppressive structures and create spaces for healing, acceptance, and support. The participant's advocacy within her family reflects the importance of amplifying the voices of those with lived experiences and engaging in collective efforts to combat stigma and discrimination.

The observation regarding the Bangladeshi community emphasizes the significance of kindness and compassion in supporting individuals with mental health diagnoses. In a Mad Studies framework, kindness and empathy are crucial elements of fostering healing and resilience. This perspective encourages communities to move away from a deficit-based model of mental health and instead embrace a strengths-based approach that recognizes the unique perspectives and contributions of people with lived experiences of mental health challenges.

Providing evidence for Goffman's (1963) argument that stigma spreads, family members described how the individuals diagnosed with ‘schizophrenia’ was a source of shame, not necessarily for the individual, but for the participant themselves. Additionally, several participants in my study believed that the community's remedies to mental health concerns were unsuccessful, with one participant citing his mother pouring holy water to cure him of his mental health difficulties. These inadequate remedies and stigmatising attitudes contribute to some participants' perceptions in my study that, in addition to a propensity for concealment, they are conclusively unable to discuss mental distress with their parents. Similarly, clinician participants in research performed by Rastogi et al. (2014) found that young South Asian patients were apprehensive about addressing difficulties with their parents out of fear of being branded as mad. Additionally, witnessing others in the community being discriminated against based on mental health issues discourages individuals from acknowledging and sharing their mental health issues; as a result, they cannot empathise with and relate to those who are similarly afflicted. This is related to Gilbert et al. (2007)'s notion of stigma awareness,' which they define as the dread of being identified with a socially stigmatised group and Ciftci's (2013) discussion of label avoidance.

While it is frequently assumed that avoidance of mainstream treatment services is motivated by fear of stigma, it is equally necessary to acknowledge that mental health care providers can and do contribute to stigma. (2014) (Bathje & Marston, p. 1714). Sometimes contributing appears to be a considerable understatement, as seen in Goffman's previous work described in Asylums (1961). The book is concerned with psychiatric hospitals as total institutions. However, even if we take the optimistic stance that the realities and customs of mental health practice are more humane today than they were during Goffman's lifetime, the argument as a whole holds: the goal of the institution, not necessarily a total one-asylum - but also of mental health services in general, even if provided in the community, is to improve mental health outcomes. This is the primary source of stigma - the institution ascribes a stigmatising label to an individual. Numerous studies have shown that mental health professionals are as likely as the public to hold and disseminate stigmatising views on mental distress (e.g. Waughs et al., 2017; Bingham et al., 2018, Lauber et al., 2006).

Power dynamics and access to mental health services

CRT emphasizes the role of power dynamics and privilege in shaping access to resources and services. Analysing the study findings through a CRT lens reveals how power imbalances influence the availability and quality of mental health services for marginalized communities. By examining the experiences shared by participants, the research explores the systemic barriers encountered by racially diverse populations in accessing mental health support, informing policy recommendations for equitable and culturally competent mental health services. Concerning ‘schizophrenia’ diagnosis, family participants perceived a continuing lack of awareness of ‘schizophrenia’ and candour. Despite the dominance of psychiatric orthodoxy, services were often disinclined to provide information to people admitted to services or receiving a diagnosis. A lack of education and information regarding the service perspective on ‘schizophrenia’ and treatment options exacerbated emotions of helplessness. Several participants were bewildered after talking with community service professionals. This is because they are dissatisfied with receiving a diagnosis for a family member without explaining it or receiving any information that aids their comprehension. This finding corroborates Krupchanka et al. (2018)'s discussion of the stigma experiences family members of people living with ‘schizophrenia’ face, two of which are the overarching issues of a general lack of understanding and misconceptions about mental illness, as well as structural discrimination and a dearth of governmental and public support systems.

Longdon and Read (2017, p.28) wrote in a review of experimental research and studies evaluating the impact of anti-stigma campaigns based on the prevailing "biomedical model": "While anti-stigma initiatives based on the "mental illness is an illness like any other" approach are well-intentioned, there is substantial evidence that they are not only ineffective but may increase risk attributions." They make a critical connection between the failure of anti-stigma campaigns and an essentialist approach to mental health problems. They review a body of research demonstrating that individuals with essentialist biases about various aspects of human diversity are likelier to exhibit prejudicial perspectives. This is especially likely to occur when the contested "essence" is framed as underlying biological distinctions between the "normal" and the stigmatised, effectively dehumanising mental health patients as defective machines and legalising coercive treatment (Stupak & Dyga, 2018).

In recent years, Critical Race Theory (CRT) has emerged as a valuable conceptual framework for examining the role of racism in health inequalities. Moreover, mad studies scholars and activists have recognised the need for a strong anti-racism positioning within mad studies and the importance of making theoretical connections with critical race theory (see Redikopp, 2021). As researchers, we can contribute to this thinking and offer evidence to inform anti-stigma initiatives. Specifically, in Study 3, my findings shed light on the impact of racial discrimination on mental health and the distressing effects of racism, providing valuable insights for advancing the goals of CRT and anti-stigma efforts.

One unexpected finding of my research was the extent to which the participants emphasised that anti-stigma campaigns are not getting to the root of encouraging people of colour to seek help for severe mental distress. The overrepresentation of mental distress such as ‘schizophrenia’ in news media accounts of violence is counterbalanced by their omission from narratives purporting to redeem mental illness from prejudice. Claiming to alleviate public fear of the individuals diagnosed with ‘schizophrenia’ who are put into categories of different mental illnesses, anti-stigma narratives purposefully invoke current depictions of ‘schizophrenia’ and other kinds of severe mental distress as violent and non-White to confirm the citizenship of more acceptable diseases such as depression and anxiety. Furthermore, a surprising revelation was uncovered when a participant reported that anti-stigma measures result in a double stigma, with people of colour more likely to be portrayed on television as having a severe mental illness than White people, who are more likely to discuss less severe mental illness.

