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Motherhood and Serious Mental Illness: a qualitative study of stigma, 'risk' and access to perinatal mental healthcare

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Abstract

The experiences of motherhood and mental illness are complex, especially for women with a history of serious mental illness (SMI). Health services provide support to women contemplating motherhood, during pregnancy and beyond, but delays in receiving care can have serious consequences for women and families. Research indicates socioeconomic and ethnic inequalities exist in relation to accessing perinatal mental healthcare and some have suggested stigma plays a significant role. Risk is a major concern of health professionals who care for women with SMI and literature on marginalised pregnancy suggests risk and stigma are closely linked. This thesis uses sociological perspectives on stigma, access, and risk to explore the reproductive-related experiences of women with SMI and their interactions with healthcare. Drawing from the experiences of 20 women with a (self-identified) history of SMI and 14 health professionals, the thesis contributes a critical understanding of how SMI affects women's reproductive lives & care and is positioned at the intersection of the sociology of health and illness and health services research.

The findings demonstrate that SMI has a significant influence on women's reproductive experiences including decisions about having children, of pregnancy and motherhood. Applying sociological lenses to the experiences of both participant groups reveals some of the institutional and structural forces that influence women's experiences of stigma, access to care and how risk is conceptualised and responded to in relation to maternal mental health. The connecting of personal experiences to broader socio-political contexts is the value of sociological inquiry. The findings of this research complements the current literature on perinatal mental health by focusing on forces influencing women's experiences and care beyond the level of the individual, providing a richer understanding of key issues in relation to maternal mental health and healthcare.

Key words: women's health, mental health, reproduction, stigma, access to mental healthcare, perinatal mental health, risk

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Glossary of Key Terms

As the thesis is intended to be interdisciplinary, I have included a glossary of key terms relevant to the study to aid the understanding of readers from different disciplinary or practice-based backgrounds. This glossary includes definitions of key mental health and healthcare related terms used frequently within the thesis.

Key Term	Definition
Mental health conditions and related terms	
Bipolar Disorder	A mental health condition characterised by significant changes in mood. These may be high moods (mania/hypomania) or low moods (depression). (NHS England, 2024c)
Complex Post Traumatic Stress Disorder (C-PTSD)	A mental health condition caused by recurring or long term traumatic events. Symptoms are similar to PTSD but may also include emotional dysregulation and relationship difficulties (NHS England, 2022a)
Obsessive Compulsive Disorder (OCD)	A mental health condition characterised by obsessive thoughts and/or compulsive behaviours, which during pregnancy/after birth may be related to the baby or women's caregiving practices (NHS England, 2023a)
Perinatal mental health/illness/condition	Mental health problems which occur during pregnancy or in the first year following the birth of a child (NHS England, 2024a)
Postnatal/antenatal depression	Depression that occurs during pregnancy or following the birth of a child. It can vary in severity and is thought to be the most common perinatal mental health condition (NHS England, 2022b)
Postpartum psychosis	A serious mental illness which can affect women after their baby is born. Symptoms can include hallucinations, delusions, mania, low mood, confusion. It is considered a medical emergency (NHS England, 2023b)
Post Traumatic Stress Disorder (PTSD)	A mental health condition caused by experiencing stressful, frightening or distressing events and characterised by symptoms such as nightmares, flashbacks, insomnia and feelings of isolation, irritability and guilt (NHS England, 2022c)
Schizophrenia	A mental health condition characterised by difficulties distinguishing between ones own thoughts/ideas and reality. Symptoms can include hallucinations, delusions, cognitive impairment, loss of interest in daily activities, personal neglect, social withdrawal and emotional difficulties (NHS England, 2023c)
Serious/Severe Mental Illness (SMI)	Debilitating psychological conditions which seriously impair someone's ability to engage in functional or occupational activities. (Public Health England, 2018)

Healthcare-related terms	
Mother and Baby Unit (MBU)	Specialist in-patient units for women who are acutely unwell with mental health problems, who are in the late stages of pregnancy or within the first year after birth. They are designed to keep mothers and babies together and staff on the ward will treat the mother's illness and promote and nurture the mother-infant bond (Royal College of Psychiatrists, 2018a)
Secondary Mental Healthcare Services	Services which provide mental healthcare that can only be accessed following referral from another healthcare professional (e.g.,a GP). It includes services in hospital settings as well as community settings (such as community mental health teams, crisis teams and home treatment teams) (Mind, 2023)
Sectioning or "sectioned under the Mental Health Act"	Where someone is detained in hospital for treatment for their mental health involuntarily, as there is a concern about the risk they may pose to themselves or others. (Mind, 2020)
Specialist Health Visitors	Health Visitors are registered nurses or midwives who have completed additional training to become community public health nurses. Specialist health visitors in perinatal and infant mental health have completed further training to deliver high quality care and play a key role in delivering and improving perinatal mental healthcare (Maternal Mental Health Alliance, 2025)
Specialist Midwives	Expert midwives who lead work with other midwives, clinicians, maternity service commissioners and providers to ensure women with mental health needs perinatally receive the care and support they need (Royal College of Midwives, 2018)
Specialist Perinatal Mental Healthcare services	Specialist care for women with (complex-serious) mental health problems who are planning a pregnancy, are pregnant or have had a baby within the last 12-24 months (depending on area). It is often provided by multidisciplinary teams including psychiatrists, clinical psychologists, nurses, occupational therapists and peer support workers (NHS England, 2019)

Chapter 1: Introduction

Across the life course, women experience a high burden of mental disorders, particularly in their reproductive years (GBD, 2019; Mental Disorders Collaborators, 2022). Globally, it is estimated that around 1 in 5 women will experience mental health problems during pregnancy or postnatally (Public Health England, 2019; Maternal Mental Health Alliance, 2023a; WHO, 2024). In the UK, in England specifically, it has been estimated that around 17,000 women a year experience the most serious forms of illness or distress perinatally (Public Health England, 2017).

The consequences for women who experience serious mental illness (SMI)[1] during the perinatal period[2] and do not access[3] healthcare can be catastrophic. In the UK, mental health related causes account for nearly 40% of maternal deaths occurring between six weeks and 12 months postpartum (MBRRACE, 2023). Suicide is the leading cause of death in this period and in the last few years rates have been rising (MBRRACE, 2023). Maternal mental illness, if unsupported or untreated, has the potential to affect the broader health and wellbeing of women and families acutely, across the life course and intergenerationally. In the UK, public services, particularly the NHS, provide care and support to women with histories of SMI who are contemplating motherhood, who are pregnant or who are already mothers. Often this support is provided via specialist perinatal mental healthcare services.

Perinatal Mental Healthcare in UK

The UK is often referred to as a world leader in perinatal mental healthcare (Royal College of Midwives, 2018). Despite this international reputation, the provision of services in the UK has historically been patchy, although over the last decade this has been changing (Maternal Mental Health Alliance, 2023b). In partnership with clinicians, women with lived experience of perinatal mental illness have played a significant role in lobbying the government and policymakers, which led to increased investment in services (Creed and Marland, 2023). In 2016, the UK Government announced a £290m investment in to perinatal mental healthcare (Prime Minister's Office, 2016). NHS England subsequently set out a commitment that by 2023/24 at least 66,000 women with moderate, complex and severe perinatal mental health difficulties would be able to access care and support in the community (NHS England, 2024a). Care would be available to women in the preconception period (time before pregnancy) and for up to 2 years postpartum, with increased availability of psychological therapies (NHS England, 2019).

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[1] SMI can briefly be defined as a group of psychological conditions which seriously impair a person's ability to engage in everyday activities (Public Health England, 2018). A more substantive definition and critical discussion of this term appears later in the thesis.

[2] Colloquially, 'perinatal' simply refers to time before and after birth. In the context of perinatal mental healthcare in the UK, the 'perinatal period' can briefly be defined as the time between conception and up to 12 months after birth (NHS England, 2024a). A more expansive definition of this term that will be used throughout the thesis will be given later in this chapter.

[3] Access to healthcare is a complex concept but one that can briefly be defined as the use of "appropriate health care resources in order to preserve or improve [… ill] health" (Guilliford *et al.,* 2002). This concept will be discussed in more detail in later chapters.

There has also been an increase in capacity of in-patient care, specifically, mother and baby units (MBUs). The most recently reported data indicates there are 19 MBUs in England housing 151 beds (Maternal Mental Health Alliance, 2023c). There are plans for another unit opening in 2024, located in the North West of England, which will also provide provision to patients living in North Wales (Cheshire & Wirral Partnership NHS Foundation Trust, 2023). These highly specialised facilities accommodate women who are acutely unwell with the most serious forms of perinatal mental illness. Women are also co-admitted with their babies. MBUs are described as best practice sites of care for women (Griffiths *et al.,* 2019), and as 'calm welcoming places that are more homely than other [psychiatric] wards' (Royal College of Psychiatrists, 2018a).

The key function, or purpose, of perinatal mental healthcare is framed as preventing as well as detecting, treating and managing perinatal mental health problems (NCCMH, 2018). The NHS Perinatal Mental Healthcare pathway (NCCMH, 2018, included as Appendix 1) includes preconception advice for women with histories of SMI, specialist and emergency assessment, psychological interventions and admissions to in-patient care. Whilst there has been increased investment into perinatal mental healthcare over the last decade, there continues to be funding pressures on services (Maternal Mental Health Alliance, 2023b). Perinatal mental healthcare services interface with many more parts of the health and social care system compared with other psychiatric specialities (Humphreys *et al.,* 2016) making it a highly complex area of practice. Whilst perinatal mental healthcare in the UK has received significant investments and provision is expanding year on year, it sits within a broader health and social care system which is under great pressure. In the NHS this includes long waiting lists, estates-related issues and workforce challenges (Wickens & Brown, 2023). Midwifery and Health Visiting are key professions which interface with perinatal mental healthcare. Midwives and health visitors often play an important role in identifying women's distress and referring them on to specialist services and are greatly affected by workforce challenges (Royal College of Midwives, 2024; Institute of Health Visiting, 2022).

Outside of public services, there is also a country-wide infrastructure of community and voluntary sector (CVS) organisations which support women and families perinatally in connection to mental health (Maternal Mental Health Alliance, 2023a). Whilst there is a rich charitable ecosystem in relation to perinatal mental health, the wider economic environment in the UK has put considerable strain on many organisations in this sector (Ferrell-Schweppenstedde, 2023); (Maternal Mental Health Alliance, 2023b).The multifaceted systems of care in relation to perinatal mental health and the broader economic contexts in which public services and community and voluntary sector organisations are operating in the UK make understanding and improving this area of health and healthcare delivery uniquely challenging.

Within the context of perinatal mental health research, historically, common mental disorders (conditions such as mild to moderate anxiety and depression) have received more attention than SMI. Leaders of the perinatal mental health research field have highlighted the need for research that seeks to understand the needs of women with a greater range of diagnoses and is cognisant of the social determinants of mental health (Howard and Khalifeh, 2020) and how these interact with healthcare. Others have quantitatively illustrated inequalities in access to perinatal mental healthcare for women from specific minoritised ethnic groups and women living in circumstances of deprivation (Redshaw and Henderson, 2016; Jankovic *et al*., 2020; Langan Martin *et al*., 2016). These authors have suggested further research is needed to understand *why*; a question qualitative research is well-poised to answer. This thesis seeks to address these gaps in the research and apply sociological lenses to

understanding the experiences of women with histories of SMI and the professionals who care for them.

The value of a sociological lens

To make sense of 'the social' (determinants, inequity and stratification) in relation to perinatal SMI, it is useful to draw on different understandings of mental health, healthcare, pregnancy, mothering and other relevant concepts. As a starting point, sociological work on reproduction and motherhood is applicable here. Despite the prevalence of women who experience mental illness or distress, particularly perinatally, some scholars have argued that mental illness is not widely seen as part of the 'ideal' of motherhood in the Global North (Davies and Allen, 2007). This may be because aspects of the perinatal illness experience (for example, suicidal and infanticidal ideation) are socially confronting in the way they challenge and complicate normative ideas about the maternal (Creed, 2024). As I discuss further in Chapter 2, there are many social norms that govern the experience of motherhood that sociology has drawn attention to. For example, the belief that 'good' mothers provide emotional stability (Lawler, 2002) and always put their children's needs first, above their own (Chambers and Gracia, 2022). Another concept from the social sciences which may help us understand inequity in relation to perinatal SMI is stratified reproduction. Arising specifically from *feminist* social science, it sees the ability to make choices about reproduction and motherhood and the resources which can enable families to thrive as strongly influenced by social positioning (Ginsburg and Rapp, 1995). This concept foregrounds the institutional and structural forces which influence inequity in relation to mothering and reproduction.

As highlighted above, there is evidence of inequalities in access to mental healthcare perinatally. Stigma[4], a profoundly social process, is often posited as a reason behind these inequalities: The implication being that women won't seek help or are reticent to because they are ashamed to admit they're not well, or not 'coping' and fear being labelled as a 'bad' mum (Humphreys *et al.*, 2016; Darwin *et al.,* 2022; Tripathy, 2020). Self-stigmatisation is just one manifestation of stigma. Sociology draws our attention to its other forms.

Sociological work on marginalised pregnancy has illustrated that ideas about risk[5] and stigma are inextricably linked and in turn influence engagement with healthcare, particularly maternity care (Stengel, 2014; Wigginton & Lee, 2013). Risk features heavily in discourse relating to pregnancy (Lupton, 1999; Wigginton & Lee, 2013). These discourses circulate in maternity care, pregnancy/parenting advice and in traditional and social media. Advocates for women's reproductive rights have argued that these discourses are often confusing, overwhelming and disempowering for women (Blaylock *et al.,* 2022). Risk is also a major professional concern for those responsible for the care of individuals with mental illness (Royal College of Psychiatrists, 2024). This indicates that women with histories of SMI are potentially subject to risk discourses from both maternity and mental healthcare sources. Paying more attention to risk and stigma which, as illustrated in chapters 2 and 3, are 'taken

[4] Stigma is a complex concept but one that can briefly be defined as a social force which has scapegoated, oppressed and shamed individuals and communities with particular characteristics, characteristics that are 'socially undesirable' (Tyler, 2020). This concept will be discussed in more detail in later chapters.

[5] In sociological terms, 'risk' is a complex concept, but can briefly be defined as the possibility of negative outcomes (Fischhoff & Kadvany, 2011). In this context, it is referring to the possibility of negative health-related outcomes for women or children. This concept will be discussed in more detail in later chapters.

for granted' concepts in relation to maternal mental health may help shed light on the complexities of access to care for women with histories of SMI.

The concepts of stigma, risk and access to care are structuring forces within this thesis. They feature in the study's research questions and three of the four findings chapters are presented according to these three sociologically-informed concepts. As will be illustrated in greater detail in chapters 2 and 3, these are areas where an appreciation of wider social and structural influences can lend insight into the experiences of women affected by perinatal SMI and the practitioners who care for them.

The study

Ultimately, this work is concerned with understanding the reproductive-related experiences of women who have a history of serious mental illness (SMI). By grounding the study in a sociological tradition, it also seeks to situate and analyse the experiences of the participants in the context of institutional and structural influences.

More specifically, the study aims to bring sociological insights in to dialogue with personal accounts of experiencing and treating women's mental health in order to:

- Understand how stigma operates in women's lives at the intersection of their mental health and reproductive-related experiences;
- Investigate barriers and facilitators to the receipt of perinatal mental healthcare for women;
- Provide a nuanced account of how women and health and care professionals construct and experience 'risk' in relation to maternal mental illness.

Across these three areas I aim to ensure that missing voices, those experiencing inequalities in access (women from minoritised ethnic groups and women living in circumstances of deprivation), are accounted for within this thesis and ultimately added to the perinatal mental health literature .

In service of addressing these overarching aims, this thesis seeks to answer the following research questions:

- To what extent and in what ways does a personal or family history of severe mental illness influence women's reproductive related experiences and experiences of stigma?
- What individual, institutional or systemic factors cause inequalities in access to perinatal mental healthcare and how could these be addressed?
- What can be learned by comparing professional and women's concepts of risk in relation to maternal mental health and healthcare?
- What are the implications for women if they are identified as being at high risk of developing severe perinatal mental illness by healthcare professionals and how does class and ethnic identity shape these processes?

The thesis draws on the experiences of 20 women with a history of SMI and 14 health professionals who work with women with histories of SMI. In-depth interviews, focus groups and paired interviews were conducted with participants who live and work across England. I applied sociologically-grounded lenses to participants' experiences to shed new light on the problem of inequality and 'the social' in relation to perinatal mental health and healthcare.

Personal interests in this area of research

My interest in this area of women's health has arisen from several places: personal, professional and academic.

My interest in women's health grew from both my academic interests and from my political interests as an intersectional feminist. This interest led me to volunteer with a group of feminist activists working to improve healthcare for women who had experienced sexual violence. Through this work I encountered women who wanted children, but for whom that decision had now become more complicated. They held fears about the impact of pregnancy and the postpartum on their mental health and well-being. These women often travelled long distances to attend a specialist clinic to discuss their concerns with professionals. This led me to think about the intersection between women's mental and reproductive health: about the often unspoken experiences that exist at this juncture and specifically, *why* these silences exist. As time went on, I thought more about the factors that meant some women could access this highly specialised form of care and not others. Related to the latter point, my interest in health and inequality has grown very much from my lived experiences: growing up where I did, having lived where I have lived, having worked where I've worked. I grew up in a working class family, in the North, in an area of the country impacted by deindustrialisation. Benefitting in many ways from New Labour policies of increasing access to further and higher education, I have spent most of my adult life living, studying and working in the South East of England often alongside those with different backgrounds to my own. These experiences have afforded me opportunities to develop (both academic and experiential) understandings of how structural (dis)advantage operates - in overt and covert ways.

I have had a longstanding academic interest in mental health and illness, which has likely stemmed from a familial, but not a personal, history of SMI. I have been fortunate enough to have explored mental health academically from several different disciplinary perspectives, including through more positivist-orientated disciplines (neuroscience and cognitive psychology) during my undergraduate degree. Exploring mental health from these disciplinary perspectives left me with more questions than answers, particularly with regards to thinking about inequity, social context and social relations. Now, through this research, I seek to explore mental health sociologically because the discipline has many valuable "tools" and lenses through which to explore and understand inequality further.

All of these interests intertwined to inform my decision to undertake research in relation to women's mental health. In late 2020, I applied for a studentship jointly funded by NIHR School for Public Health Research (SPHR) & NIHR Yorkshire & Humber Applied Research Collaborative (ARC). The call welcomed proposals in the broad area of maternal mental health inequalities and discrimination. I submitted a research proposal for a mixed methods study investigating postpartum psychosis risk and social gradients in access to perinatal mental healthcare. Once I started the studentship in 2021, the research plans evolved significantly, as illustrated above. Decisions about what precisely required further investigation was informed by a review of the literature, availability and feasibility of access to secondary quantitative data, as well as through engagement with professionals working in the area of perinatal mental healthcare and women with lived experience of perinatal mental illness.

Initial clarification of key terminology

Whilst the glossary of key medical and healthcare terms provided in the opening pages of the thesis sets out several general definitions of key terms and concepts, it is important to provide some further introductory discussion of key and contested concepts central to the study. These are SMI, perinatal, women and reproductive-related experiences. Later chapters in this thesis then build on these introductory discussions. It is important to do this at the earliest opportunity in order to orient the reader.

The language used to describe mental health and illness is important but also highly contested. In this work the phrases severe/serious mental illness/difficulties/conditions are used interchangeably and will be abbreviated by the acronym SMI. Within this thesis, SMI is defined as disorder or distress which results in "serious functional impairment, which substantially interferes with or limits one or more major life activities" (NIH, 2023). SMI was chosen as an organising category because, despite its imperfections and argued lack of specificity (which is discussed in more detail in Chapter 2), it is a widely recognised term in policy and practice, and it has resonance with important actors in this area of health, including women with lived experience.