These findings are somewhat surprising given that other research shows a lack of diversity in anti-stigma campaigns. For example, Shefer et al. (2013) conducted focus groups with members of different cultures while maintaining a psychiatric framework. A significant result was that anti-stigma programmes in the United Kingdom successfully raise awareness about mental illness and that individuals are willing to accept messages about the consequences of concealing mental disease. However, anti stigma efforts sometimes lack culturally relevant components, such as multiracial imagery, role models, or translated language. This conclusion is corroborated by those who emphasised it; for example, Knifton (2012) noted that they had not seen their ethnic group members in media advertising or volunteer speakers. Additionally, they believed multiracial pictures should be more balanced, with fewer people of colour, as this might imply that communities are "crazy," reinforcing prejudice.

Participants in my research widely discussed using images of people of colour in anti stigma campaigns. Some questioned whether this would increase public awareness of mental distress or do more harm than good. Indeed, most participants recommended that anti-stigma programmes be available to individuals whose first language is not English. When participants were asked how anti-stigma campaigns could be more tailored to people of colour, this was a frequently expressed desire. Several participants proposed strategies for reducing stigma and increasing public awareness of ‘schizophrenia.’ Participants from religious communities with a religious connection to mental illness proposed community-wide strategies to increase public awareness. This participant of Arab ancestry in Study 3 believes that having an educational session on mental health awareness could help eliminate prejudices about ‘schizophrenia’ symptoms. Those who believed it was useless argued that anti-stigma initiatives were ineffectual at persuading patients to seek treatment for ‘schizophrenia related symptoms because the public still stigmatised ‘schizophrenia.’ As a result, individuals will be free to come out without fear of judgment or embarrassment if public stigma is reduced. This is, however, hugely constrained under prevailing stigma.

Some participants in my research expressed a lack of trust in the system and anxiety about how people of colour would be treated if they sought aid. Apart from that, one of the primary concerns was the family influence. Individuals cannot speak up due to family views and barriers to seeking help, including those related to race, racism, and a perception that mental health services could not accommodate them due to cultural differences. One of the interviewees expressed concern that service providers were racist in treating Black individuals compared to White individuals.

Interestingly, when a person of colour prefers a White doctor over a doctor who looks like them in a mental health setting, it can reflect a complex interplay of factors, including perceived competence, trust, internalized stigma, and experiences with systemic racism. This preference may arise from a perception that White doctors are more competent or better trained, a view that can be reinforced by societal biases and systemic inequalities that often place White professionals in positions of authority and expertise. Internalized racism may also lead individuals to devalue professionals from their own racial or ethnic group, believing that White doctors are superior due to societal messages that favour White standards. Additionally, previous negative experiences with doctors from their own racial or ethnic group or with the healthcare system in general could influence this preference, as individuals may assume they will receive better or more impartial treatment from a White doctor.

Furthermore, cultural mistrust can play a role, where individuals might fear that professionals from their own community could judge them or disclose their issues within the community, compromising their confidentiality. Some may seek objectivity, believing that a doctor from their own racial or ethnic group might not provide a neutral perspective. Systemic racism within the healthcare system itself can also reinforce these preferences by subtly favouring White doctors through better resources, support, or prestigious roles, influencing patients' perceptions.

Additionally, the intersection of various aspects of a person’s identity, such as race, gender, and socioeconomic status, can shape their preferences, especially if they have faced significant discrimination from members of their own racial group. To address these preferences, it is crucial for the healthcare system to ensure cultural competence, break down systemic biases, provide training on the impacts of racism and internalized stigma, foster an inclusive environment, and work actively to build trust within communities of colour.

Counter stories and Alternative Narratives

CRT and mad studies highlight the significance of counter-stories and alternative narratives in challenging dominant ideologies. My research provides valuable counter-stories that disrupt prevailing narratives surrounding mental health and race, amplifying the voices of marginalized individuals. Incorporating these counter-stories exemplifies the potential of alternative narratives to reshape perceptions, reduce stigma, and foster empathy, aligning with CRT's call for diverse perspectives to challenge existing power structures and mad studies’ demands for mad people to be central to forming and acting upon a politics of madness.

A desirability for alternatives to anti-stigma campaigns was heavily vocalised within my research. For example, some participants explained using social media to support individuals in seeking help, which is helpful if it comes from people of colour. Online profiles of individuals with mental health conditions can provide both positive and negative opportunities for individuals to identify with and discuss mental distress (Ziebland & Wyke, 2012). Celebrities can serve as role models and cautionary examples of how not to live with mental health conditions, though using celebrities to reproduce orthodox thinking uncritically is problematic. However, specific anti stigma social movements can be formed online in which individuals emphasise their social uniqueness and redefine their stigmatised characteristics as contributing to the positive yet marginalised diversity (Saguy & Ward, 2011). For example, prominent YouTubers with large social media followings may 'come out' as having stigmatised identities to appeal to socially diverse audiences. Others who come out with stigmatised identities may also be described as 'brave', and at the forefront of social change, though, again, tropes of bravery and courage can be deployed in patronising and unhelpful ways. Performance pieces such as *Plant Fetish* can open up spaces for audiences to think individually or collectively to arrive at more critical, acceptable or sophisticated challenges to stigma or solidarity with mad people of colour. Addressing the intersection of ethnicity and neurodiversity within anti-stigma campaigns ensures that the specific needs and experiences of individuals with various neurodiverse identities are considered, fostering a more inclusive and supportive environment. The more radical strands of neurodiversity movements offer novel ways of thinking about human difference, and how it is subject to forces in the political economy, that could dismantle stigma by virtue of a forceful challenge to the denigration and demonisation of difference that flows from pathologizing taxonomies (Chapman, 2023). For these reasons, there have been fruitful intersections between activists and scholars associated with mad studies and neurodiversity movements[13] (see McWade et al., 2015; Spandler & Poursanidou, 2019).