The definition of the term perinatal I am using is inclusive of the "preconception" period, pregnancy and up to two years postpartum. I am including the preconception period, or as it has been sociologically described, 'zero trimester' (Waggoner, 2017) because preconception care is an important part of the NHS Perinatal Mental Healthcare Pathway (included as appendix 1), and NHS England now aspires for perinatal mental healthcare to be provided for women for up to two years postpartum (NHS England, 2019)

Parenting, mothering and motherhood are bound up within complex ideas of gender and care (Hines and Taylor, 2018). This study is focussed on the experiences of women who were assigned female at birth. With this in mind, it is important to state that this research is not purposely trans-exclusionary. Other researchers are better placed to investigate parenthood and its intersection with SMI through a more gender-diverse lens. Throughout the thesis, particularly Chapters 4-9 I will use the words 'women' and 'professionals' to differentiate between the two participant groups. I have decided to use the word women instead of patient, or mother, as it is the most appropriate shared descriptor for this participant group. Not all identified as mothers, or identified as patients.

The term reproductive-related experiences is used throughout this thesis. It is used here to refer, mainly, to women's experiences of motherhood, pregnancy and reproductive decision making (i.e., thinking about whether to have a baby or not). It also encompasses experiences such as miscarriage, infertility, menstruation and menopause (although these experiences are not as widely discussed in the thesis).

Structure of the thesis

Following on from this brief introductory chapter, **Chapter 2** provides a review of relevant literature relating to motherhood and mental health. It draws together research from a range of disciplines, illustrating gaps within the perinatal mental health literature specifically and making a case for the need for greater understanding of specific issues and discourses in relation to perinatal mental health that sociology is well placed to address.

Chapter 3 details the conceptual framework underpinning the study, drawing on sociological understandings of stigma, access to healthcare and 'risk'. The chapter outlines specific

definitions of concepts which will inform the analysis of participants' data and later discussions within the thesis. It provides a critical account of the strengths and limitations of the perspectives that the framework is constructed from, as well as an illustration of how the existing literature suggests these concepts may fit together.

Chapter 4 outlines the methods and methodology used in the research. It details the epistemological and ontological orientation of the research and will summarise the stakeholder engagement that took place during year 1 of the PhD. It includes an in-depth description of the research design, justifications for design choices and a description of challenges faced during the data generation phase of the project. An in-depth account of analysis is also provided. The chapter concludes with an introduction to the participants recruited as foregrounding to the findings chapters that follow.

Chapter 5 is the first of this thesis' four results chapters. Drawing on data from interviews with women, it provides a holistic illustration of the ways that SMI impacts their different reproductive stages. Starting with reproductive decision making it demonstrates ways in which the causes and impacts of SMI can influence women's thinking about if, how and when they will become mothers. It demonstrates how work and employment are important parts of women's perinatal mental illness narratives, particularly antenatally. It also highlights how it is not only the experiences of illness itself, but also the interventions deployed to address perinatal mental illness that negatively impact women's pregnancies and postpartum periods in ways that lead them to feel othered, a process through which women self-stigmatise. Finally, it concludes with an examination of the different ways SMI continues to influence women's experiences beyond the postpartum, including in ways that are positive for women.

Chapter 6 draws on data from both women and professionals, highlighting the key places and spaces in which women with a history of SMI are stigmatised, the nature of the stigma they encounter and how this influences their healthcare seeking practices. It builds on the findings from Chapter 5 by highlighting other facets of stigma that women experience and shows how the workplace is an important site of stigmatisation for women with SMI. It describes the nature of the stigma participants experience, anticipate and resist in health and social care, within their families, in the workplace and in maternal spaces. It demonstrates that the stigma they experience in each of these settings is highly gendered.

Chapter 7 builds on the findings from Chapter 6 by continuing to examine factors, beyond stigma, which influence access to healthcare. The chapter first discusses the perceptive practices of 'seeing', 'saying' and 'knowing' on the part of both patients and professionals which can facilitate or complicate access to mental healthcare for women. It illustrates that despite these perceptive practices operating individually or interpersonally, there are upstream forces which influence these factors. It then goes on to highlight how institutional and structural factors impact and influence inequity in access to care. This includes issues such as strains on the wider healthcare system and the way it is organised as well as the ways in which concerns about risk dictate who is prioritised for care.

Chapter 8 builds on the findings from previous chapters, which demonstrated *how* stigma, knowledge, perception, the organisation of care and structural factors can influence access to care. This chapter fully develops the finding that risk and perceptions of risk are a fundamental determinant of access to care. It also illustrates that women and professionals share many of the same risk concerns in relation to maternal mental health; however there are significant temporal differences between their concerns. It also illustrates that there is significant risk-related conflict that occurs between professionals in relation to maternal mental health. It also demonstrates other affective aspects of risk-work which can impact

professionals' wellbeing in the workplace which can, in turn, influence capacity and thereby access to healthcare.

Chapter 9 closes the thesis by outlining what I perceive to be the novel contributions of the research. It addresses the study's research questions directly and brings the findings into dialogue with existing literature. In this chapter I discuss the strengths and limitations of the research, including a final reflexive account of the methods used. The thesis concludes with suggestions of avenues for future research and potential reflection points for policy and practice.

Chapter 2: Literature Review

Introduction

This literature review brings together insights from several disciplines to apprise and frame this sociologically informed study investigating the reproductive-related experiences of women with a history of SMI. Whilst I speak about this topic primarily from a social scientific perspective, it is important to draw on wider literature to contextualise the study for the reason that the psy-disciplines (i.e., psychology, psychiatry, psychotherapy) as well as epidemiology and public health, contribute significantly to the understanding of and knowledge about mental health and illness.

The literature presented below was identified primarily through structured searches of databases of academic research and by searching for key materials, such as policy documents, reports and guidelines in the grey literature. Literature was also recommended by experts in the field, and additional sources were identified by following citations in these aforementioned key materials.

The chapter comprises three main sections. Firstly, I introduce different disciplinary perspectives on mental health and its intersections with the social categories most relevant to this study: gender, class and ethnicity. Whilst this section draws together different disciplinary perspectives, it emphasises the sociological. Secondly, I outline key social scientific perspectives on motherhood and reproduction, which are often omitted in the perinatal mental health literature. Finally, the most substantive section of this chapter provides a synthesis of the perinatal SMI research literature, highlighting its strengths and limitations, and in particular its theoretical limitations. In summary, this chapter identifies and justifies the key areas of investigation this thesis seeks to address.

This chapter is a close companion to the following chapter of the thesis, Chapter 3, which outlines the study's conceptual framework. This framework has been constructed by synthesising sociological literature on concepts that I argue in this chapter (Chapter 2) are used often in the perinatal mental health literature and broader perinatal mental health-related discourses as taken-for-granted terms: concepts of risk, stigma and access.

Perspectives on Mental Health and Illness

Perspectives on mental health and illness have been generated from different disciplinary standpoints; they are varied and often contested. The biomedical model conceptualises mental disorders as caused primarily by irregularities in brain structure and function resulting from genetic abnormalities and environmental exposures. Within this paradigm the focus for treatment is usually pharmaceutical intervention with medications targeting neurochemical imbalances (Deacon, 2013). Critiques of the biomedical model of disease have centred on its failure to deliver promises of innovations in treatments and better patient outcomes, and led to the proposition of the biopsychosocial model (Deacon, 2013). The biopsychosocial model centres social, psychological and behavioural dimensions of illness (Engel, 2012) and is a commonly adopted framework in contemporary mental health practice (Royal College of Psychiatrists, 2017).

Akin to the biopsychosocial model, public health holistically conceptualises mental health and illness. Public health perspectives on mental health are broad, but commonly emphasise the promotion of wellbeing and the prevention of mental health problems, as opposed to the treatment of illness. They acknowledge that the determinants of mental health and illness at individual, family, community and structural levels are interconnected. Interventions in this tradition take a variety of forms, operating at the different levels of determinant and may be 'targeted' (at high risk groups) or 'universal' (for everyone) (Faculty of Public Health, 2024). Though attentive to the wider social determinants of health and illness, some argue a 'lifestyle drift' in public health policy has happened in recent decades as a result of socio-political factors, such as neoliberalism and austerity measures, where implementing individualised, behavioural interventions are favoured over changes in policy to address structural level determinants of health (Berg, Harting and Stronks, 2021). Within this political context, responsibility for the management of risk and risky behaviours is constructed as being that of the individual (Wigginton & Lee, 2013). Moth (2022) has argued that neoliberal organisational and policy mechanisms in relation to mental healthcare have resulted in a preoccupation with risk which has placed increasing demands on practitioners working within already stretched services. Moth also argues these risk cultures require mental health service users to 'act as 'responsible consumers'', managing their own risk through treatment compliance (Moth, 2022).

Other perspectives on mental health and illness have arisen from the social sciences, and in particular sociology with its long history of generating knowledge about mental ill-health and distress (Brossard & Chandler, 2022). Some perspectives, such as social causation, do not problematise diagnostic categories, but instead consider what role social contexts (such as poverty or discrimination) may play in causing illness. These perspectives are associated with more positivist sociological enquiry, such as that seen in social epidemiology (Rogers & Pilgrim, 2021). The classic sociological text, Émile Durkheim's *Le Suicide* (1951) is an example of causationist work, arguing that suicide was caused by the imbalance of different social forces. By contrast, social constructivist perspectives critique diagnosis and classification through the central assumption that diagnostic categories are 'not self-evident, stable and waiting to be discovered, but a product of human activity' (Rogers & Pilgrim, 2021, p.14). My thesis integrates both of these sociological positions. Firstly, by paying attention to the social factors and contexts women and professionals describe as meaningfully contributing to women's experience of perinatal mental illness. Secondly, by retaining a somewhat critical stance on the generation of labels used medically to classify different manifestations of distress.

Related to this constructivist position, diagnosis is a particularly contested territory within mental health-related discourses. Sociologists have conceptualised diagnosis as a complex phenomenon which is simultaneously shaped by social contexts whilst also shaping the social world. It does this, for example, by facilitating access to resources such as healthcare, (de)legitimising experiences of distress and serving as a tool of social control through the construction of norms (Jutel, 2015).

Within research, healthcare and policy, mental health conditions are commonly subdivided into two umbrella terms: 'common mental disorders' usually including diagnoses such as generalised anxiety and mild to moderate depression, and 'severe mental illness' or 'serious mental illness' (SMI) commonly including diagnoses such as bipolar disorder, schizophrenia and severe depression. Despite their widespread use, these divisions have been criticised for lacking specificity (Gonzales, *et al.,* 2022). A report authored by several medical Royal Colleges on improving the health of people with SMI references the imprecision of the term and states that it may be more important to consider three important factors when classifying

the experience of mental illness or distress into either category: duration, disability and diagnosis (Academy of Medical Royal Colleges *et al.,* 2016), illustrating that a contestation of mental health-related terminology can arise even within the professions and institutions which have created the categorisations.

Despite diagnostic categories being contested, evolving and fluid, within psychiatry as a specialty there is distinct emphasis on diagnosis. Green (2014) suggests that the endurance of classification and diagnostic categories within psychiatry, despite widespread criticism, is due to 'communicative, epistemic and ethical pressures' on the specialty (Green, 2014, p.361). Rogers and Pilgrim (2021) frame diagnosis as 'precarious knowledge' in the context of mental health work, highlighting the criticism diagnostic practices have received by both service users *and* professionals, and the (un)acceptability of particular diagnoses to the people receiving them. There are some, such as Bentall (2006) who advocate for the abandonment of diagnosis altogether within mental health work, in order to focus instead on the problems or symptoms individuals experience. Perspectives on diagnosis are not simply a case of 'for-or-against'. An example of the complexities of diagnosis, and particularly the phenomenon of 'self-diagnosis', is highlighted by sociologist, Verta Taylor (1995) speaking specifically about women's experiences with postnatal depression, she asserts:

> *'it is not […] the practices of the medical and psychiatric establishment that lead women to apply psychiatric labels to their postpartum emotions; rather women medicalise their own experiences to explain and manage a set of feelings that they identify as profoundly at odds with the emotional imperatives prescribed for new mothers'.* (Taylor, 1995, p.27)

In opposition to this perspective on postnatal depression, there are others who argue that women's emotional, cognitive and behavioural experiences around the perinatal period are unnecessarily pathologised. For example, sociologist Ann Oakley (2012) describes postnatal depression as "a medicalisation of normal human distress".

These more critical perspectives on diagnosis are important to consider in the context of this study, which does not sit within the biomedical paradigm, but instead sits at the intersection between the fields of sociology and health services research. These perspectives emphasise the influence of wider social factors (for example, poverty, discrimination, social norms surrounding the experience of motherhood) contributing to the generation of distress and the formation and attribution of diagnostic categories, which is discussed in more detail below.

Social positioning and mental health and illness

By virtue of its concern with the influence of social contexts and structures on individual experience, social identities and inequalities are core concerns for sociology. Social categories such as class, ethnicity and gender, examples of key organising factors within UK society, have great importance in the context of mental health and illness. These categories have implications for the distribution of illness and distress within populations, for the patterning of the kinds of diagnoses people receive and may also influence *how* their distress is treated.

The relationship between socioeconomic positioning and mental health is well-established and highly complex. The association of mental health with material and economic conditions can be seen in increased suicide rates that are observed in times of economic crisis (Reeves, McKee and Stuckler, 2014). In the Global North, the high prevalence of common mental disorders is associated with material disadvantage (Fryers *et al.*, 2005). Rogers and

Pilgrim (2021) have similarly described differences in treatment between socioeconomic groups: poorer patients are less likely to be referred for psychotherapy, are more likely to receive unfavourable interpretations of psychometric tests and more likely to be prescribed medication compared to richer patients. They suggest these differences may be due to a 'cultural gap' between middle class professionals and working class patients. Treatment gaps are not just socially patterned by social class, but also according to other social categories such as ethnicity or gender (Rogers and Pilgrim, 2021).

Globalisation, migration and Britain's colonial history have created a UK population which is ethnically diverse. There are concerning patterns in relation to mental health health(care) in the UK for people from specific minoritised ethnic groups[6]. Consistent evidence shows Black patients are more likely to be detained under the *Mental Health Act* than any other ethnic group (UK Government, 2024). A study of Community Treatment Order (CTO)[7] use found Black patients are more likely to be subject to a CTO than white patients (Barkhuizen *et al.*, 2020). CTOs have been described by organisations supporting people with mental illness as disempowering, coercive and controlling (Cobb, 2018). Ethnic inequalities in access to mental healthcare is often attributed to linguistic and cultural barriers, or stigma circulating within minoritised ethnic groups inhibiting care seeking. However, others such as Kapadia, 2023 and Bhui, Dein and Pope, 2021, argue inequalities may be better understood as the consequences of structural and institutional racism. Returning to the issue of over-representation of minoritised ethnic groups detained under the *Mental Health Act*, at the intersection of ethnicity and gender, Jankovic *et al.*, (2020) illustrated Black African, Asian and 'White Other' women had higher rates of involuntary admissions to inpatient treatment perinatally compared to White British women. Writing specifically about the treatment of Black women within the NHS, Bonhomme (2019) urges us to think about the wider structural and political context that healthcare is embedded within. In light of ethnic inequalities within mental healthcare more broadly and particularly perinatal mental healthcare), it is vitally important that researchers are attentive to ethnicity throughout the research process.

With respect to the social category of gender, Busfield (1989) outlines two feminist sociological perspectives regarding women's mental health and illness. The first sees sexism at the heart of psychiatry as a primary concern, evident in the ways women are more likely (than men) to receive a psychiatric diagnosis, to be medicated, to suffer exploitation by therapists and to be 'confined in institutions which deny them the rights and privileges of adult life' (Busfield, 1989, p.334). The second perspective is of mental illness as a social product. This perspective sees 'the sexism of society' (rather than psychiatry) as fundamental to understanding women's mental distress, and can be linked to social causation perspectives discussed earlier in this chapter. This perspective acknowledges the importance of gender inequality in women's susceptibility to mental distress. It views factors such as gender-based violence, unequal relationships, and economic inequality as causational (Busfield, 1989).

Sexist and paternalistic attitudes towards the reproductive related experiences of women with SMI can be seen in the work of E.Fuller Torrey, a prominent American Psychiatrist (Winnerip, 1998), who conceptualises schizophrenia and bipolar disorder within the

[6] The term 'minoritised ethnic groups' will be used throughout the thesis to acknowledge and emphasise the active, power-driven processes which maintain structures, 'which diminish minoritized people's capability to lead healthy lives' (Selvarajah *et al.*, 2020, p.3).

[7] CTOs are for individuals who have been detained in hospital under the Mental Health Act but are then deemed to be well enough to be treated in the community. However, their treatment is supervised and conditional. Patients on CTO's living in the community are still subject to the Mental Health Act (Rethink Mental Illness, 2022).

biomedical model. In *Surviving Schizophrenia* (2019) – an internationally best-selling book aimed at patients, families and practitioners - women with this diagnosis are framed as simultaneously sexually vulnerable and unreliable in their accounts of sexual coercion (Torrey, 2019). Discussing pregnancy for women with schizophrenia, Torrey states:

> *"Once a baby has been conceived, the couple and their families are often caught between a rock and a hard place. Abortion and adoption should both be considered; responsible decisions frequently involve consultation with the psychiatrist, family physician, lawyer, religious advisor and social worker… This sharing of decision making will alleviate the burden on both the patient and the patient's family" (*Torrey, 2019, p.249)

Here it is implied that parenthood is not a desirable path for women with a diagnosis of schizophrenia. This view is echoed in the experiences of women with bipolar disorder reported in a study by Dolman, Jones and Howard (2016). Women in this study reported experiencing negative attitudes towards their desire to have children from health and care professionals. These are examples of ways in which reproductive choice may be limited for women with SMI, an example of the concept of stratified reproduction, which will be discussed further below.

Rogers and Pilgrim argue 'some diagnoses are inevitably limited to women' i.e., those related to the perinatal period such as postnatal depression/psychosis (Rogers & Pilgrim, 2021, p.70). However, it is important to note the distinction here between sex and gender: changing gender norms and categories challenge Rogers and Pilgrim's assertion. People born natally female (sex) may in terms of gender identify as non-binary or male, yet still possess the biological capacity to conceive, become pregnant and give birth. It is also important to note an increasing emphasis in the research and in advocacy discourse on the mental health of fathers in the perinatal period (e.g., Williams, 2020; Reid *et al*., 2017).

Evidence shows that attitudes towards mental ill health and access to treatment and care are often patterned according to class, ethnicity and gender. Sociological perspectives highlight the structural conditions and inequalities which can give rise to these patterns, I engage with these inequalities throughout the thesis. Personal experiences of perinatal mental health and illness are shaped by the wider socio-cultural factors that structure motherhood and expectations of women. These include shared norms, values and understandings of acceptable behaviour which are key sites of surveillance and scrutiny for women. Motherhood, its norms and values are rarely critically discussed in the literature on perinatal mental health. However, sociology has contributed greatly to the understanding of this area of social life. For this reason, I have synthesised some key literature on motherhood, which is discussed in more detail below in order to frame this study in greater depth.

Perspectives on Motherhood

Recent empirical research in the Global North has illustrated that even in societies where freedom of reproductive choice for women is strongly advocated for, deciding whether or not to become a mother is heavily influenced by socially transmitted ideas of idealised womanhood, where women have an innate and 'natural' longing to have children (Bodin, 2024). Women without children are perceived differently depending on the root of their childlessness: those who are unable to have children (e.g., through infertility) are seen pitifully, whereas women who choose to not have children are seen as selfish and infantile, their responsibilities are negated and erased (Letherby, 1994). Those who choose to not have children violate powerful social norms and are often pathologised or stigmatised for this

choice (Agrillo and Melini, 2008). Increasing numbers of people are choosing not to have children: factors such as housing crises, rising costs of living, costs of childcare, political and climate-related instability and changing gender norms are influencing reproductive decision making in the UK and other Global North contexts. Despite this, more recent scholarship from the field of social psychology has illustrated that negative perceptions of people without children (by choice or otherwise) are persistent (Ashburn-Nardo, 2017; Ekelund & Ask, 2021).