Advocacy and Policy Implications

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[13] See also *The Mad Studies and Neurodiversity – exploring connections symposium*, Lancaster University, 17th June 2015. https://madstudies2014.wordpress.com/archive/mad-studies-neurodiversitysymposium-archive/

CRT and mad studies call for action and social change. My research findings have significant advocacy and policy implications, informing recommendations for policy reforms and interventions to address systemic barriers ethnically diverse populations face. By emphasizing the need for trauma-informed approaches and culturally competent mental health services, the research supports evidence-based advocacy for equitable mental health services and social justice, aligning with the transformative goals of CRT and positioning the study as a catalyst for positive change. Psychiatric hegemony has, however, proven remarkably resilient to transformational critique, and this may at least partly be explained by its enmeshment with broader systems of neoliberal social control and government. The prospect of prefiguring alternatives in smaller, situated community spaces, where the neoliberal-psychiatric gaze is not always looking, remains a possibility. Furthermore, mad studies' harnessing creative arts as a vehicle for activism and inquiry appears to be a fruitful prospect in this regard, supported by evidence from my study four.

We can realise how contradictory it is to view self-stigma as a barrier to getting treatment. From this vantage point, the stated objective of fighting self-stigma becomes an institutional mechanism for enhancing the institution's capacity for stigmatisation. This knowledge does not call into question the stigma attached to being a mental health patient; rather, it strengthens the institution's capacity to alter the selfhood of treated persons. They must internalise the stigma associated with a diagnostic category while simultaneously rejecting negative public opinion associated with the diagnosis (while the opinion exists, as the stigmatising label was placed on patients by an institution acting in the public interest – often disguised as the patient's best interests). To illustrate this contradiction, consider the newly famous phrase "It's ok not to be ok," which has been included in several mental health awareness and anti-stigma initiatives (National Suicide Prevention Lifeline, 2016). The actual message appears to be: "It is acceptable not to be OK... as long as you seek therapy and take steps to avoid "being not OK." It is acceptable to be depressed as long as you act responsibly and take care of yourself; if you notice others "not being OK," you should offer support or refer them to a mental health professional; you should refrain from judging or blaming them as long as they seek professional help or take their medication. Otherwise, you can contact the authorities; involuntary therapy may be your only option.

Specific individuals believe that anti-stigma activities related to ‘schizophrenia’ are primarily useless, which is corroborated by a consensus among participants who claimed that anti-stigma programmes were inefficient in removing stigma due to (non)performativity. Others argue that legislators engaged in the anti-stigma movement profess to be "partners" in reducing the stigma associated with mental illness while escalating the severity of the situation. Some participants stated that "The "it's good to talk" tagline creates confusion and frustration because it does not equip individuals to communicate with those around them. Therefore, it is not the responsibility of those designated with a severe mental illness to inform others about their experiences.

Furthermore, because media portrayals of people with ‘schizophrenia’ can influence attitudes, there is concern that media portrayals of people with ‘schizophrenia’ contribute to stigma perpetuation (Huang and Priebe, 2003).

The participants’ scepticism regarding the motives and implications of racialized mental health representation aligns with intending to analyse how mental health conditions are portrayed critically. It encourages a critical examination of power structures, stereotypes and the need for more accurate and inclusive portrayals that capture the diversity of experiences within racialised and ethnic communities.

Relevance of findings to policy around inclusion in health provision

This research offers substantive insights into potential policy implications aimed at addressing mental health disparities and promoting equity for people of colour in the United Kingdom. By aligning with key national policies and initiatives, such as the NHS Long Term Plan, Race Disparity Audit, Mental Health Act 1983, Public Health England’s Strategic Plan, and the Equality Act 2010, this study holds promise for informing targeted interventions and systemic changes conducive to improved mental health outcomes for racialised minorities.

Alignment with NHS Long Term Plan (2019)

The NHS Long Term Plan emphasizes the imperative of reducing health inequalities and enhancing access to mental health services for all segments of the population, including ethnic minority communities. This research aligns with the plan's objectives by shedding light on the specific mental health challenges faced by people of colour thereby contributing to the broader goal of ensuring equitable access to high-quality mental healthcare services.

Contribution to the Race Disparity Audit (2017)

The ongoing Race Disparity Audit seeks to identify and address racial disparities across various sectors, including healthcare. This study's findings on mental health disparities among people of colour and enrich the audit's dataset, providing nuanced insights into the intersection of race and mental health outcomes. By contributing to a comprehensive understanding of these disparities, this research can inform targeted interventions and policy reforms aimed at reducing inequities.

Influence on Mental Health Legislation: Mental Health Act 1983

The Mental Health Act 1983, as amended by the Mental Health Act 2007, governs the treatment and rights of individuals with mental health conditions. By highlighting the specific needs and experiences of people of colour individuals with ‘schizophrenia,’ this research underscores the importance of culturally competent care within mental health legislation. These insights can inform future amendments to the Act to ensure that it adequately addresses the diverse needs of people of colour, thereby promoting equitable treatment and reducing disparities in mental healthcare provision. Indeed, recent reviews of the legislation (Wessely, 2018) and wider concerns about racialised anomalies under the psychiatric system (Fernando, 2017b) point to a burgeoning interest in making sure that future mental health law more equitably addresses the needs of people of colour. Arguably, a need to reform the Mental Health Act was accelerated by the bringing into force of the United Nations Convention on the Rights of Persons with Disabilities, which has also precipitated calls for abolition in some quarters (Wilson, 2021). Despite all of this, a putative new mental health bill was not consistently well-received (Harding, 2022) and was put aside in the run up to the last general election; parliamentary appetite for bringing forward reformed legislation appears to have been shelved for now.

Alignment with Public Health England's Strategic Plan (2020-2025)

Public Health England's Strategic Plan outlines objectives to improve mental health outcomes and reduce health inequalities, with a focus on marginalized communities. This research aligns with the plan's objectives by providing evidence-based insights into mental health disparities among people of colour. By informing targeted interventions and strategies to address these disparities, this study contributes to the overarching goal of improving mental health equity within people of colour.

Relevance to the Equality Act 2010

The Equality Act 2010 prohibits discrimination and promotes equality in various spheres, including healthcare. This research underscores the importance of equitable access to mental health services for people of colour, thereby aligning with the Act's objectives. By highlighting disparities and advocating for culturally competent care, this study contributes to efforts to ensure that mental healthcare services are accessible and inclusive for all individuals, regardless of race or ethnicity.

By integrating these policy considerations into the analysis, this research underscores its relevance to ongoing national initiatives aimed at addressing mental health disparities and promoting equity for people of colour. Through evidence-based insights and alignment with key policy frameworks, this study has the potential to inform targeted interventions and systemic changes conducive to improved mental health outcomes for people of colour.

Arguably, however, it is insufficient to simply align the implications of this research with extant policy programmes. The research also speaks to the need to argue or demand changes in policy directions, and these might better align with the objections and objectives of critical social movements, including those associated with mad studies and other allies. For example, disentangling mental health stigma and flawed anti-stigma campaigns from their enmeshment within a psy-complex that serves a neoliberal polity and corrodes race equality and other discriminated intersections (Parker, 2024), with all its attendant detriment for service users, survivors and refusers, would represent clearly novel policy demands congruent with a mad studies critique. In this vein, I would argue for policy to insist on a more nuanced understanding of stigma, including acknowledgement of the causation and exacerbations of stigma within and by services, and support for creative, community and activist led challenges to stigma, improved understandings of madness and mental health, and provision of better care and support, more appropriately suited to people’s needs and wishes. Of course, with sufficient activist energy and the support of allies, such initiatives can be expanded without formal policy support, but additional resources would be helpful. Practitioner workforce and education policies and practices could similarly be improved by an embrace of the mad studies inspired notion of unlearning, and this could be further cascaded across communities; also using creative approaches. The Plant Fetish performance and audience debates offer one such example of how to do this.

Opening up discussions about mental health can be enhanced through performance arts and offer an alternative challenge to stigma. Arguably performance art offers a means by which previously neglected or discriminated against communities can critically engage with a more complex and nuanced set of representations of mental distress. Furthermore, the impact of racial discrimination on mental health can inform anti-stigma campaigns to diminish barriers to care among individuals from minoritised communities. The utilisation of comedic and dramatic performance may encourage audiences to think more critically about matters such as stigma and its intersection with race, laying the foundations for more meaningful and informed conversations about mental distress and associated experiences within services and wider society.

Current anti-stigma campaigns tend to use approaches that attempt to normalise notions of mental illness, likening this to physical illness. The public, however, resists and rejects such simplifications. Recognising errors of the ‘illness like any other illness’ mantra, however, is not sufficient on its own. This recognition can lead to either stigma and discrimination or a more sophisticated engagement with understanding mental distress. A range of alternative perspectives and understandings is necessary to thoroughly tackle such stigma. The mad studies field, with its affinities for mixing survivor narrative, activism, and artistic expression, offers a scholarly standpoint for supporting this challenge.

The Plant Fetish show typifies how we might represent alternative ways to challenge stigma and discrimination and how these can relate differently within different groups in society. The writing, performance and theatre setting provided a space to enable the audience to engage safely with sensitive issues, individually via introspective reflection and collectively via audience discussion and the potential for ongoing conversation beyond the confines of the theatre. This confirms the previous theorising about the positive contribution that art and humour can bring to expressing and sharing thoughts, feelings and psychosocial understandings of health and wellbeing.

On the whole, anti-stigma campaigns are relatively silent on the intersection between race and mental health. Yet, the impact of racial discriminations on mental health is extensive, extending into service anomalies in access and outcome. Therapeutic relations may be complicated or disrupted by intricacies of difference and othering, transacted between staff and service users of different ethnic identities, or the delivery of care and support from within an undoubtedly ethnocentric service system. Indeed, such conjunctures may result in cumulative layers of stigma, with the stigmatised identity of madness adding to an already stigmatised racial identity. Knowledge of this can potentially inform anti-stigma campaigns, though there is little evidence that such ideas have been influential in the mainstream. Successful work in this regard could reduce barriers to care among individuals from ethnic minority communities and support practitioners within the mental health system to not intentionally or unintentionally disseminate racism in the process of collaborating with individuals from ethnic minority communities. More specifically, severe mental distress, such as that diagnosed as Complex PTSD, demands more sophisticated responses, for example, those informed by considerations of trauma.

Methodological Reflection

A strength that defined this PhD was the dynamic relationship between researcher and participant by establishing trustworthy relationships in a shorter period. Several participants brought up the subject of racial similarities during the interview. Due to their lack of likeness with White people, participants believed they would be less receptive to talking with them. Although minor cultural distinctions between myself as a Black African researcher and the participants were addressed at the outset of each interview, it was evident that some participants were comfortable discussing racial disparities when they were unfavourable. This may have resulted in people engaging in a more productive debate about pertinent problems. Toma (2000) agrees. "Closeness to the people and the phenomenon through intense interactions provides a subjective understanding that can significantly increase the quality of qualitative data (as cited in Marshall & Rossman, 2011, p. 101). However, developing a trusting relationship with participants quickly could have been challenging. Without an established relationship before the interview, it may have been difficult for the participants to be candid.