Mothers, mothering and motherhood are distinct but closely related concepts (Schmidt *et al.,* 2023). Writing in the early '90s, prominent sociologists of motherhood defined a 'mother' as an individual with the capacity for enacting both biological and social reproduction (Oakley and Clay, 1993). Scholars writing more recently have placed less emphasis on the biological processes (i.e., pregnancy, birth, breastfeeding), instead foregrounding the relational, nurturing and caring practices of mothering (Arendell, 2000; Schmidt *et al.,* 2023). Motherhood is both an experience and an 'institution' (Oakley and Clay, 1993) and has been conceptualised in different ways over time. Synthesising two decades of research in relation to motherhood in the Global North Schmidt *et al.* (2023) illustrated five key norms of motherhood that women are expected to enact or inhabit. These included being attentive to the child; securing their successful development; integrating employment into mothering; being in control; being happy and content (Schmidt *et al*., 2023). Many of these norms have the potential to be disrupted by experiences of illness, particularly mental illness.

A key ideology in relation to motherhood which is relevant to this area of inquiry is "scientific motherhood". Scientific motherhood constructs women (mothers) as responsible for their children and, by extension, society's success or failure and establishes the relations between parenting and medical knowledge (Hamilton, 2022). An illustration of this can be seen in Bell, McNaughton and Salmon (2009) who highlight how mothers are positioned by biomedicine and public health as responsible for children's (ill) health. They argue that public health discourse oversimplifies the complex relationships between risk factors (such as obesity, smoking, alcohol consumption) and health outcomes. These oversimplifications fail to properly recognise structural or contextual factors in women's lives which affect health behaviours. Later in the literature review, I will illustrate this in relation to maternal mental illness.

Wigginton & Lee (2013) argue that risk discourses play a key role in constructing ideas of the "good" pregnant woman and the "good" mother, i.e., women who are self-sacrificing and police their own behaviours to reduce risks to the foetal subject. Bodin (2024) argues that parenting norms dominant in the Global North are characterised by close, 'intensive' and risk oriented parenting, where children's wellbeing is primary, and these characteristics of 'good' parenting extend to pregnancy and pre-pregnancy periods. Intensive mothering as an ideology is underpinned by the belief that women should respond to their children's needs ahead of their own, and sees a 'good' mother as one who is able to invest significant physical, emotional and financial resources in to raising their child (Hamilton, 2022).

Sociocultural framings of 'good' motherhood are significantly influenced by social positions such as class and ethnicity (Chambers and Gracia, 2022). Hamilton (2022) argues that the norms that determine intensive mothering, hence what is deemed a 'good' mother, are white and middle class in origin, which results in an implicit exclusion of women who do not occupy these narrow social locations. A key concept introduced in Chapter 1, and relevant to understanding motherhood and inequality is 'stratified reproduction'. This concept 'describes the power relations by which some people are empowered to nurture and reproduce, while others are disempowered' (Ginsberg & Rapp, 1995, p.3). Stratified reproduction can be

created and reinforced through policy (McCormack, 2005) and access to care (Greil *et al.,* 2011). I will return to this concept to interpret some of my findings and in the final chapter of the thesis.

So far I have introduced some sociological perspectives on mental health and mothering, and on inequalities in experiences of mental ill health and access to care. These are significant for my thesis by reason of its core aims and the fields it is situated within. In the next sections, I will build on my introduction of perinatal mental healthcare in the UK presented in Chapter 1 and provide an overview of the perinatal mental health literature. Here I will illustrate key gaps within this literature, including its conceptual limitations that this thesis seeks to address. In the following chapter, I will detail sociological perspectives on the concepts I identify below as important for further study, whilst. Chapter 3 constitutes my conceptual framework.

Perinatal Mental Health Research Literature

The next section of this chapter is a synthesis of key literature on perinatal SMI and perinatal mental healthcare in the UK. Literature was identified initially by performing structured searches in databases such as (PubMed, Google Scholar and Scopus) to identify relevant quantitative, qualitative and review studies. Initially, I prioritised reading systematic reviews and identified further literature through these papers. Additional papers were identified through engagement with experts in the field. I found grey literature through searching the websites of relevant government departments, NHS England, professional bodies, charities and advocacy organisations. Additional grey literature was identified through engagement with experts in the field. Within the thesis, I prioritised the inclusion of literature that focusses specifically (although not exclusively) on perinatal SMI.

Much of the research literature on perinatal mental health states that maternal mental illness can contribute to a range of adverse outcomes. There is extensive literature investigating the effects of maternal mental illness on a wide range of child outcomes, including children's mental and physical health (Goodman *et al.*, 2011; Pierce *et al*., 2020). The economic impact of perinatal mental illness in the UK is thought to be £8.1billion per year, where 72% of that cost relates to adverse impacts on the child (Bauer *et al.*, 2014). Lack of prompt and effective treatment for women who are acutely unwell can have serious consequences. As highlighted in Chapter 1, suicide is one of the leading causes of perinatal mortality in the UK (MBRRACE-UK, 2023).

Chapter 1 outlined the policy and practice landscape in the UK relating to perinatal mental healthcare, including NHS England's ambitions to extend care to up to two years postpartum and increase access to psychological therapies for women with moderate, complex and severe perinatal mental health needs (NHS England, 2019). A recent report on specialist perinatal mental healthcare highlights that whilst there has been progress towards achieving these aims, wider social and system challenges have hindered efforts. In addition to the myriad effects of the COVID-19 pandemic, these challenges have included funding and workforce issues as well as gaps in knowledge about equity and quality in care delivery (Maternal Mental Health Alliance, 2023b). Whilst work is ongoing, in 2023, only around half of specialist perinatal mental health services in England reported they provide care from preconception to 24 months after birth or have increased provision of psychology services (Maternal Mental Health Alliance, 2023b).

Gurol-Urganci *et al.* (2024) investigated the effects of the rollout of community perinatal mental health services on access to care and maternal and neonatal health outcomes. They

found that the presence of services reduced the risk of acute relapse and increased use of secondary mental healthcare services. However, there was also evidence in their analysis to suggest negative neonatal health outcomes (i.e., higher risk of still birth and neonatal death) in areas with perinatal mental health services. Whilst the authors were careful to underscore that more research was needed to ratify the findings, they postulated that negative neonatal health outcomes could be a result of complex social processes operating within healthcare. For example, where obstetric risk factors are overshadowed by intensive psychiatric input or where discrimination could influence women's access to maternity care.

Humphreys and colleagues have argued that the *Health and Social Care Act (2012*) underlines the imperative for preventative as well as 'restorative' care to be delivered by the NHS and that perinatal mental health 'fits neatly' alongside a public mental health agenda (Humphreys *et al*., 2016). Service documents outlining the key functions of perinatal mental healthcare frame its purpose as *preventing* as well as detecting, treating and managing perinatal mental health problems (NCCMH, 2018). Prevention and the concept of risk are inextricably linked. The purpose of preventative care is to reduce the risk of illness occurrence or severity. This is often posited as a universal "good", however, there is some caution that should be applied to preventative care and mental health. Corsico and Singh, (2020) highlight that there are ethical implications when identifying and treating *risk* as opposed to illness.

Despite the recent policy focus and strengthening of provision to reduce a perinatal 'postcode lottery'[8], inequalities persist in access to perinatal mental healthcare (Maternal Mental Health Alliance, 2023b), particularly for women from minoritised ethnic groups and women living in circumstances of deprivation (Redshaw and Henderson, 2016; Jankovic *et al.,* 2020; Langan Martin *et al.,* 2016): these studies will be discussed in more detail later in this chapter.

The perinatal mental health literature is large and multi-disciplinary. In this section of the chapter, I present work from clinical perspectives, epidemiology, psychology and health services research. In this literature, there is a significant focus on diagnoses of postnatal depression. Demonstrating the permeability of diagnostic categories 'perinatal mental health' is often used synonymously (and arguably erroneously) for postnatal depression. This may be due to postnatal depression being the most commonly experienced perinatal mental health condition (WHO, 2024). However, this has meant that other conditions, particularly more serious or complex, have been comparatively overlooked, hence the importance of focussing on a broader range of illness experiences and severities in this study. As highlighted earlier in this chapter, there is an emerging focus in the perinatal research literature on men, however, I am focussing largely on the maternal literature. This section also focusses more substantially on *particular* SMI diagnoses (i.e., postpartum psychosis) reflecting the leaning of the literature. As discussed earlier, SMI can be a nebulous term; it is, however, usually associated perinatally with diagnoses such as bipolar, schizophrenia, psychosis and severe depression (McKee *et al.,* 2020; Howard *et al.,* 2020).

Perinatal SMI: prevalence and causation

SMI in the perinatal period can occur in women with no previous history of psychiatric illness (personal or familial) or it may be a continuation of an existing illness. The early postpartum period is thought to be a particularly crucial time in terms of risk of SMI, with women's risk of admission to inpatient psychiatric care being significantly high compared to the two years before or after birth (Kendell, Chalmers and Platz, 1987). In the postpartum period, serious

[8] This term generally refers to the variations in healthcare service quality or availability between different geographical areas (Karpusheff, 2023)

episodes of mental illness are typically termed postpartum psychosis, although other diagnostic terms may be used, such as puerperal psychosis, postnatal psychosis, mania or bipolar disorder triggered by childbirth; schizoaffective disorder with onset following childbirth and postnatal depression with psychotic features (Action on Postpartum Psychosis, 2021). Postpartum psychosis constitutes a medical emergency and is characterised by mania, hallucinations, delusions, paranoia, confusion and depression (Royal College of Psychiatrists, 2018b).

For women with a history of SMI, there is evidence to suggest women with a pre-existing bipolar condition are at particularly high risk of developing postpartum psychosis, there may well also be higher risks for women with schizophrenia although fewer studies have investigated this (Jones *et al.*, 2014). Prevalence of postpartum psychosis is frequently cited as between 1-2 per 1000 births; a WHO-led study identified the incidence of this condition ranged between 0.89 and 2.6 in 1000 births across several countries (VanderKruik *et al.*, 2017).

Within the literature on postnatal SMI, there is an emphasis on *biological* causes or risk factors. In a review on Postpartum Psychosis, Perry et al, 2021, suggest "the aetiology of postpartum psychosis is likely to be explained by a complex interaction of biological, psychological and social factors" (Perry *et al.*, 2021, p.4) but whilst summarising the evidence, emphasis was placed on obstetric factors (such as complications in pregnancy or delivery), hormonal changes, circadian rhythm disruption; immunological factors and genetics. The authors highlight that evidence suggests psychological and social factors appear to play a significant part in the triggering of postpartum *depression* (e.g., the association between postpartum depression and experiences of violence and abuse (Dennis and Vigod, 2013), but less of a role in the triggering of postpartum psychosis (Perry *et al.*, 2021). However, a more recent study by Hazelgrove *et al*., (2021) has demonstrated that a history of childhood trauma was a significant predictive factor in the development of postpartum psychosis for women who also had a high risk status due to diagnoses of bipolar, schizoaffective disorder or histories of postpartum psychosis. This indicates trauma is an important psychosocial factor to consider in relation to maternal mental health.

It is worth highlighting potential limitations in the evidence base for the role of psychosocial factors in the development of postpartum psychosis. Often studies have limitations in terms of sample size/representativeness and also in terms of the quality or relevance of the variables selected for analysis. By way of example, one study assessing the role of early childhood life experiences in the development of postpartum psychosis found no evidence of an association (Perry *et al.*, 2016). The limitations in the representativeness of the sample (white-only and mostly university educated) were not acknowledged, and the study also used a narrow selection of adverse childhood experiences. This is in contrast to a study by Kim *et al*., (2020) which included a wider range of adverse experiences in the analysis. These included environmental stressors such as poverty, witnessing domestic violence, living with a parent with mental illness, experiencing racism or living in a violent neighbourhood. They also surveyed women from various ethnic and educational backgrounds and found women with moderate to severe perinatal mental illness had experienced a high number of adverse experiences, and women from Black backgrounds were more likely to have experienced more adverse experiences than White women – which the authors argue 'underscores how the lived experience of women of colour differs from many white women' (Kim *et al.,* 2020, p.782).

History of previous mental illness is often cited as the strongest predictor of perinatal SMI. A history of bipolar disorder is particularly pertinent, as studies suggest around 1 in 5 new

mothers with bipolar disorder require inpatient treatment for psychiatric illness soon after birth (Wesseloo *et al.,* 2016). Histories of mental illness, both personal and familial, feature prominently in the Royal College of Psychiatrists advice for patients on postpartum psychosis. It suggests histories of bipolar disorder, schizoaffective disorder, previous personal experience of postpartum psychosis or a first degree relative who had postpartum psychosis are important risk factors, carrying different levels of risk (Royal College of Psychiatrists, 2018b). The literature identified highlights a preoccupation with the concept of risk in relation to perinatal SMI, more specifically this includes risk factors, the risk of relapse or risk of developing perinatal SMI.

Treatment and intervention

Howard and Khalifeh (2020) summarise evidence on interventions for perinatal mental disorders and highlight psychological and psychosocial interventions are largely focussed on tackling common mental disorders rather than SMI. The authors highlight the relative lack of interventions that target the family or address structural and social determinants of mental health, such as poverty, racism, sexism, gender-based violence, poor housing, limited education or food insecurity. In relation to this, they suggest and research on 'improving access to treatment for women with difficulties owing to poverty, racism [and] stigma' is of pressing need (Howard and Khalifeh, 2020, p.323).

Women experiencing SMI perinatally are often treated with medication and admitted to hospital (Action on Postpartum Psychosis, 2024; Royal College of Psychiatrists, 2018b). A systematic review of research into the treatment and prevention of postpartum psychosis found that antipsychotics, mood stabilisers, hormones, propranolol and electroconvulsive therapy have all been explored (Doucet *et al.*, 2010). The authors highlighted small sample sizes as a significant limitation of the primary research studies. 88% of studies included in the review had 10 or fewer patients. Although the authors' search strategy and inclusion criteria would not have excluded studies of psychological, public health or social interventions for prevention or treatment of postpartum psychosis, none were included in the review (Doucet *et al.*, 2010). This highlights the dominance of a biomedical framing of postpartum psychosis, whereby social causation and socially focussed forms of treatment and intervention has largely, historically, been neglected.

In the UK, women with acute perinatal SMI are *usually* admitted to either a general psychiatric ward or a mother and baby unit (MBU), but some are looked after in the community with intensive home treatment. Rubio *et al.,* (2021) found that whilst some women appreciated not being treated in hospital, this intervention was not always well suited to the needs of women. It was widely reported that women found it intrusive, lacked in 'continuity of carer'[9] and was heavily risk focussed. This shows that risk management and assessment practices ubiquitous in mental healthcare (Moth, 2022) impact women's experiences perinatally. MBUs are sites of care that are designed to support and nurture the relationship between mother and baby whilst the woman recovers (Royal College of Psychiatrists, 2018a). Griffiths *et al.*, (2019) qualitative study compared the experiences of women treated in MBUs and general psychiatric inpatient units, and found that women's experiences of MBUs are generally more positive comparatively and that MBU care seems preferred to general wards. Both women and healthcare professionals described general acute psychiatric wards as places which struggle to care adequately for women in the

[9]'continuity of carer' is a model of care delivery whereby patients have a relationship with the same clinician or small group of clinicians over time, allowing trust to be built and knowledge about the patient to be accumulated (Fraser and Clarke, 2023; Smith, 2024)

perinatal period. This is concerning in light of the findings of another study which used whole-country admissions data from Scotland to investigate access to perinatal mental healthcare. The authors of this study found that women admitted to an MBU were more likely to live in affluent areas, compared with women who were receiving treatment in general psychiatric wards. The authors suggest this may reflect a 'health inequality in terms of access to MBU admission' (Langan Martin *et al.*, 2016, p.3).

A study using whole-country data from England found women with lower access rates to community mental health services have a higher proportion of involuntary admissions. They found this pattern specifically applies to women identified as Black African, Asian and White Other, compared to White British women. The authors suggest inequalities in access to community care may have serious consequences for illness severity for women of different ethnicities (Jankovic *et al.,* 2020). Involuntary admission, being 'sectioned' under *The Mental Health Act*, occurs if patients who are acutely unwell are deemed a risk to themselves or others. Whilst this is likely a complex issue, it is possible there may be social patterning in the risk assessments for women who are detained under *The Mental Health Act* in the perinatal period. In the next section I explore the issue of inequality further, in relation to accessing care.

Accessing perinatal mental healthcare

An important route into services for women with perinatal mental health concerns is through contact with one of the many professionals (e.g., midwives, health visitors) who are involved in their ante and postnatal care. One study presenting a secondary analysis of a national maternity survey demonstrated women living in more deprived areas and those with fewer years of education were less likely to be asked postnatally about their mental health or offered treatment or support. Similar patterns were seen for women from minoritised ethnic groups. The authors argue the *'inverse care law'* operates in perinatal mental healthcare, where women in most 'need of support and treatment are the least likely to be offered it and are consequently at higher risk of serious adverse outcomes' (Redshaw and Henderson, 2016, p.1). In the context of perinatal mental healthcare, this may be more meaningfully critically articulated as an example of how reproduction may be stratified for women living in poverty and women from minoritised ethnic groups. As highlighted earlier in this chapter, stratified reproduction can be created and reinforced through unequal access to care (Greil *et al.,* 2011).

In contrast to Redshaw and Henderson's findings, in 2019 the National Screening Committee (NSC) conducted a review investigating whether clinical detection for common mental disorders in the perinatal period was effective. After reviewing relevant evidence, the NSC was satisfied that most women were asked about their mental health. However, the review did not feature any analyses of inequality. Addressing this, Prady *et al., (2*021) conducted an equity focussed systematic review, which reanalysed literature used in the NSC's review. They found evidence of inequalities in care, particularly for women from minoritised ethnic groups. The authors highlight several institutional and structural factors which may influence care delivery for minority ethnic women. This includes a lack of professionals from minority ethnic backgrounds (contributing to lower cultural competence in services) as well as the workforce planning and cost implications of longer appointments for women needing an interpreter. The authors acknowledge several limitations in the primary data and suggest this may have resulted in an underestimation of disparity. They highlight an absence of women's voices in the studies they examined (Prady *et al.*, 2021), suggesting the need for further qualitative research.

Sambrook Smith *et al.*, (2019) systematic review of qualitative studies to synthesise a theoretical multi-level model of barriers to perinatal mental healthcare illustrated how barriers interact across the care pathway. The primary studies drawn upon only included a small

number focussed on SMI. This indicates there may be value in understanding barriers from the perspective of women with SMI. The authors highlighted there were few studies in the literature which have sought to understand organisational or structural level factors that affect access; most have focussed on those at individual level. This indicates research which seeks to surface institutional and structural-level determinants of access to care would be of value, something sociologically informed studies are well-equipped to address. Stigma featured significantly in women's accounts the review drew upon, it was discussed in 11 of the 32 studies. The authors identified stigma as a barrier, but it was not conceptually defined. It is unclear whether this is a limitation of the review or the primary literature it drew upon. However, the ubiquity of stigma in qualitative accounts indicates it is significant in women's lives and a clear conceptual framing of the term could be valuable to further shed light on this aspect of women's experience. Conceptual framings of the concept of stigma arising from the sociological literature will be discussed in greater detail in the following chapter of the thesis.

Experiences of women and professionals

Much qualitative research has sought to understand personal experiences of perinatal mental illness which includes illness experiences of women themselves as well as the experiences of their partners or broader family members. This literature also includes studies seeking to understand the experiences of professionals who care for women with perinatal mental illness and the concepts of risk and stigma feature prominently in this literature.

Noonan *et al.*, (2017) qualitative meta synthesis explored public health nurses[10] working with women with perinatal mental health difficulties and highlighted the varied understandings nurses hold about postnatal depression. The review discussed nurses' wariness of imposing 'English standards' on women's' postpartum experiences suggesting a 'cultural gap' between patients and professionals as well as different standpoints on whether postnatal depression is a natural reaction to new motherhood or something more concerning and requiring intervention. Earlier in this chapter, I highlighted varying perspectives on postnatal mental illness from the sociological literature (Oakley, 2012; Taylor, 1995). Noonan *et al.* (2017) demonstrate that perspectives are varied within the healthcare workforce also. An empirical study by Noonan *et al.,* (2018) investigated the role of GPs in responding to perinatal mental illness: professionals perceived that social expectations of mothers can make help seeking and care giving challenging. They also highlighted challenges in services influencing this too, for example, services and referral pathways being under resourced, fragmented and uncoordinated. They also identified stigma as a barrier to women seeking help. However, the source of the stigma was not explicitly defined. This highlights a need for research paying specific attention to the nature of stigma circulating in perinatal care (Noonan et al., 2018).

Dolman, Jones and Howard (2013) systematic review highlights health professionals' perspectives on caring for reproductive-age women specifically with SMI. The authors argue a substantial focus of clinicians is on risk. In a study conducted with mental health nurses working in general adult psychiatric care, McConachie & Whitford (2009) found they held mixed attitudes towards mothers with SMI. Here too, the professional participants talked extensively about risk: the risk women may pose to their children, women's increased risk of suicide, infanticide and relationship breakdowns as well as the importance of the early identification of risk and the difficulty of talking about risk to patients. In another study conducted with a broader range of professionals, women with schizophrenia were framed as

[10] known more commonly in England as Health Visitors.

a ‘high risk group in their transition to motherhood’ (Wan, Moulton and Abel, 2008, p.277). These studies illustrate the ubiquity of risk-related discourses in relation to perinatal SMI, particularly in the context of healthcare delivery. In Wan, Moulton and Abel’s study, stigma also arose as a key theme, highlighting the stigma attached to schizophrenia and parenting and that stigmatising attitudes towards mental illness in society more generally were also held by healthcare workers (Wan, Moulton and Abel, 2008).

Much qualitative literature explores women’s experiences of being acutely unwell or recovering from perinatal SMI (see Robertson and Lyons, 2003; Glover *et al.* 2014; Engqvist and Nilsson, 2013; Plunkett *et al.*, 2017; McGrath *et al.*, 2013). In terms of ‘risk’ concerns, compared to studies of professional experiences, less emphasis is placed on medication in these women’s accounts. Women talk instead about their concerns about the risk of future illness and how this influences their decisions to have more children (Robertson and Lyons, 2003; McGrath *et al.*, 2013). Women in the McGrath *et al.*, (2013) study discussed stigma extensively; talking about their fear of being stigmatised/facing stigma, how they were motivated to ‘fight’ or decrease stigma, and how stigma silenced them from talking about their mental illness. In terms of methodological insights, Glover *et al.* (2014) highlighted that participants were asked directly to tell their story of illness from the point at which their symptoms started. However, many participants insisted on starting their narrative pre-pregnancy. This highlights an important methodological consideration for future qualitative research. Specifically, it underscores the importance of participants having the time and freedom to tell their stories from the starting points that are important to them.

Dolman, Jones and Howard (2013) systematic review of qualitative literature on motherhood and SMI highlights the prevalence of stigma in women’s accounts in the primary literature. As is seemingly common in this literature, a specific, conceptual understanding of stigma is not utilised. Nonetheless, stigma was seen as a significant factor in preventing women from seeking help and discussing their problems more openly. Women also feared involvement of social services and loss of custody of children. Dolman, Jones and Howard (2013) also highlight an interesting contrast between women’s and professionals’ concerns around risk. Risk concerns of women were related to the risk of their children inheriting their illness; highlighting that there may be incongruences in women’s and professionals’ priorities in relation to risk. This may be a meaningful area for further enquiry considering the prevalence of risk-discourse in relation to maternity and mental health. Dolman, Jones and Howard, (2013) analysis demonstrated significant differences in the experiences of women with different diagnoses, particularly for women with postpartum psychosis compared with women with other SMI. This underscores the heterogeneity that women with different illness experiences may have and why it is important for research to include women with a variety of histories, diagnoses or symptom profiles.

Social positioning and perinatal mental health(care)

Historically, a limitation of much qualitative literature on experiences of perinatal SMI is its reporting of the demographic characteristics of their participants, as can be seen in Glover *et al.*, (2014). Where characteristics are reported, participants are highly educated, employed and mostly White British (see McGrath *et al.*, 2013; Plunkett *et al,* 2017). This is concerning, particularly in light of the social patterning seen in inequalities in access to services highlighted throughout this chapter. There is an assertion that SMIs, such as postpartum psychosis, can ‘affect women from all social classes, education levels and occupational

backgrounds' (Heron *et al.*, 2012, p.155); however, much of the research literature on perinatal SMI is based on the experiences of a relatively narrow cross-section of women.

The proxies of socioeconomic positioning used most commonly in these studies are years of education and occupational status. Education as a sole measure of social position in health research has received criticism for being oversimplified and assumptive (Bartley, 2016). Occupational status in perinatal mental health research is rarely reported beyond broad descriptors such as 'full-time', 'part-time' or 'homemaker'. There is no indication of the *quality* of participants' employment: Are participants subject to precarious contract types? Are they the recipients of universal credit? What is their housing status? Knowledge about the material, educational and economic circumstances of women is vital to understanding the wider context of their lives and may be useful in understanding socioeconomic inequity in access to services.

With regards to ethnicity and perinatal mental health, Watson *et al.,* (2019) examined the literature on ethnic minority women's experiences: drawing largely on studies of women experiencing common mental disorders rather than SMI. Women from minoritised ethnic groups perceived health services as culturally insensitive and fragmented. Stigma was also discussed extensively, with the authors suggesting that women from ethnic minority backgrounds may experience "double stigma […] the intersectionality of experiencing prejudice and discrimination in healthcare service settings added to the public and internal stigma of suffering with mental ill health" (Watson *et al.*, 2019, p12), which illustrates the importance of understanding the stigma experiences of women from varied cultural backgrounds.

In recent years, much research and advocacy has sought to address the issue of ethnic inequalities in perinatal mental healthcare. Bains *et al.*, (2023) interviewed a range of professionals to understand their perceptions of barriers to care for women from minoritised ethnic groups. The authors recommend the need for more research to include patients from minority ethnic backgrounds, underscoring the importance of recruiting diverse participant groups. In their paper, racism or discrimination are not explicitly discussed in relation to the issue of access to care. Instead the authors utilise the language of 'unconscious bias', a term which has been critiqued by critical race scholars as one which obscures institutional and structural racism by rendering it an individualised problem which can be 'remedied through retraining and therapy for the individual' (Bourne, 2019).

Conneely *et al., (*2023) investigated Black and South Asian women's experiences of accessing perinatal mental healthcare. In contrast to the findings of Watson *et al.,* (2019), they found many women felt heard and supported by services. Conneely *et al., (*2023) concluded that the main barriers to access were women and families understanding distress through non-medical lenses, stigma, mistrust, a lack of visibility of services, and gaps in referral processes. In relation to stigma women felt that professionals understood stigma circulating in their cultures, and described different forms of mental health related stigma circulating in their families and communities. In contrast to Bains *et al.,* (2023) (despite being different strands of the same research project) this study did discuss racism in detail. In terms of interpersonal racism, participants in the study did not widely report experiencing racism and discrimination whilst accessing care. The authors highlight their findings are not in line with other studies in the literature but this could be attributable to many different factors, including the positionality of the interviewers, underscoring the need for strong reflexive practice when researching ethnicity and mental health; a theme I will revisit in more detail in subsequent chapters of this thesis.

Before concluding this review of the perinatal literature, I wish to return to Bains *et al.,* (2023) study, which highlighted positive experiences of perinatal mental healthcare as characterised by empathy, kindness, being remembered and professionals showing interest in the broader lives of patients. These are all highly relational practices, (i.e., those which rely on relationships and connections between people) indicating that relational understandings of access to care could be valuable to draw upon. Bains *et al.,* (2023) also highlight that often in access-related research the focus is on negative aspects of patient experience, on what has gone wrong, which illustrates there is analytical value in paying attention to the facilitators as well as barriers to accessing high quality care.

To conclude this synthesis of the perinatal mental health literature, I have highlighted three significant areas of concern in relation to maternal mental health that warrant further investigation; areas which could meaningfully be examined using sociological lenses. These areas are access to care, stigma and risk. One critique of studies of access to healthcare, such as that by Jankovic and colleagues (2020) is the reductive use of 'utilisation' as a measure of equity of access (Dixon-Woods *et al.*, 2006). This, as well as the limitations highlighted by Sambrook Smith *et al.*, (2019) and Prady *et al., (2021),* suggests qualitative exploration of access to perinatal mental healthcare, informed by different conceptual understandings of access, may be a valuable focus for this research. I have illustrated how ubiquitous talk of stigma is within the qualitative literature and how it is talked about in taken-for-granted ways. As such, our understanding of this social process in the lives of women with perinatal SMI is relatively thin, meriting further inquiry. I have also demonstrated a preoccupation with risk within the perinatal SMI literature and perinatal mental health discourses more broadly. Sociology has critically examined the concept of risk and these perspectives may usefully be brought to bear within a study which seeks to understand perinatal mental health(care). Rubio *et al.,* (2021) findings regarding risk management negatively impacting patient care indicates a potentially fruitful avenue for future research; one which seeks to understand *how* different risk practices and discourses may impact women who are treated in different settings or at different points in their perinatal journey.

Conclusion

This chapter has brought together literature from a wide range of disciplines to situate this study of motherhood and mental health. This is necessary because much of the research on women's experiences of perinatal mental health and illness have not been situated within more critical, socio-culturally informed understandings of mental health, motherhood or the wider determinants of health and inequity. This is needed to understand the social influences on women's experiences, maternal mental health and healthcare.

Prior research on perinatal mental health has provided strong evidence on the nature and distribution of perinatal mental illnesses and has demonstrated that previous psychiatric illness is an important risk factor for perinatal SMI. Quantitative evidence has also indicated inequalities in access to perinatal mental healthcare exist for women from minoritised ethnic groups and women from lower socioeconomic backgrounds. Qualitative research suggests stigma may affect help-seeking and be present within healthcare encounters. It also demonstrates both women and professionals are concerned about different forms of risk and risk-related processes, making it a common discourse in relation to maternal mental health. In relation to risk, examining the qualitative research has also potentially signified differences in the 'risk' concerns of women and professionals. Sociological perspectives on risk (outlined in the next chapter) suggest these may be fruitful differences to illustrate, analyse and understand the consequences of, and indicates that a qualitative investigation, drawing on the experiences of women and health professionals, is warranted. A key focus of the

qualitative literature on perinatal SMI is on the *postnatal* experiences of women, highlighting an empirical gap in understanding women's wider (i.e., preconception and antenatal) experiences. Detailed investigations of the wider context of women's lives will contribute to a richer understanding of motherhood and mental health. A significant limitation of the qualitative research literature on perinatal SMI is that it has unintentionally foregrounded and universalised the experiences of women from relatively narrow social locations, indicating qualitative research with a more diverse group of women may be needed. The gaps identified in the perinatal mental health(care) related-literature in particular have been key to framing the study's aims, objectives and research questions.

Sociological theories, methods and concepts, in view of the attention they pay to the wider social contexts in which experiences of illness take place, can improve our understanding of health and healthcare. In the next chapter of this thesis, I will summarise, critique, synthesise and connect key sociological understandings of access to care, risk and stigma. I will bring these into dialogue with insights from research on both perinatal mental health and maternal health more broadly to illustrate how they may be of value to the framing and analysis of this study.

Chapter 3: Conceptual Framework

Introduction

Sociological theories, methods and concepts, by reason of the attention they pay to the wider social contexts in which experiences of illness take place, can help improve our understandings of health and healthcare. The previous chapter highlighted key areas of concern and taken-for-granted concepts in the literature on perinatal SMI. I argue these areas can be explored productively through sociological lenses; areas to which the terms stigma, access to care, and 'risk' are applied. To the best of my knowledge, the sociological understandings of the three concepts I outline in this chapter have not yet been applied to this aspect of women's health. I argue there are opportunities to make a meaningful and original contribution to knowledge about maternal mental health by drawing on critically orientated work on these topics. This chapter summarises key sociological work and conceptualisations of access to care, risk and stigma. It synthesises these with insights from research on both perinatal mental health and, more broadly, maternal health to illustrate how they may be of value to the framing and analysis of this study. The strengths and limitations of the perspectives are discussed together with how the literature suggests the concepts may fit together. The connections between the concepts are also rendered visually in a conceptual framework diagram.

Access

In previous chapters of the thesis, I demonstrated that inequalities in access to care is a core area of focus within the perinatal mental health research literature as well as in the key health system (NHS England, 2024a) and advocacy discourses (Maternal Mental Health Alliance, 2023b). As I illustrate in this section of the chapter, "access" is a complex concept but one that was briefly introduced in Chapter 1 as the use of healthcare resources to preserve or improve (ill) health (Guilliford *et al.,* 2002). Utilisation of healthcare is often used in quantitative studies seeking to understand equity & access to care. However, studies using 'utilisation' have been critiqued as reductive, over-reliant on normative assumptions about what the 'right' level of use is, and uses poorly conceptualised estimates of 'need' (Dixon-Woods *et al.*, 2006). As discussed in the previous chapter, studies such as Bains *et al.,* (2023) illustrates that accessing healthcare and the delivery of care is contingent on highly relational practices (i.e., those which rely on relationships and connections between people). Sambrook-Smith *et al.,* (2019) also highlight the relative scarcity of research on access to perinatal mental healthcare which focusses on institutional and structural factors. This indicates that research informed by relational understandings of access to care could be valuable as well as that which uses lenses which draw in to view meso- and macro-level influences on access. It is for these reasons that I selected the concepts of candidacy and cultural health capital to form part of the study's conceptual framework.

Shim's concept of 'Cultural Health Capital' (CHC) draws upon Pierre Bourdieu's notions of cultural capital (i.e., the non-material, non-financial assets that help people succeed in life) (Shim, 2010). Shim argues that CHC accrues with the enactment of particular health-related

practices, for example, using medicalised language, being ‘health literate’ and having the resources to practice ‘self-discipline’. In healthcare encounters, she argues, we respond in ‘habitual ways that are rooted in experiences, schemes of thought and perception… and general sensibilities about how the world works’ (Shim, 2010, p.4). She cautions against thinking that individuals can gain and use these resources at will as CHC is embedded ‘within durable social processes that produce inequality’ (Shim, 2010, p.4). Finally, she impresses that CHC is ‘profoundly relational’, that healthcare providers and institutions do not just passively respond to patient’s CHC, but rather signal to them the kind of patients they want them to be (Shim, 2010).

Dixon-Woods *et al.*, (2006) notion of ‘candidacy’ conceptualises access as a process which involves iterative interactions between potential patients and healthcare professionals and suggests that there are various stages in this process at which barriers can exist which restrict access to care. These stages include people recognising their condition as in need of support (‘identification of candidacy’), knowing where to go to get support (‘navigation’), the ease with which people can use a service (‘service permeability’), asking for help (‘appearances at health services’), professionals’ judgements about whether patients need help (‘adjudications’) and offers of and resistance to care (Dixon-Woods *et al.* 2006). They also argue that these stages are influenced by broader institutional and structural factors which impact on the availability of resources (‘the operating conditions and the local production of candidacy’) (Dixon-Woods *et al.* (2006). In common with cultural health capital, candidacy emphasises socially patterned perceptions of health and healthcare services as important factors in regards to access. Shim’s (2010) attention to the clinical encounter and the ‘codes’ of presenting (i.e., using medicalised language, providing a coherent account of symptoms) within them add to the ‘candidacy’ model’s latter stages, particularly ‘appearance’ and ‘adjudication’. Dixon-Woods and colleagues (2006) describe the different ways middle-class people may present in healthcare settings that influence professionals to review their claims to care as valid, therefore granting them access to services.

Candidacy has been applied to studies of other aspects of women’s healthcare (Hinton *et al.,* 2023) and mental healthcare (Liberati *et al.,* 2022), suggesting they may be useful in the context of understanding perinatal mental health. If applied theoretically to perinatal mental healthcare, these perspectives suggest women’s access to help and support for mental health in the perinatal period are negotiated, highly complex and dependent on previous experiences of healthcare. The concepts of Cultural Health Capital (Shim, 2010) and Candidacy (Dixon-Woods *et al.,* 2006), with their emphasis on the relational in conceptualising access, underscore the need to understand the perspectives of both patients and healthcare professionals in any investigation of access to perinatal mental healthcare.

CHC’s emphasis on the importance of histories of engagement with services is related to another concept within theories of access, ‘recursivity’. Kovandžić *et al.,* (2011) articulate recursivity as the interdependency between a user’s past experiences of health services and their future help-seeking. They argue help-seeking behaviour is mediated through not only personal experience but also through what people have heard through their social networks and they then internalise this experience as if it were their own. Secondly, they articulate the concept of ‘imagined services’ – which they describe as underlying assumptions about services. This concept may be useful to understand how the experiences of women who may have had significant contact with secondary mental health services in the past, might perceive perinatal mental health services in the future.

These three concepts, forming part of this study's conceptual framework, were brought together purposefully. Whilst the concepts of candidacy and cultural health capital do emphasise connecting the interpersonal to broader structural forces and conditions, there is a distinct emphasis on the patient-professional dyad at the exclusion of other forms of social relationships in patients' lives (i.e., that of their wider social networks). They also are distinctly ahistorical (i.e., in that they do not emphasise the importance of past experiences of healthcare). It is for this reason that CHC and Candidacy are brought together with the concept of Recursivity to guide the data generation an analysis.

Stigma

As highlighted earlier in the thesis, stigma is commonly discussed by women and healthcare practitioners in qualitative perinatal mental health research (and more broadly in perinatal mental health-related literature). It's often posited as a factor influencing women's help-seeking (Noonan *et al.* 2018; Tripathy, 2020). In a systematic review, Hadfield & Wittkowski (2017) highlighted women across several studies perceived there was stigma attached to postnatal depression and had internalised this stigma through feelings of shame and embarrassment. Their analysis locates women as the source of the stigma they experience but does not interrogate where these ideas arise from. As argued earlier in Chapter 2, despite its ubiquity in accounts of lived experience and as an analytical theme in much of the qualitative perinatal mental health literature, stigma is often used as a 'taken-for-granted' term and rarely clearly conceptualised. Trying to understand stigma in more depth, and from a deeply sociological perspective, may be a potentially fruitful area of inquiry. Earlier in the thesis, stigma was briefly defined as a social force which has negatively affected individuals and communities with characteristics that are deemed socially 'undesirable' (Tyler, 2020).

Stigma has a long history as an object of sociological inquiry, with many regarding Erving Goffman's work from the 1960s as foundational to our understanding of stigma (Tyler, 2020; Scambler, 2009). In *Stigma: Notes on the Management of Spoiled Identity* (2022), Goffman argues that stigma is generated socially when a person fails to maintain or inhabit a set of imposed norms and that both the stigmatised and the unstigmatised are born from the same collective norms. (Goffman, 2022, Chapter 4). Whilst Goffman's work has been heavily critiqued within the discipline of sociology, it has an enduring popularity outside of the discipline which has left a problematic legacy (including within mental health-related discourse). Critiques have centred on how Goffman's work obscures the perpetrators of stigma, of the role of institutions and of broader systems of power in producing and reproducing stigma. It is for this reason that I have selected more recent sociological work to form part of this study's conceptual framework, work which centres the perpetrators (rather than the stigmatised), institutions and structural forces which may generate stigma.

Imogen Tyler (2020) argues that Goffman's account of stigma is strangely apolitical and denuded of power, 'both the macro-level structural power relations of patriarchy and the power-inflected micro-aggressions of everyday interactions' (Tyler, 2020, p.99). This blind spot, she argues, means that his account did little to analyse the role of those who were the *perpetrators* of stigma. The enduring popularity of Goffman's account in subsequent research on stigma has meant that stigma is conceived largely as 'a social problem that can be ameliorated through education, by changing individual attitudes and by teaching the stigmatised how to better manage the stigma pinned upon them' (Tyler, 2020, p.17).