By examining narrative descriptions of participants' journeys to mainstream mental health services, capturing the complete spectrum of participants' sources of assistance was feasible, which is not possible when examining service referral data. Additionally, it allowed for a contextual examination of obstacles and facilitators, highlighting their interconnections. For example, facilitators might be viewed as being on a continuum with barriers (e.g. lack of information and knowledge/value of information and knowledge) or as coexisting with obstacles, enabling the latter to be overcome (e.g. reluctance to disclose/recognition of the need for help).

The research's limitations include expecting participants to recall and articulate clear paths into services with a specified beginning point. For example, several individuals could not recollect the first time they felt emotional discomfort, and for others, the beginning occurred years earlier, or there had been many bouts of mental health issues and help-seeking. As a result, it was sometimes impossible to recollect the precise sequence of help requested, including why judgments were taken and why help was sought at a specific moment. It is likely that people who have not received services face other hurdles or that the facilitators described here are unavailable. For instance, given the critical role of primary care physicians in recognising mental health problems and encouraging access to psychological services, those who do not access services may do so because their primary care physicians failed to recognise mental health problems or refer them to alternative services.

Inequalities do not operate on just one level of society or one dimension of identity. Usually, they occur on many intersecting axes, so injustice and unequal treatment overlap with factors such as poverty, gender, racism, and socioeconomic positioning. This overlap increases the impact on individuals and groups and makes it difficult to pinpoint the causes of differential patterns. Rather than issues of race, class, or gender, for example, treated as epiphenomena, occupying a role on the periphery of the central debate, intersectional realities mean that ‘classes are always gendered and racialised and gender is always classed and racialised…’ (Anthias 2010: 241). For example, ‘race’ cannot be disembodied from a systematic understanding of severe mental distress because it is firmly embedded within a maelstrom of intersectional dimensions.

Impact of the research

This research has significant potential to inform and shape policies specifically tailored to the mental health needs of people of colour in the UK. The unique experiences people of colour experience with the label of ‘schizophrenia,’ coupled with the insights gained from evaluating anti-stigma campaigns, provide a robust foundation for advocating for more equitable and effective mental health policies. One of the primary contributions of this research is its illumination of the health disparities and systemic inequities faced by people of colour living with schizophrenia. These findings can inform policymakers about the specific barriers to accessing mental health services that people of colour encounter, such as cultural stigma, discrimination, and a lack of culturally sensitive care. By highlighting these issues, this research can drive the development of targeted policies aimed at reducing health disparities and ensuring that people of colour receive equitable access to mental health services.

The evaluation of anti-stigma campaigns provides valuable evidence on the effectiveness of current strategies and highlights areas for improvement. This research can guide the development of more effective campaigns specifically tailored to people of colour. By addressing cultural stigmas and promoting mental health literacy within these groups, these campaigns can reduce the stigma associated with ‘schizophrenia’ and encourage individuals to seek help. Tailored messaging and community engagement are crucial for the success of these initiatives. This research underscores the need for increased resources and support for mental health services that cater specifically to people of colour.

Policymakers can use these findings to justify the allocation of additional funding and the development of targeted services. Enhanced funding can support the establishment of specialised mental health clinics, community outreach programs, and support groups that are culturally relevant and accessible to people of colour. The findings offer robust evidence of the unique challenges faced by BAME individuals living with ‘schizophrenia’ and the effectiveness of culturally tailored anti-stigma campaigns. These strategies could include community outreach and education programs designed to raise awareness about mental health issues and available services. The findings can also be utilized to advocate for legislative changes that address the specific mental health needs of people of colour. This might involve the introduction of new laws or amendments to existing legislation to ensure equitable treatment, enhance antidiscrimination measures, and provide greater support for people of colour. Legislative advocacy can lead to systemic changes that promote mental health equity and protect the rights of minoritised individuals in the UK.

Contributions to the field

In this thesis, I have made several original contributions to understanding mental health stigma and anti-stigma campaigns within communities of colour. By adopting a Mad Studies framework, I have challenged dominant narratives surrounding mental health and emphasized the importance of centring the experiences and voices of individuals with lived experience. This lens allowed me to amplify the agency and empowerment of people of colour in challenging stigma and advocating for change.

One of the critical contributions of this research lies in exploring the subjective experience of the effectiveness of anti-stigma campaigns in increasing help-seeking among people of colour. By delving into individuals' lived experiences and perspectives within these communities, I have offered unique insights primarily overlooked in existing research. Additionally, I have shed light on the underrepresentation of racially and ethnically diverse individuals in anti-stigma campaign measures and its potential impact on help-seeking behaviours and stigma endorsement within people of colour communities. This was the first research to explore this. This has opened up important questions about media representation and its role in shaping attitudes surrounding mental health. Moreover, I have extended the exploration beyond the commonly studied South Asian and African Caribbean populations to other communities of colour. This broader focus allowed for a more comprehensive understanding of the nuances of stigma and help-seeking experiences across diverse cultural contexts.

In navigating apparent paradoxes and addressing the impact of austerity, I have drawn upon critical commentators and integrated the Mad Studies framework to contextualize stigma within the broader socio-political landscape. This has led to a more comprehensive discussion on service provision and combating stigma within a neoliberal context. By incorporating qualitative methodologies, I have gone beyond quantitative measures to understand better the effects of stigma on individuals, their families, and mental health service utilization within people of colour communities. This has enriched the analysis and offered more profound insights into the impact of stigma on diverse populations. By investigating stigma using qualitative methods, we can better understand the consequences of stigma on mental health care utilisation and contemplate alternatives. Several significant policies and practice recommendations are made to reduce stigma and emphasise the relevance of culture. These include the following: anti-stigma campaigns must be culturally and linguistically appropriate and sensitive; mad people of colour should lead anti-stigma campaigns, and perhaps the best of these will be highly creative in form; such campaigns will sophisticatedly engage with movement politics and take account of cultural sensitivities, challenge racisms and Eurocentrism, and balance individual rights with collectivist concerns; they must also recognise that stigma is powerfully generated by and within mainstream services and there is an urgent need to imagine and enact alternatives. A situated, prefigurative politics associated with the aforementioned critical creativity is one means for supporting such imaginings of alternatives.