This framing of stigma is prevalent within the perinatal mental health literature where references to 'more education' and 'more awareness' are rife: an example can be seen in

Humphreys and colleagues' suggestion that celebrity accounts of perinatal mental illness might 'encourage patients to defy stigma' (Humphreys *et al.*, 2016, p.365). One study which has sought to understand stigma in the context of perinatal SMI is that by Edwards and Timmons (2005) who conducted a qualitative study with six women who had been formally diagnosed with a serious postnatal mental illness with no previous psychiatric history. Goffman's work was referenced throughout and the authors found women's experiences of stigma were grounded in a concern that they were perceived as not fulfilling the societal norm of a 'good mother'. The authors suggested that stigma existed within health services, as have other studies highlighted in this review (for example: Dolman, Jones and Howard, 2016). This relates to Tyler's conceptualisation of stigma which she argues is often woven into structures providing disciplinary and social control functions (Tyler, 2020). As Busfield (1989) and Rogers & Pilgrim (2021) have outlined, some argue social control and discipline are a primary function of psychiatry. Tyler further argues that within the context of austerity, stigma circulating in systems of social provision make help-seeking a 'desperate task'. Tyler's perspectives thread together the concepts of access and stigma, which I have illustrated are central problems in the context of perinatal mental health(care).

Tyler's account of stigma draws upon the work of Bruce Link and Jo Phelan, which has gained significant influence in the last twenty years. They conceptualise stigma as processes of labelling, stereotyping, separation, status loss and discrimination that can only occur in a context where power is exercised (Link and Phelan, 2001). With respect to power, they assert that whilst individuals may create labels and stereotypes and treat others differently on the basis of a characteristic, if those individuals do not possess forms of power (social, cultural, economic, political) to enact serious consequences on those they think poorly of, then they cannot be said to be stigmatising the other. In other words, 'while [these] cognitive processes may be necessary […] for the production of stigma, they are not sufficient causes' (Link and Phelan, 2001, p378). They also highlight a tendency of stigma research to portray stigmatised individuals as passive and helpless victims. They remind us that many stigmatised individuals engage in acts of resistance, challenging stigma, rejecting or reclaiming labels.

Link and Phelan also highlight key limitations of research into the phenomenon of stigma. They argue the literature is overwhelmingly piecemeal, comprising studies often investigating single outcomes at an individual level of analysis, ignoring structural conditions, for example, how institutional practices or policies disadvantage those with stigmatised characteristics (Hatzenbuehler, Phelan and Link, 2013). They suggest research on stigma in the future should be multifaceted in its considerations of outcomes of stigma and multi-level in its considerations of sources. Their later work on the concept of 'stigma power' emphasises the role of the perpetrators, arguing that stigmatisers have strong motivations to stigmatise others. As stigma is purposeful for those who deploy it, addressing stigma is unlikely to be remedied by individually focussed, awareness campaigns but rather only via significant social actions such as liberation movements or legislative change (Link & Phelan, 2014).

Finally, Graham Scambler has written extensively on the topic of stigma in a specifically health-related context. He conceptualises stigma as a social process which is 'characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or a group' (Scambler, 2009, p.441). In the context of health-related stigma, Scambler notes that the stigmatising judgements are related to the health problem or condition in some capacity and is usually a judgement that is 'medically unwarranted' (Scambler, 2009). Applied to this

health context, this could manifest as a judgement that a mother with a history of mental illness is never going to be a ‘good’ mother, as illustrated in Torrey (2019).

An important aspect of Scambler’s work on stigma is his assertion that stigma and deviance have often been used as synonyms but that there is an important analytical distinction between these terms. He argues stigma indicates an ‘ontological deficit’ which invokes shame, but by contrast deviance is a ‘moral deficit’ which solicits blame. He has suggested that this distinction may be immaterial to those experiencing stigma but is an important sociological distinction (Scambler, 2012). This may be an important consideration when applied to understanding the accounts of women with schizophrenia or bipolar disorder compared with women whose perinatal mental illness ‘came out of the blue’.

In empirical work undertaken by Scambler and Paoli (2008) their account of stigma distinguishes between enacted or experienced stigma and felt or anticipated stigma. The former would be actions of discrimination enacted by others against the stigmatised, the latter involves a process of internalisation of shame and the anticipation of enacted stigma from others. Scambler and Paoli’s distinction between experienced and anticipated stigma coupled with Link and Phelan’s components (labelling, stereotyping, isolating, loss of status and discrimination) and condition (occurring in context of a power relation) of stigma will constitute important analytical definitions to apply to any relevant data generated.

As I have shown, stigma has a long and rich history as an object of sociological enquiry. This is also true in relation to understanding marginalisation and pregnancy beyond mental health. Wigginton & Lee (2013) sought to explore the often silenced and concealed experience of smoking in pregnancy and illustrated how stigma can operate to negatively influence women’s help-seeking practices. Women were subject to stigmatising discourses from friends, family, colleagues and health professionals that were both medical and moral in nature. Women both accepted and rejected stigma, sometimes simultaneously, and constructed themselves as ‘good’ mothers by framing their actions within discourses of risk management and harm reduction. In another study examining the experiences of women who use drugs during pregnancy, stigma was perceived as a significant risk factor by women which influenced their access to care. They perceived health professionals as both ‘adversaries and allies’ who could help them manage risks in pregnancy as well as stigmatise them through moralising attitudes towards their drug use (Stengel, 2014). These studies illustrate how specific conceptual understandings of stigma can help surface insights into how stigma influences access to care and its relation to risk-discourse. Using specific conceptual ‘tools’ to understand stigma that have arisen from the sociological literature may be helpful to draw upon in this study of SMI and women’s reproductive-related experiences.

As highlighted in earlier chapters, ideas about ‘good’ motherhood are governed by a set of specific norms, many of which may be disrupted by the experiences of mental illness. As such, an aim of this thesis is to explore experiences of stigmatisation within the context of perinatal mental health and care in order to better understand how these experiences might influence women’s reproductive-related experiences as well as their access to and experiences of care.

Risk

In Chapter 2, I demonstrate that risk is a common discourse in relation to both maternity and mental healthcare. Risk (such as access and stigma) is also a complex concept. In Chapter 1, it was briefly introduced as the possibility of negative outcomes occurring (Fischhoff &

Kadvany, 2011). Applied to the context of perinatal mental health, it can plainly be described as the possibility of negative health-related outcomes for women or children occurring. However, as I illustrate below and at other points in this thesis, it is a highly dynamic and somewhat mercurial concept in the context of perinatal mental healthcare.

Easter, Howard and Sandall (2019) highlight that risk in relation to maternal mental illness is complex and highly dynamic. It is an area of healthcare delivery where levels of risk can fluctuate rapidly and in a non-linear fashion. This is demonstrated in literature highlighting the prevalence of risk discourse and practices in perinatal mental healthcare. For example, Griffiths *et al.*, (2019) sought to compare the experiences of care given to women on MBUs and acute general psychiatric wards by drawing on data from both women and professionals. Within the themes of access and barriers, risk-related discourse was present in many of the quotes and much of the discussion, more specifically risk management, risk assessment and triage as well as the risk-related capacity of MBUs. This feature of the data relating to the theme of access indicates a deeper analysis of risk in the context of perinatal mental healthcare has the potential to yield interesting insights into the issue of access to care. Within Rubio *et al.,* (2021) study of home treatment for perinatal SMI, risk emerged as a common theme. The authors highlighted the risk-related conflict between women and professionals meant women were fearful of disclosing their feelings to professionals, in case they would be sent to hospital or would be deemed 'bad' mothers and have their children removed from their care. This illustrates that risk management and risk discourses pervade perinatal mental healthcare encounters in different settings and is an area that may be fruitful to examine in greater depth across different sites of care. Easter, Howard and Sandall (2019) exploring professional perspectives on mental health-related near miss events for women with perinatal mental illness, found that the care and attention women receive is strongly influenced by professional cultures and differences in understandings of risk held by the different professionals involved. They suggest that in order to prevent future near misses, attention should be paid to organisational and professional cultures within healthcare; something which sociologically-grounded research is well-placed to explore.

The sociological work I will draw upon to contribute to the conceptual framework of this study has been selected because it aligns with the philosophical positioning of this research. This is discussed in greater detail in the following chapter but, to briefly summarise, is grounded in an interpretivist paradigm. This perspective emphasises the importance of understanding the *meaning* embedded in social phenomena and the social realities that are constructed through interactions between different actors (Mason, 2018). Through this lens, 'risk' is not seen as an objective hazard that can be measured and quantified, but rather those occupying this position seek to understand how risk is perceived, experienced, constructed and given meaning (Lupton, 2013). In the context of this study, it is in the lives of women and professionals that I will seek to understand risk within. This will enable me to lend equal weight to the 'expertise' of both 'lay' and professional perspectives on risk in line with my feminist research approach. An approach which techno-scientific and positivist positions on risk do not enable, framing expert judgements of risk as 'neutral' and 'unbiased' (Lupton, 2013). A core critique of research which seeks to problematise the view of risk as objective and value-free is that is undermines "efforts do 'do something' about phenomena which may have harmful effects on people or the environment" (Lupton, 2013, pp.39-40). I argue that this study's sociological and feminist stance (discussed in more detail in the next chapter) means that the findings generated through this study in relation to risk will not just be thought about critically. They will also be thought about practically, to answer the question "so what?", what could these findings mean for improving care and practice?

The sociology of risk encompasses a vast and rich literature, and due to the prevalence of risk discourse in relation to maternal mental health, can provide useful insights into experiences of those both accessing and delivering perinatal mental healthcare. Some of this literature focusses specifically on pregnancy, which these authors argue is portrayed as inherently risky in settings where reproduction is highly medicalised (Lupton, 1999). Stengel (2014) and other feminist social scientists have argued that in contemporary societies in the Global North, much of professionals' work therefore seeks to monitor, minimise and manage risk. She argues that the ways in which risk is managed during pregnancy:

> *"locates risk within the individual woman's body and is based on the assumption that women have the ability and thus the responsibility [to] manage potential risks in their lives during pregnancy and birth" (Stengel, 2014, p.37)*

Ruhl (1999) argues that risk discourses in relation to pregnancy, with its focus on prevention and harm reduction, are dependent on the entrenchment of an ethic of personal responsibility. This individualisation of risk, where women are seen to have a responsibility to manage their 'risky' selves, has been conceptualised by Salmon (2011) as 'reproductive citizenship'. This is where women and mothers are expected to self-regulate and take personal responsibility for their actions, behaviours and choices for the health and wellbeing of their children (Lupton, 2012) and is a mechanism through which norms and expectations about 'good' motherhood are generated (Stengel, 2014). Ruhl argues that by examining risk discourses, attention can be drawn to 'the moral regulatory impulses that are hidden by the statistical calculation of risk' (Ruhl, 1999, p.3) which could in turn help us understand further the tension between empowerment and control that exists in the context of contemporary mental healthcare (Brossard & Chandler, 2022). Exploring this in a specifically perinatal context, to the best of my knowledge, has not been done before.

Lupton also argues that risk is of discursive importance in the establishment of norms. As discussed earlier, norms are central to concepts of stigma and also ideas of 'good' motherhood. In neo-liberal societies, the ideal citizen is one who is 'autonomous and self-regulated', one who seeks to 'maximise their life opportunities and minimise the risks to which they are exposed' (Lupton, 1999, p.61). In the context of pregnancy, Lupton identifies two expert concepts of risk: clinical risk and epidemiological risk (Lupton, 1999, p.63), which both locate women comparatively to other women. Lupton's account of risk and pregnancy is largely confined to corporeal concerns and maternal mental health is largely neglected. This is not to say that Lupton's conceptual framings of risk are not of value to studies of perinatal mental health; all women who are pregnant will encounter clinical and epidemiological concepts of risk. However, as there are many different professionals involved in the care and support of women with perinatal mental health concerns, and perinatal mental health services interface with many other parts of health and social care (Humphreys *et al.*, 2016), it is likely women will be subject to multiple concepts of risk. If referred to social services, women may be subject to those used in social work practice, if women are deemed to lack capacity to make decisions about their own care they may also be subject to those utilised in medico-legal proceedings (White, 2020). Corsico and Singh (2020) highlight that clinical and legal concepts of risk differ in nature and not acknowledging these different professional concepts of risk may have harmful consequences for patients. This underscores the importance of understanding what the implications of being identified as 'high risk' are for women too.

Lupton's empirical work highlights the differences between the risk discourses of women and that of experts and shows that women draw on the knowledge of experts and their own experiences, or the experiences of other women they know within their own cultural context

(Lupton, 1999, p76). Bell, McNaughton and Salmon (2009) highlight that risk discourse in relation to child health in the Global North is connected to practices of surveillance, intense intervention and legal sanctions for pregnant women and mothers. Their work suggests that whilst all women are subject to these discourses, some women are labelled riskier than others, particularly single mothers, women of colour and women living in poverty. This illustrates the need for contextualisation of accounts of risk from women occupying different social locations, further justifying the overarching aim of this study and my aims to recruit a diverse participant sample.

Constructing the conceptual framework

As illustrated above and in previous chapters, stigma, access to care and 'risk' are ubiquitous and often taken-for-granted concepts in relation to perinatal mental health - in research, policy, practice and advocacy discourses. I combine the perspectives on stigma, risk and access outlined in this chapter to form this conceptual framework for the reason that I believe their combination may help us to make more sense of the 'social' in relation to perinatal mental health(care). Specifically, I believe they can help generate knowledge about social determinants, social inequality and social stratification that is seen in relation to this area of women's health.

Figure 1 illustrates the links between the concepts that form the conceptual framework which literature outlined in Chapter 2 and in this chapter suggests exist. The links between the concepts are suggested within literature on both perinatal mental health and sociological work on pregnancy and maternity more broadly.

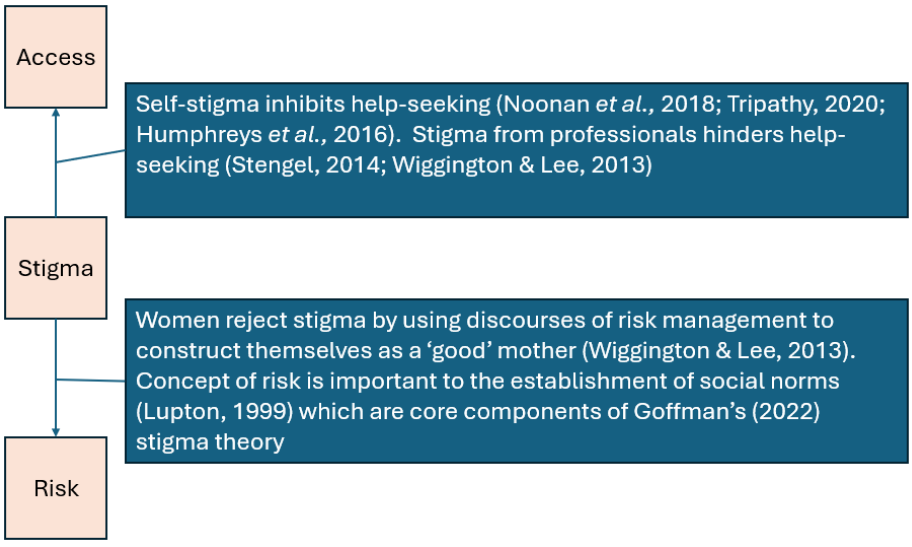

Figure 1: Conceptual framework diagram.

These concepts informed the research questions of the study. The conceptual framework informed the tools which supported the generation and analysis of data from women and professionals (i.e., it informed the interview guides, memo templates, coding frameworks).

Conclusion

To conclude, the conceptual work outlined above will, I believe, provide valuable lenses to apply to the issues of risk, stigma and access in the context of maternal mental health and healthcare. As outlined above, perinatal literature and sociological literature suggest productive connections between the concepts, which I hope to explore further through the data generated with women and professionals. I believe that using these conceptual 'tools' has the potential to deepen our understanding of the reproductive-related experiences of women with histories of SMI and their use of perinatal mental healthcare. In particular, with regards to the social processes, often not self-evident, which can generate inequity. Perspectives presented, justified and critiqued in this chapter constitute the conceptual framework for the empirical study, which most significantly will inform the analysis of data generated. A detailed account of the process of analysis (and particularly the coding of the data) can be found in the following chapter of the thesis, which outlines the study's methodology in more detail and introduces the study's participants.

Chapter 4: Methods and introduction to participants

Introduction

This chapter starts by outlining the overall research aims and questions guiding the study. It describes the disciplinary and philosophical positioning of the project and the rationale for taking a qualitative approach to answering the research questions. The chapter also includes discussions about reflexivity and positionality, an integral component of robust qualitative work, and follows on to describe the stakeholder engagement, which shaped the scope of the research, and outlines how this informed the development of my methodology. Following a discussion of research ethics, the most substantive part of the chapter details the methods used for data collection with each of the participant groups. I discuss significant challenges which arose during the course of the data generation and how I addressed these, before providing a detailed account of my approach to analysis. The chapter concludes with an introduction to the study's participants, detailing their demographic characteristics.

Research aims and questions

To reiterate the aims and research questions outlined in Chapter 1, the overarching aim of this study is to provide in-depth qualitative insights in to the reproductive-related experiences of women with a history of serious mental illness (SMI). More specifically, the study aims to bring sociological insights into dialogue with personal accounts of mental health and healthcare in order to:

- understand how stigma operates in women's lives at the intersection of their mental health and reproductive-related experiences;
- investigate barriers and facilitators to the receipt of perinatal mental healthcare care for these women;
- provide a nuanced account of how women and health and care professionals construct and experience 'risk' in relation to maternal mental illness.

Across these areas I aim to ensure that missing voices, including those of women from minoritised ethnic groups and women living in circumstances of deprivation are included in the research.

In service of the aims outlined, the study seeks to answer four key research questions. These questions guided the generation and analysis of the data. In Chapter 9, as part of the thesis' final discussion, these research questions will be responded to directly. They are:

- to what extent and in what ways does a personal or family history of SMI influence women's reproductive related experiences and experiences of stigma?
- what individual, institutional or systemic factors cause inequalities in access to perinatal mental healthcare and how could these be addressed?

- what can be learned by comparing professional and women's concepts of risk in relation to maternal mental health and healthcare?
- what are the implications for women if they are identified as being at high risk of developing perinatal SMI by healthcare professionals and how does class and ethnic identity shape these processes?

Disciplinary, epistemological and ontological orientation

Qualitative research is especially useful in investigating sensitive, challenging or difficult areas of social life (Silverio et al, 2022) as it provides opportunities for participants to explain experiences in great depth and for qualitative research on topics related to health help to unpick and illuminate the 'mundane or taken-for-granted aspects' of health and healthcare (Bourgeault, Dingwall and De Vries, 2010, p.5). The aims and questions of the research, with their emphasis on both sensitive (stigma) and everyday (access, risk) aspects of maternal mental health(care), justify the use of a robust, theoretically-informed qualitative approach. This approach will facilitate the development of an in-depth understanding of the reproductive lives of women with a history of SMI, paying particular attention to interactions with healthcare.

This thesis draws on perspectives from the academic discipline of sociology as well as public health and health services research. Research in sociology is often grounded in constructivist or interpretivist paradigms, in which researchers seek to clarify the subjective meanings and interpretations people make of their own lived experiences (Mason, 2018). This is in contrast to research in disciplines that are traditionally contributing to the perinatal mental health literature (epidemiology, psychology) and which are often grounded in positivist approaches (commonly framed by the medical model (Joseph *et al.*, 2009)). This means conducting research that pursues 'facts' that illuminate an objective reality (Giacomini, 2010). The assumptions underlying positivist paradigms are often taken for granted. As Marecek (2003) argues, many researchers operating in these paradigms "swim in the waters of logical positivism, empiricism, realism and quantification without knowing they are wet" (Marecek, 2003. p.51), thus underscoring the importance of clarity about the philosophical positions underlying research. This study is grounded in an interpretivist approach: ontologically, this position assumes that 'the social world is constantly being constructed through group interactions and thus social reality can be understood via the perspectives of [the] social actors enmeshed in meaning-making activities' (Hesse-Biber, 2017, p.6); epistemologically, this interpretivist position views researcher and participant as 'co-creators' in the generation of knowledge with an emphasis on the participant perspective (Hesse-Biber, 2017), hence why throughout the thesis I will use the term data generation rather than data collection.

Feminist Research Paradigm

This research is situated in a feminist research paradigm. Historically, feminist research has focussed on women's experiences, highlighting gender norms and systemic patterns of gender inequality. Feminist research increasingly has sought to understand how gender intersects with other identities, positions or experiences (e.g: class, ethnicity, disability). In doing so it has sought to centre women whose voices are marginalised, seldom sought or heard within discourses relating to particular areas of inquiry (Hankivsky *et al.,* 2010). Research in this tradition seeks to illustrate the ways social norms, practices and structures generate inequality and injustice, which is experienced differently by different groups of

women (Leavy & Harris, 2018; Ackerly & True, 2008). Feminist research often, but not exclusively, utilises qualitative methods. These methods help us to understand experiences and subjectivities in-depth, rending visible the often invisible complexities of social life. Core to this are epistemological and ontological positions which take a critical stance on the concept of objectivity (Bell, 2014). Feminist research also utilises a particular set of ethical practices in its endeavour to be inclusive and seeks to finds ways of disrupting dominant power relations between researcher and participant (Bell, 2014).

This topic of this research is clearly within the feminist tradition in that it seeks to understand the gendered reproductive-related experiences of women with a history of SMI. Its research questions are focussed on generating understanding of how social norms, practices and structures affect women occupying different social locations. As described above, its epistemological and ontological underpinnings align with a feminist research paradigm. Applying feminist research practices within my research, I designed the study to take place in phases which were purposely planned to centre women's voices. I thought carefully about how to recruit a diverse participant group, to include women whose narratives are not often present within literature on perinatal SMI. I also consulted women with lived experience of perinatal mental illness to help shape the research focus and design as a way of disrupting power imbalances between researcher and researched. Each of these aspects is described in greater detail later in this chapter.

Justification of Methods

Mason (2018) argues that talk-based methods and qualitative interviewing in particular serves well those whose ontological position values people's 'knowledge, views, understandings, interpretations, stories, narratives, language and discourses, experiences, interactions, perceptions, [and] sensations' (Mason, 2018, p. 111) as meaningful to the social reality being explored. Therefore, talk-focussed methods, such as interviews and focus groups, align well with the nature of the research questions this study is seeking to answer. A range of talk-based methods was considered whilst scoping the study.

For data generation with women-participants, an unstructured interview technique, largely informed by Spradley's work on ethnographic interviewing (Spradley, 1978) was deemed to be the most appropriate. May (2011) argues that unstructured interviews allow for the generation of data characterised by great qualitative depth because it allows the participant "to talk about the subject of interest within their own frames of reference… drawing upon ideas and meanings with which they are familiar" (May, 2011, p136). I thought this particularly important for this study on the grounds that I was seeking to interview women from a variety of different sociocultural backgrounds who may draw on different 'idioms of distress' (i.e., culturally informed, alternative modes of expressing distress when talking about their experiences of SMI (Desai & Chaturvedi, 2017)). As SMI is stigmatised, it was also anticipated that women may use euphemistic ways of speaking about or around the topics of interest. In addition, as discussed in Chapter 2, methodological insights from other qualitative perinatal research indicates that women wish to start telling their stories of illness from starting points that are important to them, often pre-pregnancy (Glover *et al.*, 2014). All of these considerations justify taking an unstructured approach to interviewing, which is not commonly utilised in other qualitative studies in the perinatal mental health literature.

It is important to be mindful of the limits to what can be 'known' through qualitative interviews. Qualitative interviews do not provide direct 'access' to events and experiences of participants. Interviews are a social interaction where participants' representations and

accounts of their experiences may be shaped by that interaction (Kelly, 2010). It is also a form of data collection which is reliant on participants' abilities to remember and on skills such as the ability to express one's self and narrate past experiences (Mason, 2018). These qualities of this form of data generation mean it is especially important to be reflexive and consider the ways in which the relationship between the researcher and participant and the interaction between them in an interview setting may shape what is discussed (Kelly, 2010).

For data generation with professionals, talk-based methods, particularly group interviews and focus groups, were deemed appropriate as they can reveal convergences and divergences in norms and perspectives that may exist between different professional groups (May, 2011). They are also useful for revealing group dynamics and interactions (Mason, 2018), which in this research context is crucial as women with SMI come in to contact with different groups of professionals throughout their perinatal journeys. Smithson (2008) cautions that focus groups may be likely to reproduce 'socially accepted, normative discourse […] people with unpopular views […] may be reluctant to air their views in a group context' (Smithson, 2008, p364). To mitigate this, 'ground rules' encouraging the respect of different view-points were shared with participants prior to participation (King, Horrocks and Brooks, 2019).

I purposely chose to use a different methodology with the different participant groups. Focus groups with professional participants were selected as I thought they would best generate data in-depth discussions of similarities and differences in practices and understandings of issues in perinatal mental health(care) between different professional groups and between professionals practicing in different regions of the UK. Smithson (2008) highlights that focus groups can also generate and reveal interactional dynamics between participants. Therefore, it was reasonable to assume that they could also highlight interactional differences that may operate in the context of healthcare delivery between professional groups. Focus groups were considered in the early stages of scoping this project for use with the women participants. However, due to the sensitive nature of the research topic, focus groups were not ultimately used with women participants. The rationale for this decision is described in more detail in the 'stakeholder engagement' section later in this chapter. Although there is a strong rationale for utilising focus groups with professional participants in this study, part-way through the data collection phase with professionals, I chose to 'flex' my methodological approach because in practice they were difficult to implement. The rationale for this decision is described later in the chapter, in the section on 'difficulties and challenges'.

Prior to discussing reflexivity and positionality in greater detail, I wish to highlight the issue of quality in relation to qualitative research; an issue which is highly contested along paradigmatic lines (Melia, 2010; Kelly, 2010). In line with the orientation of this research, several approaches have been taken to illustrate its quality, drawing on aspects outlined by Mays and Pope (2000) and Kelly (2010). Firstly, a transparent and detailed account of the sampling strategy, methods of data collection and analysis are presented later in this chapter. Attention to negative cases has been paid (Mason, 2018; Lareau, 2021; Kelly, 2010) during analysis and will be discussed in subsequent results chapters where relevant. Reflexive and detailed considerations of the relationships between researcher and participant is also an important component of high-quality qualitative research (Kelly, 2010). These considerations are developed below.

Reflexivity and positionality

In contrast to positivist oriented research, feminist researchers operating in this interpretivist paradigm do not see the researcher as an objective, neutral observer (Roberts, 1981). Therefore, it is important that researchers are explicit and reflexive about the assumptions they bring into the research process and how these shape the data generated, its analysis and interpretation (Finlay, 2002). Throughout this chapter and the wider thesis there are reflexive statements. They illustrate how I have been responsive to challenges and how the decisions I have made have influenced the shape of the project overall. Being reflexive about one's positionality in relation to the research, particularly thinking critically about how data is generated and analysed, is part of striving towards quality and rigour in qualitative research (Lareau, 2021; Mason, 2018). Finlay has articulated several forms of reflexivity; the nature of the reflexive research practices I employed and the statements I have made throughout the thesis are in line with Finlay's formulations and are introspective (self-reflections on my own beliefs/assumptions), intersubjective (reflections on the relationship between myself and the participants), socially-orientated (reflections on the broader contexts the research is taking place in) or discursive (reflections on the influence of language used in the research) in nature (Finlay, 2003).

In relation to this research topic, I see my position as an insider or an outsider as somewhat fluid, occupying the space between insider and outsider, neither fully one nor the other. I am perceived, based on my gender presentation, to be a woman, but I am not a mother. I have never been diagnosed with a mental illness nor have I ever been hospitalised for my mental health, although there is history of SMI within my family. My experiences of healthcare are likely not to be negatively influenced by my ethnicity (White British), but are likely to have been influenced by health professionals' perceptions of my social class (which has presented differently at different stages in my life) and my gender presentation. I am not a health professional, however, I have volunteered in women's healthcare settings supporting survivors of sexual violence. It is these parts of my own lived experience I think are particularly pertinent to this study. I anticipated at the start of the study that because of these positions, I may be more attuned to accounts of mental illness in women's wider families, accounts of classed experiences in relation to motherhood or in the clinical encounter, or accounts of trauma/trauma-based fear within healthcare settings. I believe these experiences and aspects of my identity influenced some of the research questions' focus on inequity. I believe the woman-centred work I had carried out previously in relation to sexual violence influenced the study design in that I believed women's experiences should be central to the research. I therefore decided to interview women first before interviewing professionals in order that the women's concerns were central to the analysis and focus.

My perception of my own positionality in relation to the research shifted throughout the course of the project, closer to that of partial insider. During interviews with healthcare professionals, we discussed who would be prioritised to access particular parts of the perinatal mental healthcare pathway. It became clear that it was not just women with a personal history of mental illness who were deemed 'high risk', but also those with a first degree relative who had a history of psychosis; I am myself in this bracket. Doing this research at a particular time in my life, where many friends and family are having their own children, meant this realisation became imbued with an ever heavier weight. A weight which likely contributed to greater emotional demand felt at different timepoints in the research than I had anticipated at the outset. Had the data collection with women not already ceased, I believe this may have influenced the ways in which I asked women about their reproductive decision making. It is not unreasonable to expect that this realisation influenced the analysis of women's and professionals' data. In particular that presented in Chapter 5 where I have

included a detailed account of the ways SMI is influencing women's reproductive decision making.

As outlined in Chapter 1, my interest in this area of research stemmed from several strands of my professional, academic and lived experience. During the scoping phase of the project (described in more detail in the proceeding section of this chapter), some of the women I spoke to initially assumed my interest in this topic was informed solely by lived experience. They assumed that I was a mother who had experienced mental illness perinatally. These early, informal conversations and literature on feminist research practices (for example, Leavy & Harris, 2018; Ackerly & True, 2008; Oakley, 1981; Doucet & Mauthner, 2008) informed my decision to tell women more about myself before the interview formally began. I shared much of what I outlined above in the sub-section above. Specifically what I shared can be seen in the interview guide which is included as Appendix 2.

I employed this as a strategy to reduce as much as possible the hierarchies between researcher and researched (Oakley, 1981) and to provide women with information so as they could assess the distances between their experiences and mine to make up their own minds about the extent to which I was an insider or an outsider. As the sample I recruited was heterogeneous across many aspects of identity and experience, it makes it difficult for me to state clearly whether I am an insider or an outsider in relation to the research and the participants. As Duncomb & Jessop (2012) highlight, the multiplicity of identities and experiences we all hold (e.g., class, ethnicity, sexuality) make that boundary between insider/outside inherently situated. Feminist researchers (see Doucet & Mauthner, 2008) have heavily critiqued the practice of rapport building in qualitative interviews and caution researchers to be mindful of the ethical tensions 'associated with the misuse of the interviewer's power of persuasion exercised through the ideologies of shared 'womanhood' and […] 'friendship'' which may inadvertently result in participants making unintended disclosures (Duncomb & Jessop, 2012). Prefacing the interview with personal disclosures was not a practice I employed to establish or simulate 'friendship' with participants or even to build rapport, but to outline where we stood in relation to one another. However, I think with some participants this practice may have helped build rapport and made women feel more at ease disclosing particular aspects of their experience. I discuss this in Chapter 5 in more detail.

I chose not to reveal these aspects of my identity/lived-experience to professional participants but this this decision was largely a practical one. I was acutely aware of the time pressures on professional participants and was mostly speaking to multiple participants at once, so I wanted to reserve as much time as possible for them to speak. This is not to say I revealed nothing of myself to this participant group, but I instead chose to foreground my outsider status in relation to our professional roles. I was clear I was not clinically trained and leveraged this professional naïveté during interviews and focus groups to probe further.

Before concluding this section, I wish to outline how I practiced reflexivity throughout the research. The practice of writing memos at different stages of the research process enabled me to reflect on the ways I thought aspects of my identity and lived experience may have influenced data generation. It also allowed me to see where I may have initially listened more keenly to participants' accounts on particular topics during the interview and to track how my attention might have been drawn elsewhere during subsequent readings of the data. Writing reflectively enabled me to challenge assumptions and document any discomfort I identified both in myself and in my participants. It was a vehicle for thinking critically about what discomfort or assumptions meant in relation to what was and was not disclosed, and how data was analysed. An example of a completed memo is included as Appendix 3.

Selected memos were shared with project supervisors during supervision meetings for deeper discussions in relation to positionality which enabled further reflection. Reflexive sections of participant-level memos and notes from supervision meetings were revisited during the drafting process of the thesis and relevant insights have been integrated throughout.

Scoping activities, stakeholder engagement and preparing for the field

My methodological approach combined with my professional experiences outside of academia shaped my desire to involve those affected by and working in the area of perinatal mental health in different parts of the research process. Whilst the funders of this research strongly encourage patient and public involvement (PPI) in the research process, this was not my primary motivation for undertaking stakeholder engagement. The activities I undertook aligned with my methodological approach as they centred lived experience and I was responsive to their research priorities and concerns. Whilst the National Institute for Health Research (NIHR) encourages the involvement of patients, the involvement of other stakeholders is not mandatory. Nevertheless, I wanted this research to be as relevant and impactful as possible and I therefore also sought to consult other relevant groups.

Stakeholder Engagement

During the first year of the PhD, in parallel with conducting the literature view, I had informal discussions with members of key maternal mental health stakeholder groups. This included four clinicians working in perinatal mental healthcare or maternity care; five staff of relevant local and national charities and thirteen women who had a history of perinatal mental illness. During these conversations I sought to understand their perceptions of the priorities for perinatal mental health research.

I contacted women with lived experience via community organisations, community leaders or social media. They were provided with an accessible summary of early research plans and draft research questions (included as Appendix 4) and they were also provided with a list of questions to reflect on in advance, to help guide their critical thinking. Women were given the option of providing feedback via a video-call, over the phone or via email. Nine conversations with professionals all took place via video calls. Women were provided with a shopping voucher as a small token of thanks, in line with NIHR guidance for PPI (NIHR, 2022).

Key professionals were identified through a stakeholder mapping exercise and contacted directly. Some professionals were provided with a similar document to the women, others were not, and conversations were less structured. Professionals were not provided with remuneration for their time. The stakeholder engagement, in parallel with insights from the literature view, influenced the aims, research questions and the methods as I will explain in more detail below.

The research proposal I submitted as part of my PhD application to the University was focussed solely on understanding more about the experiences of women in relation to a specific diagnostic category (postpartum psychosis). The shift of focus away from a single diagnosis to SMI more broadly was in-part informed by the literature (including areas for future research suggested by Howard and Khalifeh, 2020) and the views of clinicians consulted. Many stakeholders also talked about stigma. Women in particular underscored

the significance of stigma in relation to maternal mental health and this was echoed by much of the perinatal literature. In light of this, stigma became a key focus of the research aims and questions, where it had not been before.

During the initial stages of designing the study I had considered adopting a range of qualitative methods. Two potential methods for data generation with women participants I considered were focus groups or interviews incorporating photo or object elicitation. Literature indicates that incorporating creative elements into interviewing practice can facilitate discussions of difficult or sensitive subjects and can be empowering for participants, as they can set the direction of the interview and foreground issues which are important to them (Liamputtong, 2007; Mason, 2018). Qualitative studies from the perinatal mental health literature indicates how isolated women often feel during recovery from perinatal SMI and how peer support can be helpful in addressing this (Forde, Peters and Wittkowski, 2020). This led me to consider whether focus groups could be an empowering and appropriate method to use, one which could connect women to others who shared their experiences. However, women challenged these assumptions that I had made based solely on engagement with the literature. Some women said they would not take part in a focus group at all, others said they would participate but might not share a lot of their experiences because of fear of judgement. Women were also asked what they thought about being asked to bring along photographs, drawings or small objects and starting the interview by talking about the object they chose to bring. Many said they liked the idea of being in control of what to talk about, but were not keen on bringing objects to discuss. Some thought it might be difficult to find the time to think about what to bring alongside the day-to-day of childcare. Some thought they might feel stressed about whether the object they picked was the ‘right’ one to tell their story. Others said that picking an object could be a painful experience too. As a result, the research design was revisited and an approach to 1:1 interviewing was developed which would still encourage women to start their stories where they wanted but did not incorporate any creative elicitation techniques.

Women were not engaged at other points in the project due to limitations in financial resources, time and capacity. However, several women who took part in the scoping activities expressed interest in taking part in dissemination. Should I be successful in leveraging additional funds, it is hoped these activities could place after the submission of the thesis. My rationale for this is partly practical as I hope to have more capacity post submission to plan activities and write an application for funding. It is also hoped that the feedback I will receive via the examination process will further clarify the contribution of the research and the relevance of its findings.

Clinicians were engaged informally after data generation with women ceased and before data generation with professionals began. This was via presentations at clinical/academic network meetings. These informal conversations informed decisions about the length and timing of the interviews/focus groups with professionals. Feedback was also sought from a practising healthcare professional on the topic guide and vignettes used as part of the fieldwork with professionals.

Preparing for fieldwork

As outlined earlier in the chapter, I occupy an outsider positionality in relation to this work in many important ways. I am not a health professional, someone with a history of SMI or a woman with children. To enable me to ask more directed questions during interviews/focus groups and to generate data with greater depth, I sought to cultivate understandings of the lives of women and professionals’ practice.

It recommended that preparing for data collection on sensitive topics should involve familiarising oneself with the affective experiences of potential participants (Cowles, 1988). To do this, prior to starting fieldwork with women, I read a number of memoirs written by women who'd experienced different postnatal mental health conditions (Dockrill, 2020; Cho, 2021; Igwe, 2022; Brathwaite, 2020; Lam, 2015). I also listened to radio programs, podcasts and watched documentaries about perinatal mental illness. To prepare for fieldwork with professionals, I read relevant publications from professional organisations. I also shadowed a practicing health visitor on home visits and observed an multi-disciplinary team (MDT) meeting led by a specialist perinatal mental health team.

Research Ethics

Ethical approval to conduct the study was granted by the University of Sheffield Research Ethics Committee on 14th March 2022 (Ref: 043513). When granting approval for the study, the committee recommended an application to the Health Research Authority (HRA) be made, in order that recruitment of healthcare professionals could take place via their workplaces as well as outside of this route. This approval was granted by HRA on 3rd February 2023 (IRAS Project ID: 314145). All procedures related to consent and confidentiality were approved. Participants were provided with an information sheet and gave consent in either written, digital or verbal form. Information sheets and consent forms can be found in the appendices (Appendix 5, 6, 7 and 8).

Literature on the use of incentives in qualitative work indicates that both monetary and non-monetary incentives can facilitate participation but they should be modest in nature so as not to unethically coerce participants (Negrin *et al.,* 2022). I wanted to demonstrate gratitude towards my participants and, as such, small tokens of thanks were offered to both groups of participants in the form of £25 shopping vouchers. Following the suggestion of one of the clinicians consulted during scoping, professional participants were also offered a certificate of attendance for their CPD portfolios. All women participants accepted the token of thanks. 13 of 14 professional participants accepted the voucher and certificate of attendance.

Sensitive and challenging research topics such as the subject of this thesis create a possibility of causing distress to participants (Silverio *et al.*, 2022). In light of this, great care was taken to minimise the effects of emotional harm both during and following the interviews and focus groups. In practical terms, this meant participants were advised that they did not have to answer any questions they didn't want to and were told they could take breaks at any time or withdraw without justification. I was watchful of signs of distress during the interviews, and interview schedules were designed to be sensitive to participant welfare. In the days following the interview, I contacted the participants to check-in on their well-being since the interview and share the post-interview follow-up sheet. For women this included guidance on where to seek support if they were distressed (the follow-up sheet is included as Appendix 9). In line with university guidelines a formal safeguarding plan was also developed to ensure that there were escalation routes should any safeguarding issues arise.