Rather than argue for a naïve and immediate dismantling of the whole of psychiatry, the thrust of my findings suggests both the scale of the dominance of the psychiatric system, impacting the preparedness of oppressed ethnic minority groups to be in the vanguard of change, and the potential for enacting change through alternative, creative means of consciousness-raising on the first instance. This chimes in with the mad studies goal of unlearning what has gone before. If I was to strike an abolitionist pose, I look forward to the day when sufficient change has occurred that psychiatry as we know it would not make sense to a public versed in alternative modes of thinking and practice and that this happy state of affairs is conducted with fair access and outcomes across intersections of difference.

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Appendix list

Appendix A – Interview probes

Questions covered

1. Can you tell me briefly about yourself? In particular, your first time in experiencing symptoms of schizophrenia.
2. When did you first seek help for your symptoms?
3. Was your experience seeking help for your symptoms positive or negative?
- Probe: Why
- Probe: Stigmatised? If Yes: Why? If No: Why? What do you think of stigma?

4. How was the quality of mental health services when you accessed help?
    - Healthcare professionals attitude?

5. Did you receive support from family and/or friends? - Probe: Who?
- Probe: How did they feel about it?
- Experienced stigma from family?

6. Social stigma
- Does your family treat you differently?
- Probe : If Yes: why? Probe: If No: why
- Do your friends treat you differently? Probe: If Yes: why If no: why - Probe: Do you work?
- If yes: are your work colleagues aware of your diagnosis? If yes: Do, they treat you differently? If no: why?

Phase 2

Questions covered:

1. Can you tell me briefly about yourself? In particular, when you first found out about your relative's diagnosis of schizophrenia.
2. Did you know about schizophrenia before their diagnosis?
3. Have you experienced the use of mental health services with your relative?
- Probe: Can you describe your experience

. What do you think of stigma?

. Have you experienced emotional, social, or interpersonal consequences?
- If yes: what? If No: why do think that?

Phase 3

Questions covered:

1. What do you think of current anti-stigma campaigns for mental health?
2. What do you think of anti-stigma campaigns for schizophrenia?
3. Are current anti-stigma campaigns working for individuals from BAME backgrounds?
    - If yes: how? If no: why?
4. Are there any suggestions for anti-stigma campaigns for individuals from BAME background with schizophrenia?

5. How can we decrease stereotypes/discrimination for individuals with schizophrenia?

Appendix B – Information sheets for studies 1, 2 and 3

Study 1 - Information sheet

Exploring help-seeking experiences in individuals diagnosed with schizophrenia

Overview

My name is Salma Qasim, and I am conducting research for the purposes of obtaining a PhD at the University of Central Lancashire. Before you decide to take part, it is essential you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please ask. Take the time to decide whether or not you want to take part.

What is the purpose of the study?

The purpose of the study is to explore the experience of persons diagnosed with schizophrenia seeking help when first experiencing symptoms of schizophrenia. I am interested in your views on this topic and would value your input.

Why have I been invited to participate?

We are inviting individuals from a BAME group who have a diagnosis of schizophrenia and have sought support for treatment.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be able to keep a copy of this information sheet, and you should indicate your agreement on the consent form. You can still withdraw at any time. You do not have to give a reason.

During the interview, you do not have to have to answer any questions and can stop the interview at any point.

What will happen to me if I take part?

Participating in this research will involve a Microsoft Teams interview by myself which will consist of open-ended questions that focus on your first-time seeking support. With your permission the interview will be tape recorded. I will lead the interview by asking you a set of questions where you are free to answer. You can expect the interview to be approximately 45 minutes to an hour. The interviews will be arranged at a convenient time and place. The questions will be open-ended, and there are no right or wrong answers.

If you are happy to take part and are satisfied with the explanations from the research team, you will be asked to confirm you agree to take part in the study (a consent form).

What are the possible benefits of taking part?

While there are no immediate benefits for those people participating in the research, it is hoped that this work will have a beneficial impact on exploring the experiences of members of BAME communities diagnosed with schizophrenia and how these experiences impacted on seeking help and support.

What are the possible risks of taking part?

Participating in the research is not anticipated to cause you any harm or discomfort. It is possible that you will feel negative emotions during the interview or afterwards. During the interview, please tell the researcher if you feel distressed, take a break, and focus on your well-being and don’t be afraid to discontinue altogether if you find going on too difficult. The researcher will be able to tell you about sources of support.

Will what I say in this study be kept confidential?

Any data you provide will be treated under the UK Data Protection Act 2018. The interviews will be recorded, and you will be able to review the transcripts. However, you will not be identified in the recordings. The data will be held confidentially, and only the staff working on the project will have access to the data. The data generated in the course of the research will be kept securely in an electronic format for 5 years from the end of the project.

What should I do if I want to take part?

If you are interested in participating in the interview fill out the consent form and return it back via email or if you have any questions, please contact the researcher Salma Qasim (Phone number: 07864894240, Email: SMQasim@uclan.ac.uk) for further information and to ask any questions you might have.

What will happen to the results of the research study?

The results of this research will form part of a PhD research programme. We also plan to present the results in conferences and publications. These publications and presentations will not identify any participants. If you would like, we can send you a copy of the final report. You will have to indicate your interest on the consent form.

Who is organising and funding the research?

This research is conducted as part of a student PhD research within the School of Nursing at the University of Central Lancashire.

Who has reviewed the study?

The research has been approved by the University Research Ethics Committee. If you have any concerns about how the study has been conducted, you should contact the University Officer for Ethics (Email: OfficerforEthics@uclan.ac.uk).

Contact for further information

Name	Position	Email
Salma Qasim	Student researcher	SMQasim@uclan.ac.uk
Mick Mckeown	Professor	MMckeown@uclan.ac.uk
Roxanne Khan	Senior Lecturer	RKhan2@uclan.ac.uk
John Wainwright	Senior Lecturer	JPWainwright@uclan.ac.uk

If you have any questions, you can contact the researcher directly. You can also contact the supervisory team for this project:

Thank you for taking the time to read this information sheet

Study 2 – Information sheet

Exploring the views of help-seeking in family members of individuals diagnosed with schizophrenia

Overview

My name is Salma Qasim, and I am conducting research for the purposes of obtaining a PhD at the University of Central Lancashire. Before you decide to take part, it is essential you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please ask. Take the time to decide whether or not you want to take part.

What is the purpose of the study?

The purpose of the study is to explore and discuss experiences of relatives of individuals living with schizophrenia through an individual interview. Relatives of individuals living with schizophrenia are vital factor in supporting the process of seeking treatment. We invite you to share your unique experiences and contribute to the knowledge around schizophrenia and how your experiences affect the lives of Black and minority ethnic people living with schizophrenia within the healthcare setting.

Why have I been invited to participate?

We are inviting individuals from a BAME group who have a relative with schizophrenia.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be able to keep a copy of this information sheet, and you should indicate your agreement on the consent form. You can still withdraw at any time. You do not have to give a reason.

During the interview, you do not have to have to answer any questions and can leave the interview at any point.

What will happen to me if I take part?

Participating in this research will involve a 45 minutes to 1 hour interview on Microsoft Teams by myself which will consist of open-ended questions that focus on your views when your family member was first diagnosed with schizophrenia. With your permission the interview will be tape recorded. I will lead the interview by asking you a set of questions where you are free to answer. You can expect the interview to be approximately 45 minutes to an hour. The interviews will be arranged at a convenient time and place. The questions will be open-ended, and there are no right or wrong answers.

If you are happy to take part and are satisfied with the explanations from the research team, you will be asked to confirm you agree to take part in the study (a consent form).

What are the possible benefits of taking part?

While there are no immediate benefits for those people participating in the research, it is hoped that this work will have a beneficial impact on finding out the extent to which members of BAME communities who are related to individuals with schizophrenia experience stigma in the healthcare setting and how this impacts their medical care.

What are the possible risks of taking part?

Participating in the research is not anticipated to cause you any harm or discomfort. It is possible that you will feel negative emotions during the interview or afterwards. During the interview, please tell the researcher if you feel distressed, want to take a break, and focus on your well-being and do not be afraid to discontinue altogether if you find going on too difficult. The researcher will be able to tell you about sources of support.

Will what I say in this study be kept confidential?

Any data you provide will be treated under the UK Data Protection Act 2018. The interviews will be recorded, and you will be able to review the transcripts. However, you will not be identified in the recordings. The data will be held confidentially, and only the staff working on the project will have access to the data. The data generated in the course of the research will be kept securely in an electronic format for 5 years from the end of the project.

What should I do if I want to take part?

If you are interested in participating in the interview fill out the consent form and return it back via email or if you have any questions, please contact the researcher Salma Qasim (Phone number: 07864894240, Email: SMQasim@uclan.ac.uk) for further information and to ask any questions you might have.

What will happen to the results of the research study?

The results of this research will form part of a PhD research programme. We also plan to present the results in conferences and publications. These publications and presentations will not identify any participants. If you would like, we can send you a copy of the final report. You will have to indicate your interest on the consent form.

Who is organising and funding the research?

This research is conducted as part of a student PhD research within the School of Nursing at the University of Central Lancashire.

Who has reviewed the study?

Name	**Position**	**Email**
Salma Qasim	Student researcher	SMQasim@uclan.ac.uk
Mick Mckeown	Professor	MMckeown@uclan.ac.uk
Roxanne Khan	Senior Lecturer	RKhan2@uclan.ac.uk
John Wainwright	Senior Lecturer	JPWainwright@uclan.ac.uk

The research has been approved by the University Research Ethics Committee at the University of Central Lancashire. If you have any concerns about how the study has been conducted, you should contact the University. Officer for Ethics (Email: OfficerforEthics@uclan.ac.uk).

Contact for further information

If you have any questions, you can contact the researcher directly. You can also contact the supervisory team for this project:

Thank you for taking the time to read this information sheet

Study 3 – Information sheet

Anti-stigma campaigns for people living with schizophrenia

Overview

You are being invited to take part in a PhD research study. Before you decide to do so, it is essential you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please ask. Take the time to decide whether or not you want to take part.

What is the purpose of the study?

The purpose of the study is to explore and discuss how current mental health stigma campaigns is helping individuals with schizophrenia seek treatment or continue with their treatment. Your experiences will help us identify any changes that need to be made to help inform future mental health campaigns to support people when they want to seek help. You will be asked to discuss various issues relating to anti-stigma campaigns and how it helps individuals ask for help.

Why have I been invited to participate?

We are inviting individuals from a Black and minority ethnic group diagnosed with schizophrenia to take part in our study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be able to keep a copy of this information sheet, and you should indicate your agreement on the consent form. You can still withdraw at any time. You do not have to give a reason.

During the focus group, you do not have to have to answer any questions and can leave the focus group at any point.

What will happen to me if I take part?

If you are happy to take part and are satisfied with the explanations from the research team, you will be asked to confirm you agree to take part in the study (a consent form).