The sensitive nature of the research topic has ethical implications for the research in terms of the data produced and the analysis. Owing to the sensitive nature of the topic and the potential vulnerability of women participants, it was not ethical to interview those who were still acutely unwell. Therefore the experiences of those women are not represented in the study. Cowles (1988) suggests that participants in highly sensitive research about their own experiences are often acutely aware of the responses of others to their narratives. In light of this I endeavoured to be non-judgmental in order to minimise any harm from participants

feeling stigmatised when they made difficult disclosures and to engender trust. For research on sensitive subjects, the issue of identifiability is particularly important, since it can generate (mis)trust between researchers, participants and broader systems/institutions (Silverio *et al*., 2022). It is also possible that there could be potentially serious material or affective consequences for participants if they were able to be identified. This has influenced how I think about confidentiality and what data I have chosen to present in the thesis so as to reduce the risk of identification of individual participants, i.e., their places of work, etc.

Due to the nature of the research topic, it was reasonable to anticipate that the research may also place emotional demands on me as a researcher (Kumar & Cavallaro, 2017). I had worked on sensitive subjects in relation to women's health before and as such knew the signs of deteriorating well-being and had developed suitable coping strategies. This combined with an awareness of how to access formal and informal means of support from the university was deemed by the ethics committee to provide a sufficient safeguard against distress generated by conducting the research. I anticipated that the data collection phase of the project may be the most emotionally demanding by reason of the interpersonal interactions that interviews involve. However, in reality, data analysis proved to be more emotionally demanding than data generation. Reed & Towers (2021) highlight how much of the literature on emotionally demanding research underscores the fieldwork phase as particularly challenging and go on to argue there are also significant affective dimensions to analysis. To address this, supervision with the project's secondary supervisor (a consultant psychiatrist) was conducted in a manner similar to clinical supervision. This also acted as a useful reflexive forum where I considered my own positionality and lived experience in relation to the data generated.

Methods: Data Generation

As discussed earlier, this research is grounded in an interpretivist approach which emphasises that the social world can be understood via the perspectives of different actors involved in making meaning (Hesse-Biber, 2017). Important actors in relation to the research questions include not just women but health professionals too. This interpretivist approach underlines the importance of generating a dataset which includes multiple perspectives. Both women and health professionals were interviewed as part of the study and different approaches to recruitment and data generation were used for the two different respondent groups. This section details the inclusion criteria, recruitment strategies, research locations, descriptions of the data generation processes, key challenges that emerged during fieldwork and how these were addressed. It is worth noting before proceeding further that in line with the research paradigm this study utilised, its aim was to generate in-depth accounts of experience rather than aiming to be representative of or generalisable to a wider population, which as Mason (2018) explains, is not commonly an aim of qualitative research.

Women participants

Inclusion criteria, sampling and recruitment

The inclusion criteria for women participants were women who had a personal or family history of SMI[11] and who were already mothers, were pregnant or who had contemplated

[11] On advertisements (see first item in appendix 10) for the study a guiding definition of SMI was included. This included examples of particular diagnoses, mentioned that participants may have received inpatient treatment for their mental health in the past whilst also emphasising that formal diagnoses were not required in order to take part. This definition was formulated in lay language and

becoming a mother. This criteria were selected since it is women with these characteristics who are eligible to receive care and support from specialist perinatal mental health teams.

Kelly (2010) defines convenience sampling as the seeking of respondents from easily located groups among a population and purposeful sampling as when the researcher uses a set of criteria 'to select respondents that are most likely to yield appropriate and useful information' (Kelly, 2010, p317) about the phenomenon of interest. Women who are mothers, pregnant or contemplating motherhood are easily located groups among a population. However, the common reproductive-related experiences and the additional criterion of having a history of SMI (which are relatively rare conditions within the population) indicate a purposeful sample criteria was used. However, I adopted a convenience sample approach to recruitment in that women who came forward and who met the inclusion criteria, which was made explicit in the recruitment materials, were invited to take part in the study. I did not use a quota sampling approach (Mason, 2018) to inform which volunteers I would go on to interview. i.e., I did not decline to interview anyone on the basis that I had already interviewed (for example, too many women with bipolar, or too many white women already) and one participant was also recruited via snowball sampling.

Women were recruited through different routes. The decision to recruit via social media, community & voluntary sector organisations and via physical spaces was intentional, as was the decision to not recruit via NHS services. A core domain of inquiry for this work was to understand more about inequalities in access to NHS perinatal mental healthcare services and it was therefore important to try to use modes of recruitment which would target women who were eligible to use these services, but may not have used them before. This approach was successful.

Most women were recruited via charitable organisations who promoted the call for participants through their digital channels (i.e., newsletters, Facebook pages). Women were successfully recruited via three main organisations, which included:

- A local-level perinatal mental healthcare charity located in the North of England;
- An umbrella organisation made up of grassroots survivor-led groups and people with lived experience of mental distress, ill-health and trauma from across the UK;
- A national-level charitable organisation that seeks to improve the inclusion of people with lived experience of mental health problems in research.

The study was also advertised via my Twitter account which is mainly used for professional purposes.

To ensure women who may have been digitally excluded were reached, posters were placed in a small number of physical spaces in my local area. This included a local mental health charity, in children's centres, a local food bank and a local library. I took this approach since I live in an area with a highly ethnically diverse population and much economic inequality. Language used in the posters was altered slightly from advertisements shared online, i.e., heading of the poster used "mental health conditions" instead of SMI. This was intentional, being mindful that people may be concerned about being seen by members of their local community to be taking a contact slip for a study about SMI.

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took into consideration both definitions of and critiques of the term SMI and the acknowledgement of the 'treatment gap' for mental health conditions.

Women referred themselves to the study by contacting me via email, WhatsApp or telephone/moblie, and were then provided with the study's participant information sheet and invited to ask questions in an introductory, informal telephone call with me or via email or WhatsApp.

Examples of promotional materials and information sheets can be found in the appendices 5, 6 and 10.

Research Location

Interviews took place between May and October 2022. Women were given the choice of the interview taking place in person, over the telephone or online via video call. In accordance with women's own preferences, all interviews took place online via GoogleMeet (n=15) or over the phone (n=5). It is likely the recent COVID-19 pandemic as well as some participant day-to-day routines (e.g., caring responsibilities) influenced women's preference for an online/telephone interview.

Whilst I believe that flexibility with the mode of interviewing enabled wider participation, it is important to be mindful that conducting the research online may have impacted rapport building and power dynamics in both positive and negative ways. Roberts *et al.,* (2021) suggest that rapport can be interrupted by technical difficulties, but also built by email correspondence prior to interview. Some interviews were affected by technical difficulties and other participants wished to correspond extensively prior to interview (I took their lead on this), which I believe helped establish rapport as I drew on subjects from our earlier correspondence during the interview. Roberts and colleagues also suggest that power can be shared by providing choice in relation to participation (Roberts *et al.,* 2021). I did this by providing participants with the choice of when and where the interview should take place and did not insist that participants appeared on screen should they did not wish to do so.

Although the interviews took place 'remotely', Mason (2018) reminds us that online interviews are not 'location-free'. With the exception of one interview, I conducted all of the interviews from my home. The majority of women took part in the interview in their own homes also: in their living rooms, bedrooms, children's bedrooms or home offices. A smaller number took part in the interview in less domestic locations, e.g., in a parked car, on public transport, in a hostel, a meeting room in their workplace. For some women, being at home may have made them more comfortable talking about such sensitive and emotionally weighty topics. For others, the presence of children, family members, support staff or the wider public clearly influenced the way they presented their narratives, I suspect in ways they may not have had they been alone.

Interviewing women

Prior to the first formal interviews with women, a pilot interview was conducted to ensure the interview structure, demographic questions and explanations of the project were clear. It also provided an opportunity to practice the largely unstructured interview technique. Feedback was sought from the pilot participant (a peer with experience of conducting qualitative research). Relevant feedback was incorporated into the interview guide and I was mindful of feedback on my interviewing technique (e.g., asking follow up questions with greater confidence) in future interviews. Although the interviews were largely unstructured, they were supported by a guide, acting as an aide memoir to the interviewer rather than a strict interview schedule (Hesse-Biber, 2017). A copy of the interviewer's guide is included as Appendix 2.

The majority of interviews lasted between 1hr 15mins and 1hr 30mins, although there was some variation. The shortest was 49mins and the longest was 3hrs 45 mins.

The interviewer's guide (Appendix 2) details the pre-interview discussion. Once the recorder was turned on, women were asked a series of closed questions intended to capture descriptive demographic information. This included questions about age, ethnicity, education, employment, housing, income support, family life and mental health. These questions were asked to ensure that the sample was diverse in terms of ethnicity, age and socioeconomic status, diagnosis and parity. In this part of the interview, women were also asked to self-describe aspects of their identity that were most important to them and asked if they'd like to pick a pseudonym. This was intended as an empowering practice for women and enabled women to choose meaningful or culturally congruent names if they wished. Around half the participants chose to pick their own pseudonym.

The most substantive part of the interview was informed by Spradley's ethnographic interviewing guide (Spradley, 1979). This part of the interview started with me outlining the 'explicit purpose' of the interview, and the 'ethnographic explanations', making clear to participants which aspects of their experiences as women I wished to learn more about before asking the expansive, 'grand tour' questions (Spradley, 1979) . This question invites the interviewee to provide a rich, detailed account, foregrounding things which are important to them. This was intended to provide an insight into how important features of the interviewee's experiences relate and fit together. Subsequent 'structural' questions were then asked to clarify particular points which arose and enabled enquiry into areas of relevance to the research aims, questions and key concepts.

To bring the interview to a close, in line with training I had received on conducting research on sensitive topics, questions with affirmative and empowering intentions were asked. After the recording ceased, prior to ending the call, I asked women about their plans for the rest of the day or week ahead, to mark a shift the conversation from past experience to the present and day-to-day.

Professional participants

Inclusion criteria, sampling and recruitment

The inclusion criteria for professional participants were health (and social care) professionals who were currently practicing in the NHS in England and were part of one of three professional groups. Professionals were excluded from participating if they were not currently in professional practice (e.g., they were retired), if they practiced in the other nations of the UK (Wales, Scotland or Northern Ireland) or belonged to a different professional group (e.g., were a GP, an obstetrician). These criteria were selected as women participants were all resident in England and was largely informed by the literature review and the scoping activities. Studies such as Easter, Howard and Sandall (2019) have highlighted different perceptions of risk existing between professional groups in relation to perinatal mental health; therefore seeking views of a range of different health professionals who support women was important. The women consulted as part of the scoping phase highlighted midwives and health visitors as important influences on their getting help.

Drawing again on Kelly's (2010) definitions of types of sampling (described earlier in the chapter), the sample criteria was purposeful, but I adopted a convenience sample approach to recruitment in that professionals who came forward who met the inclusion criteria, which was made explicit on recruitment materials, were invited to take part in the study. Only one

potential professional participant was excluded from the study, on the basis they claimed[12] they were practicing in Wales. I did not use a quota sampling approach (Mason, 2018) to inform which volunteers I would go on to interview or include in a focus group, i.e., I did not decline to interview anyone on the basis that I had already interviewed, for example, too many health visitors, or too many people practicing in the South East.

HRA approval was sought to recruit professionals working within two NHS Trusts. Eligible staff were told about the study via an email from team leaders. Participation in the study was voluntary. I also attended an in-person team meeting at one of the Trusts to promote the study and to answer questions from potential participants. 8 participants were recruited via their NHS workplaces.

The rest of the participants (n=6) were recruited via adverts on social media (n=1) or through drawing on relationships with relevant professional organisations/networks (n=5). Members of the organisations promoted the call for participants through newsletters, or email circulation.

Professionals (regardless of recruitment route) referred themselves to the study by contacting me via email. They were then provided with the study's participant information sheet and invited to ask questions prior to agreeing to take part in the study.

Research Location

Professionals were given the choice of participating in person or online via video call. A practical advantage of online focus groups is they enable participants who are geographically distant and time-poor to participate in research (Smithson, 2008). All participants preferred to participate online. Whilst participants were not explicit about their preference for online participation, I presume that this mode of taking part reduced the time burden of travelling to a meeting external to their workplace.

I conducted all interviews or focus groups from my home. The professional participants took part in their homes, their individual and shared offices and in staff rooms. For some professionals, particularly those who were participating in shared spaces in their workplaces, it is possible that this may have influenced the extent to which they could be critical or talk about challenges in their work.

Video calls were conducted via GoogleMeet or Microsoft Teams. Part way through the professional participant recruitment phase, an alternative video call software had to be found. The need for this was only apparent during the third focus group, when a potential participant was not able to join as their Trust had blocked all Google services. Moving forward, an alternative platform was identified and used, and Microsoft Word versions of consent forms were provided as an alternative to GoogleForms for participants who were unable to access them.

Data generation with professionals

Once the participants had agreed to take part in the research, a document was sent to them to read in advance. This included the ground rules for the group discussion (King, Horrocks and Brooks (2019, pp.93-113) and patient vignettes.

Data with professionals was generated via discussions in a focus group, paired interview or a 1:1 interview. Participants were allocated pragmatically, i.e., their schedules were the main

[12] I use the word 'claimed' deliberately, as will be explained later in this chapter in the section on "Bots and fraudulent participants".

determinant of what group they were allocated to or what format they participated in. A semi-structured technique to interviewing was employed. Conversations were supported by a topic guide which was developed in-part in light of preliminary analysis of the interviews with women. It was not feasible to conduct a pilot focus group; however, to test the language and flow of the topic guide I discussed this in detail with the project supervisors and also a practising healthcare professional.

The formal part of the interviews/focus group discussions had 4-5 key phases. Firstly, participants were asked to introduce themselves, their roles and a brief summary of their working week that week. Following these 'warm-up' questions, most participants were asked to discuss one of two vignettes. Vignettes are used in qualitative research to provide ways of talking about decision making in context and are particularly effective for exploring sensitive research topics (Barter and Renold, 1999). The vignettes were composed in-part to stimulate discussion around issues or topics which had arisen in light of the interviews with women. Work and employment was a strong sub-theme which emerged from women's data (which will be discussed in more detail in Chapters 5, 6 and 9), hence the vignettes included some occupational information. Many women interviewed had complex diagnostic histories which included some diagnoses being reformulated and as a result some diagnostic ambiguity was included in one of the vignettes. Three of the fourteen participants did not discuss the vignettes. This was by reason of unforeseen time restrictions on the interviews owing to busy work schedules or technical issues delaying the start of the interviews. Following a discussion of the vignettes, questions from the topic guide were asked which coalesced largely around the themes of access, risk and stigma (weighted more heavily on risk and access). Before the interview ended, mirroring the approach used with women, a more positively oriented question was asked as a 'decompressor'. Finally, participants were given the opportunity to talk about anything else they thought was important in relation to the topic that had not yet been discussed.

The approach to data collection with this participant group was highly iterative. Ahead of each discussion the topic guide was revisited and questions were reprioritised, added or removed in light of what had been discussed in the previous interview, and in light of the professional composition of the proceeding participant group.

An example topic guide and the patient vignettes can be found in Appendix 11.

Difficulties & Challenges

Bots and fraudulent participants

An issue which was not anticipated at the start of the project related to bots and potentially fraudulent participation. This is an emerging issue in relation to qualitative research conducted online (Pullen Sansfaçon *et al.*, 2024; Roehl and Harland, 2022; Owens, 2022; Ridge *et al.,* 2023).

In terms of bots, during the recruitment phase with women, I received several emails from potential participants that seemed unusual. Some of these were undoubtably from bots. Hallmarks of this kind of correspondence include responses from email addresses using traditionally male names, the structure of the email addresses that the messages came from, the times the messages were sent and the short, clipped content of the emails (see

screenshot (Figure X) below for example).

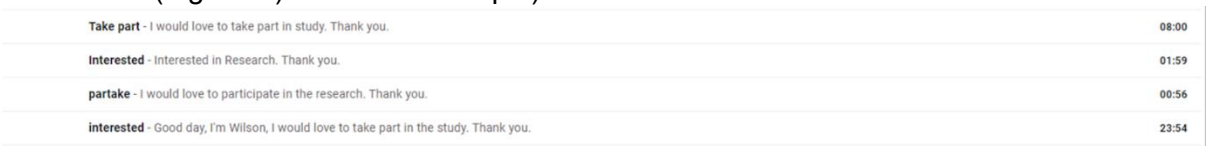

Figure [X]: Screenshot of emails sent from suspected bots

I ignored these contacts as I was confident they were automated. Other researchers have reported similar hallmarks in correspondence from bots (Santinele Martino, Perrotta and McGillion, 2024).

I explored this issue informally in dialogue with other qualitative health researchers from across the UK, US and Canada. Through these engagements, I heard stories of researchers interviewing participants they suspected were acting in a fraudulent manner. Learning about the details of their experiences led me to reflect on the interviews with women participants I had already conducted. A small number (n=3) of participants sprang to mind, whose engagement prior to and during our interview seemed different to other participants and mirrored some of the experiences of other researchers who had concluded that they may've interviewed 'fraudulent' participants (Ridge *et al.,* 2023) (Pullen Sansfaçon *et al.,* 2024).

During initial email correspondence, unlike other participants, they had included scant detail about their interest in the study. They were vague on their mental health histories and the number of children they had, even after being pressed for more detail. During the interview, their responses to questions had not been as in-depth and seemed a little generic in comparison to other participants. I also concluded the lack of depth in their responses may have been due to the presence of children and other family members where they were being interviewed. Additionally, they had not turned their cameras on. However, all these factors also seemed explainable. I thought language skills may have been a factor in the brief written communication and the comparative lack of depth in responses compared with other participants. I thought turning the camera off may be because they did not wish their children (who they were looking after at the time of interview) to be filmed. Not wishing to put in writing details of their diagnoses I thought could be for personal safety or privacy reasons. I also tentatively considered whether they may have suspicions about digital technology ("cyber-paranoia"), if paranoia or delusions were part of their experience of mental illness.

I had a detailed discussion regarding this issue with my supervisors, particularly around inclusion and exclusion of these participants' data. Ultimately, it was decided – as there were reasonable explanations for their interactions being different to other participants - to not exclude them from the study. In addition to practical rationales being possible for their interactions/behaviours it was also deemed an appropriate course of action which aligned with the epistemological and ontological underpinnings of the research. These orientations see interview data not as a direct 'window' to reality, but as co-constructed within the interview encounter and it is therefore difficult to draw a definitive line between 'truth' and 'lie' as argued by others who have encountered this issue (Owens, 2022). Whilst I did ultimately decide to include them, it is worth highlighting that their experiences are drawn on less in the thesis, as the level of detail they gave about their experiences meant that there was less richness in the data generated in these interviews.

The hesitancy and questioning about the legitimacy of some participants only arose after the data collection phase with women had ceased, and thus no changes to how eligibility for the study was verified were made. However, additional safeguards, based on what had been

learned informally from other researchers' experiences, were implemented for the data collection phase with professionals.

By the time I was recruiting healthcare professionals I was more aware of the issues conducting qualitative research online can engender. Other researchers I engaged with informally on this issue mentioned that professional participants are sometimes easier to screen and identify as their eligibility can be ratified through publicly available information. In the UK, potential participants can be asked to provide professional registration numbers that can be cross referenced with open source databases.

Whilst recruiting professionals, I received many emails which I judged to be sent from bots. They were sent from email addresses with similar formats, at unusual times of day, had similar subject lines and main bodies of the emails. I also received several emails which I judged to not be from bots, but the nature of the correspondence raised suspicions that they may not be from eligible participants. These potential participants often only offered vague details and emailed from private addresses[13]. Most legitimate potential participants in their initial contact email provided information unprompted. They shared their job title and professional role, what NHS Trust they were working in, where they'd heard about the study, why they thought the research was important, and they also often emailed from their work email addresses.