The interview will be arranged at a convenient time for the people involved. The questions will be open-ended, and there are no right or wrong answers in a discussion of this kind – we are only interested in your opinions.

What are the possible benefits of taking part?

While there are no immediate benefits for those people participating in the research, it is hoped that this work will have a beneficial impact on how we understand how stigma campaigns are viewed by the individuals.

What are the possible risks of taking part?

Participating in the research is not anticipated to cause you any disadvantages or discomfort.

Will what I say in this study be kept confidential?

Any data you provide will be treated under the UK Data Protection Act 2018. The focus groups will be recorded and transcribed.

The data generated in the course of the research will be kept securely in an electronic format for 5 years from the end of the project.

What should I do if I want to take part?

If you are interested in participating in the focus group or if you have any questions, please contact the researcher Salma Qasim (Phone number: 07864894240, Email: SMQasim@uclan.ac.uk) for further information and to ask any questions you might have.

What will happen to the results of the research study?

The results of this research will form part of a PhD research programme. We also plan to present the results in conferences and publications. These publications and presentations will not identify any participants. If you would like, we can send you a copy of the final report. You will have to indicate your interest on the consent form.

Who is organising and funding the research?

This research is conducted as part of a student PhD research within the School of Nursing at the University of Central Lancashire.

Who has reviewed the study?

The research has been approved by the University Research Ethics Committee. If you have any concerns about how the study has been conducted, you should contact the University Officer for Ethics (Email: OfficerforEthics@uclan.ac.uk).
Contact for further information
If you have any questions, you can contact the researcher directly. You can also contact the supervisory team for this project:

Thank you for taking the time to read this information sheet

Name	**Position**	**Email**
Salma Qasim	Student researcher	SMQasim@uclan.ac.uk
Mick Mckeown	Professor	MMckeown@uclan.ac.uk
Roxanne Khan	Senior Lecturer	RKhan2@uclan.ac.uk
John Wainwright	Senior Lecturer	JPWainwright@uclan.ac.uk

Appendix C – Consent forms for studies 1, 2 and 3

Study 1 - Consent form

CONSENT FORM

Exploring help-seeking experiences in individuals diagnosed with schizophrenia

Please read the following statements and initial the boxes to indicate your agreement

	Please initial box
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.	☐
I agree to take part in the above study.	☐
I agree that my data gathered in this study may be stored (after it has been anonymised) in a specialist data centre and may be used for future research.	☐
I understand that it will not be possible to withdraw my data from the study after final analysis has been undertaken (30 June 2021).	☐
I understand that the interview will be audio-recorded	☐

I agree to the use of anonymised quotes in publications ☐

Name of Participant Click or tap here to enter text.

Date Click or tap here to enter text.

Signature Click or tap here to enter text.

Name of Researcher Click or tap here to enter text.

Date Click or tap here to enter text.

Signature Click or tap here to enter text.

Study 2 – Consent form

CONSENT FORM

Exploring the views of help-seeking in family members of individuals diagnosed with schizophrenia

Please read the following statements and initial the boxes to indicate your agreement

	Please initial box
I confirm that I have read and understand the information sheet for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.	☐
I agree to take part in the above study.	☐
I agree that my data gathered in this study may be stored (after it has been anonymised) in a specialist data centre and may be used for future research.	☐
I understand that it will not be possible to withdraw my data from the study after final analysis has been undertaken on 30th June 2021.	☐

I understand that the interview will be recorded. ☐

I agree to the use of anonymised quotes in publications. ☐

Name of Participant	Click or tap here to enter text.
Date	Click or tap here to enter text.
Signature	Click or tap here to enter text.

Name of Researcher	Click or tap here to enter text.
Date	Click or tap here to enter text.
Signature	Click or tap here to enter text.

Study 3 – Consent form

CONSENT FORM

Anti-stigma campaigns experiences in individuals with schizophrenia

Please read the following statements and initial the boxes to indicate your agreement

Please initial box

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

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

I agree to take part in the above study. ☐

I agree that my data gathered in this study may be stored (after it has been anonymised) in a specialist data centre and may be used for future research. ☐

I understand that it will not be possible to withdraw my data from the study after final analysis has been undertaken ☐

I understand that the interview will be audio-recorded ☐

I agree to the use of anonymised quotes in publications ☐

Name of Participant Click or tap here to enter text.

Date Click or tap here to enter text.

Signature Click or tap here to enter text.

Name of Researcher Click or tap here to enter text.

Date Click or tap here to enter text.
Signature Click or tap here to enter text.

Appendix D – Debrief sheet

Participant Debrief Sheet

Thank you for participating in the research study of help-seeking experiences in individuals with schizophrenia from a BAME background. We hope you have found it interesting and have not been upset by any of the topics discussed. Feedback from the research will be available four months after 30 June 2021.

However, if you have found any part of this experience distressing and you wish to speak to someone, contact the student researcher Salma Qasim on SMQasim@uclan.ac.uk. If you are feeling distressed and cannot contact a person associated with this study, there are also several organisations listed below that you can contact.

Organisations

Samaritans (24-hour helpline)

Call: 116 123

Email: jo@samaritans

bsite: https://www.samaritans.org/how-we-canhelp/contact-samaritan/

NHS 111 (24 hours)

Call: 111

Website: 111.nhs.uk

Mind

Call: 0300 123 3393 (9am to 7pm, Mon-Fri)

Email: info@mind.org.uk

Website: https://www.mind.org.uk/informationsupport/helplines/

SANE

Call: 0300 304 7000 (4.30pm – 10:30pm daily)

Website: http://www.sane.org.uk/what_we_do/support/

Withdrawing from study

If you would like to withdraw your data, you may do so until 30 June 2021. You will only have to email Salma Qasim at SMQasim@UCLan.ac.uk and state that you would like to withdraw (you do not have to give a reason why). Thank you again for your participation