For potential participants who were not emailing from NHS email addresses, I did brief initial checks online before responding to their request for further information about the study. This included, for example, checking the Nursing and Midwifery Council (NMC) register and 'googling' their given name and "perinatal". If I was unable to find any relevant information to dispel my suspicions, I responded asking for the potential participant to confirm further information, e.g., asking which region of the UK they were practising in. I did not hear from many of these potential participants again following my probe for further information. There was one participant however who proceeded to provide further false information (they claimed to work for a charity which did not exist). I was able to turn down their offer to participate by stating that professionals working in the region they claimed to be practising in were not eligible to participate.

Professional-participant scheduling challenges

As highlighted in the first and later chapters of the thesis, there were (and continue to be) significant challenges facing staff delivering services. Discussions in interviews and focus groups with professionals confirmed this, as did the difficulties encountered in trying to recruit to focus groups. It is perhaps unsurprising that recruitment of professionals to the study was challenging in light of what is known about the operating conditions of the NHS presently. At the start of the fieldwork with professionals, focus group discussions were planned as the 'tool' to enable this. However, it was very difficult to recruit more than three participants to at a time for these. There were several reasons, for example, aligning part time working patterns of different participants, last minute changes to workload, and clashes with school holidays. Often apologies were sent last minute as changing clinical priorities or absences within the wider team had meant workloads had shifted rapidly and participating in the research was no longer feasible.

In response to this, it was thought that greater methodological flexibility was needed to ensure that enough participants could be recruited within the limited timeframe of the study. As such, data was generated via focus groups, paired interviews and 1:1 interviews. In the

[13] All were from Gmail accounts.

context of this study, focus groups were defined as groups of two or more participants who did not share a professional background and/or practised in different areas of England. Paired interviews were defined as conversations with two participants who did share a professional background and/or practised in the same region of England.

As data analysis happened in parallel with data generation, I brought quotes/themes emerging from earlier groups into the topic guide in order to simulate a focus-group style interaction. It is important to be mindful of how this pragmatic approach may have influenced the data generated, and not necessarily in solely negative ways. One participant interviewed 1:1 explained that had there been other members of their profession present, they may have been hesitant to express certain opinions. In groups or pairs with shared professional backgrounds, this seemed to enable more critically inflected talk of other professional groups compared with groups or pairs where the participants did not share a profession.

Analysis of data

As is common in qualitative research, analysis took place in parallel with data collection, throughout the two data collection phases and extended beyond this once the data set was complete. I used a thematic narrative approach to analyse my data, drawing on both thematic and narrative approaches to identify common concerns, experiences and sub-themes within the data. This was appropriate because the style of questions I had asked both groups of participants and the vignettes used with the professional participants, enabled the telling of stories and generation of data often (but not always) in narrative form. By this, I mean data characterised structurally as sequences of events told by ‘an embodied narrator from an experiential point of view’ (DeVault & Gross, 2011, p.220).

As Bornat (2008) summarises, there is no set, prescriptive way to analyse narrative data. However, I drew on several approaches outlined by others to analyse my data which I will detail below. To summarise succinctly: overarching themes were identified according to predefined areas of interest which stemmed from the study’s research questions and key areas of focus (reproduction, stigma, access and risk). Sub-themes within these areas were generated through close engagement with the data. Coding was a core part of the process of identifying subthemes.

I considered utilising a widely used, structured, highly prescriptive approach to thematic analysis such as Braun and Clarke’s Reflexive Thematic Analysis (Braun & Clarke, 2019) to analyse the data, but ultimately deemed this approach inappropriate due to its instruction that codes be generated solely inductively. A core aim of this research was to bring sociological concepts I had identified within the literature productively into dialogue with the data in order to advance our understanding of taken-for-granted issues and social processes relevant to perinatal mental health. In light of this aim, it was clear that coding would need to be both inductive and deductive. In addition, thematic analysis has been critiqued for the way it can ‘atomise’ or ‘fracture’ data, losing richness and context (Mason, 2018). Similarly, feminist researchers have underscored the value of analysing and utilising ‘longer stretches of talk’ as they ‘offer distinct possibilities for maintaining the coherence of a person’ perspective’ (DeVault & Gross, 2011, p.219),

Much – although I should stress not all – of the women’s data was in distinctly narrative form. Many of their stories had a beginning, middle and end as well as ‘characters’, and they described the distinct settings of their experiences. Many used metaphor and distinctly symbolic ways of talking about their experiences, so it was appropriate to incorporate elements of narrative analysis into my approach (Riessman, 2007). This is not to say that professional participants did not talk in narratively inflected ways. Distinct stories did emerge

from their interviews and focus groups, although this was rarer in comparison with the women participants. Because of the nature of the data set, I concluded taking a solely narrative approach was not appropriate either. Firstly, I was concerned that the voices of women I interviewed who did not give 'rich' and reflective accounts of their experiences might be marginalised by applying narrative analysis. Additionally, the relative scarcity of narratives presented in the professional data may have denoted that their perspectives may also have been marginalised in such an analysis. I therefore used a combination of narrative and thematic approaches to analysis.

Data Preparation

Immediately following the interviews or focus groups a reflective memo was completed. All interviews or focus groups were recorded and transcribed.

Of the 1:1 interviews with women participants, I transcribed 11 of the 20 transcripts. 9 were transcribed by university approved transcribers. Allocation of transcriptions was either random or based on the quality of the audio recording (i.e., recordings with poorer audio quality were transcribed by me). In the case of one interview, it was important to the participant that I personally transcribe our interview as they had specific concerns about confidentiality. I transcribed 3 of 7 transcripts from focus groups or interviews with professional participants, the remainder was transcribed by university approved transcribers. Allocation of professional transcripts was random.

Significant pauses, hesitant speech, laughter, inhales/exhales were noted in the transcript. Women participants transcripts were pseudonymised and anonymised with the replacement of specific names and places. The names of participants were replaced with a pseudonym (either participant selected or picked by me). Their friends and family members, names of healthcare professionals, geographical places, NHS Trusts/hospitals they were treated at, charities, workplaces were replaced with high-level descriptors. For professional participants, transcripts were anonymised by replacing names with professional roles and numbers to distinguish the participants. High level descriptors of the geographical region replaced NHS Trust names.[14]

Immersion in data and memos

Transcription is often argued to be a good way for the researcher to become more immersed in the data. To aid the process of immersion as an analytical step, whilst transcribing, I took hand-written notes in my fieldwork journal of things of note. This included drawing out parts of the data that were relevant to the research questions, gaps/questions the transcript left me with, any feelings the transcript brought up for me, etc. I then drew on these handwritten notes whilst completing the post-transcription section of the reflective memo for each interview/focus group. For transcripts created by university-approved transcribers I re-read/re-listened to the recording and followed the same process. Making notes in my fieldwork journal during the process of listening and using them as sources of information whilst completing the post transcription section of the reflective memo. Appendix 3 shows a completed example of a reflective memo. This process allowed me to see where my interpretations of the data had changed or stayed the same at a different point in the analytic process.

[14] Within this thesis I have used gender-neutral pronouns when discussing professional participant quotes in order to protect professional participant anonymity as there are significant gender imbalances in the relevant workforces.

Narrative clustering and 'writing with the data'

In order to read across the data, strengthen the observable links between women's experiences and start to build claims, I attempted to group women participants transcripts into clusters. I chose to not do this demographically (e.g., by age, diagnosis, ethnicity or social class indicator), but rather based on common aspects of experience women shared. Significant narrative groupings included:

- First episode of SMI was perinatal (n= 4)
- Significant social services intervention perinatally (n= 4)
- Hospitalised perinatally for mental health-related reasons (n =4)
- Women of faith/religious belief (n=5)
- Disclosed earlier trauma/abuse (n=10)
- Involvement of criminal justice actors in relation to their illness experiences (n=3)
- Disclosed own parents had history of mental illness (n=6)
- Estrangement/difficulty in relationship with family of origin (n=7)
- Born outside the UK (n=5)
- Not a parent but openness to motherhood (n= 3)

I then selected a small number of narrative clusters to "read closely" across. This process involved creating grid maps to compare aspects of their experiences and selecting some of the study's research questions to answer by drawing on the data from the small number of transcripts grouped together. This process was an important analytical tool enabling deeper immersion into the data.

This was a particularly important part of the process of analysis for the women's data as the narrative groupings and what women said informed the vignettes and topic guides used with professionals.

Coding

Coding is a crucial stage of much qualitative data analysis. In this analysis, coding took place in two stages and at different levels of 'depth', guided by Mason's descriptions of 'reading' data at different levels: literal, interpretive and reflexive (Mason, 2018).

Coding cycle 1: Descriptive coding

Women's transcripts were initially coded with 'high-level' descriptive codes which would allow their larger narratives to be drawn out of transcripts intact. This approach also allowed me to start to see connections between different concepts (e.g., how risk and stigma intersect). These high-level descriptive codes were generated both deductively (based on the research questions of the study and the main components of the conceptual framework) and inductively (based on important emerging commonalities across the dataset identified through the memo-ing process).

Table 1: 'descriptive' coding framework applied to women's transcripts only

Code Name	Description
Access – mental health services	Account of mental health-related care outside of the perinatal period - delivered in NHS/CVS/Privately

outside of perinatal period (MHSOPNP)	
Access – perinatal period (PNP)	Account of mental healthcare inside the perinatal period (including 'preconception'; Account of maternity-related care inside the perinatal period - delivered in NHS/CVS/Privately
Stigma	Descriptions of stigma in relation to their experiences; includes anticipated stigma, self-stigma and resistance to
Risk	Talk about risk in relation to mental health/illness; "worries" in relation to mental health/illness
RR Experience	Descriptions of reproductive-related experiences. I.e., deciding to have a baby or not, conceiving, pregnancy, birth, postpartum, motherhood
Social Services	Descriptions of encounters with social services; fears about social services intervention
Family	Where family members are mentioned in relation to Risk, Stigma or Access - includes family-of-origin, family of creation, extended family
Identity	Descriptions of women's concepts of their own identity, descriptions of their own identity/social positioning specifically in relation to their experiences of Risk, Stigma or Access.
Work	Where paid work and employment is mentioned in relation to Risk, Stigma, Access or Reproductive-Related Experiences

An adapted version of this same coding framework was used to code the data generated with healthcare professionals. Some of the codes from the framework above were removed as they were not relevant to this data set and descriptions for the codes were updated in light of the different orientation of the professionals' data.

Table 2: 'descriptive' coding framework applied to professionals' transcripts only.

Code Name	**Description**
Access - MHSOPNP	Descriptions of mental health-related care delivered outside of the perinatal period - delivered in NHS/CVS/Privately

Access - PNP	Descriptions of mental healthcare delivered inside the perinatal period (including 'preconception', account of maternity-related care inside the perinatal period - delivered in NHS/CVS/Privately
Stigma	Discussions of stigma in relation to perinatal mental health and patient, families, communities, etc., experiences
Risk	Talk about risk assessment/safeguarding, risk awareness, risk calculation etc. in relation to women's mental health/illness, talk about 'perinatal red flags'
Social Services	Descriptions of interactions with social services colleagues; interface between healthcare and social care
Family	Where family members are mentioned in relation to Risk, Stigma or Access - includes family-of-origin, family of creation, extended family

Once the fieldwork had ceased and the first stage of coding was completed, this approach allowed the relevant parts of each of the datasets to be brought together rapidly so that emerging themes and connections between them could be seen. Transcripts were coded in NVivo. I chose to use a digital tool to complete the coding process as the programme functionality allowed me to collate coded data from different transcripts easily and to iterate the code labels without difficulty as the framework developed.

Coding cycle 2: Interpretive coding

Interpretive reading and coding of the data enabled me to make sense of the data in light of the research questions, the literature review and other forms of immersion in the topic I had done, thereby facilitating deeper engagement with the data.

Data extracts coded as "RR-experiences" were further coded largely inductively and came solely from the women's data. Data from both respondent groups coded as "Stigma" was collated and subsequently coded at a deeper analytical level. This process was repeated for data coded as "Access - PNP" and "Risk". A mixture of both inductive (based on content of the data) and deductive codes (informed by the literature review and key concepts) was applied.

Using a shared coding framework enabled some integration of perspectives from both respondent groups. The foundation of the overarching coding framework was the data generated by women. This is in part for practical reasons, as the analysis of the interviews with women started much earlier and as data collection with professionals was ongoing. However, it has ensured women's voices and experiences stayed central to the analytical work.

Generation of sub-themes

During this stage I collated the coded data and undertook repeated readings of it, making notes of the patterns and commonalities seen in what I read, making lists, printing and

grouping codes or creating mind-maps of what, grounded in the data and literature, I judged to be significant themes and experiences.

During this stage, Lareau (2021) cautions analysts to be mindful that interpretations are not 'overly persuaded by particularly eloquent speakers' (Lareau, 2021, p.214) and that the existence of discrepant cases in the data should be acknowledged. A hallmark of high quality, qualitative analysis (see Lareau, 2021; Mason, 2018) is an analytical focus on "negative" cases (i.e., where participants' experiences or viewpoints differ from the main body of evidence). Being analytically robust by searching for 'disconfirming' cases enabled a more holistic view of the different aspects of participants' experiences to be brought to the fore. These cases are presented within the narrative of relevant sub-themes throughout Chapters 5, 6, 7 and 8. I collated quotes from different transcripts which addressed the arguments and claims which I was starting to build from the data. I also read, mapped and refined ideas about sub-themes in parallel with revisiting memos. These activities allowed me to see commonalities and coalescence in different participants' experiences but also give equal attention to experiences that differed.

Sub-themes are presented and discussed in each of the four results chapters. The results chapters are organised by the higher-order themes of reproductive-related experiences; stigma; access to care and 'risk'. They each speak to one or more of the study's research questions. As highlighted earlier in the thesis, the research questions were informed by the literature and scoping, which then informed the data generation and analysis.

Introduction to participants

Before concluding this chapter and commencing with presenting the findings of the study, I wish to introduce the study's 34 participants and share some of the characteristics of the two participant groups.

Women with history of SMI

20 women were interviewed in total. Women were aged between 23 and 63 at the time of interview (Mean Age = 38 years old). As outlined in Chapter 1, this study is utilising a broad definition of perinatal, including the preconception (or "zero trimester") period. With this in mind it is important to note that 6 participants were not mothers at the time of interview, 1 participant was in the late stages of pregnancy and the remainder (n=13) had 1 or more children. Table 3 details the participants' pseudonyms, age categories, parental status and whether they had experienced an episode of perinatal mental illness.

Table 3: Participant pseudonym, age, parental status and perinatal mental health history

Pseudonym	Age Bracket (at time of interview)	Parent at time of interview? (Yes/No)	Experienced episode of perinatal mental illness? (Yes/No)
Fay	40-49	Y	Y
Laura	30-39	Y	Y
Katie	20-29	N	N
Melanie	30-39	Y	Y

Stephanie	20-29	Pregnant	N
Fee	40-49	Y	Y
Asma	30-39	N	N
Sofia	50-59	N	N
Elton	30-39	Y	Y
Willa	20-29	Y	Y
Isa	40-49	Y	Y
Mae	20-29	N	N
Anna	30-39	Y	Y
Alice	30-39	N	N
Bella	40-49	N	N
Jeanette	40-49	Y	Y
Grace	60-69	Y	Y
Kimberley	30-39	Y	Y
Cammi	40-49	Y	Y

Participants were from diverse socioeconomic and ethnic backgrounds. As some perinatal mental illnesses are extremely rare, it is important I try to preserve the anonymity of my participants as much as possible and I therefore have chosen not to display ethnicity and socioeconomic characteristics within Table 3. Tables below provide some high-level ethnicity and socioeconomic information about the participants as a collective group.

Table 4: Breakdown of ethnicity of women participants

2021 Census Ethnic Group Category Selected	Number of participants
Asian or Asian British	4
Black, Black British, Caribbean or African	4
Mixed or multiple ethnic groups	1
White	11
Other ethnic group	0

Table 5: Socioeconomic characteristics of the sample

SES Proxy	Sample percentage
% participants who were homeowners	35%
% participants in receipt of income support	70%
% participants in employment	60%
% participants who completed higher education (i.e., with an undergraduate or postgraduate degree)	80%

The different diagnoses women participants disclosed having experienced included:

- Depression (including postnatal, antenatal and outside of perinatal period)
- Anxiety (including postnatal, antenatal and outside of perinatal period)
- OCD
- Schizophrenia/Schizoaffective Disorder

- Postpartum Psychosis
- Bipolar Disorder (Types 1 and 2)
- Eating Disorders (including Anorexia, Bulimia, ARFID)
- Personality Disorders (including BPD and EUPD)
- Trauma Disorders (PTSD or C-PTSD)

It is worth noting that, collectively, women's relationships with their diagnoses were profoundly complicated. Some participants rejected their formal diagnostic label. Some participants had formally and informally reformulated their experience around alternative diagnostic categories which they felt better described their experience (e.g., sought C-PTSD as an alternative to a personality disorder diagnosis, or ARFID as an alternative to Anorexia Nervosa). Some participants had retrospectively identified their distress as having a diagnostic label but did not seek help for it at the time and did not therefore have a formal diagnosis (e.g., with postnatal depression). It is for this reason that I purposely chose not to include the number of participants diagnosed with each condition listed above. However, for context the most common diagnoses included bipolar disorder (n=5) and personality disorder/C-PTSD (n=5). Postpartum psychosis and anxiety were also highly prevalent.

As demographic questionnaires can be limiting and not allow participants to foreground the parts of themselves that are most important to them, women were asked to self-describe aspects of their identity that were important to them. This question was also asked as a preparatory question, intended to help participants become used to reflecting and talking about themselves before commencing with the core interview questions.

When responding to this question, women emphasised their gender identity, their working or professional roles and identities, their education, their faith, sexuality and their class backgrounds. They described in detail their ethnic heritage. Their gendered family roles were important parts of their identity too; that of mother, daughter, sister, wife and grandmother, as was their identity as a friend. Some identified as survivors of trauma. Women also emphasised personal characteristics when asked to describe important aspects of their identity. They described themselves as open, confident, friendly, socially conscious, an ally to others, loud and wanting to give back to society. The women asserted that they were active, adventurous, empathic, sensitive, reserved, creative, passionate, compassionate, curious, determined, optimistic, outgoing and a lover of life. This helped provide me with wider context, to make sense of their experiences of SMI and their reported interactions within healthcare both within the interview and during analysis. It also helped me with interpersonal interactions within the interview, e.g., knowing if a participant saw themselves as reserved I might need to ask different kinds of questions to elicit more detail about their experiences.

Health professionals

A total of 14 professionals practicing within the NHS (in England) participated in the study. They were part of one of 3 professional groups:

- Specialist Perinatal Mental Health Team (SPNMHT) members working in any professional role (n = 7)
- Midwives (n = 2)
- Health Visitors (n = 5)

The tables below detail their areas of practice and further information about their professional backgrounds.

Table 6: Geographical spread of professional participants

Region of England	Number of Participants
North East	0
North West	3
Yorkshire & Humber	7
Midlands	1
East of England	1
South East	2
South West	0

Table 7: Professional role of participants

Individual Professional Role	Number of Participants
Specialist Midwife	2
Specialist Health Visitor	3
Health Visitor (non-specialist role)	2
Nurse	1
Social Worker	1
Psychologist	1
Psychiatrist	3
Clinical Lead	1

Concluding comments

In this chapter I have outlined the research aims and questions guiding the study, its disciplinary and philosophical grounding and the methodological approach taken to generate the data. What follows are several chapters detailing the results of the analysis of the data generated. The first of these chapters, Chapter 5, draws solely on the data arising from interviews with women participants. It seeks to demonstrate the myriad ways serious mental illness influences women's experiences of motherhood, pregnancy and reproductive decision making. The subsequent chapters draw together data from both groups of participants and are more conceptually grounded. Chapter 6 discusses stigma in relation to women's mental health and reproductive related experiences. Chapter 7 explores the barriers and facilitators to mental healthcare that exist at different levels for women with histories of SMI. Finally, Chapter 8 is a critical exploration of the concept of risk as it is deployed in relation to maternal mental health.

Chapter 5: Pregnancy, motherhood and reproductive decision making whilst living with SMI

Drawing solely on data collected through interviews with women with experience of SMI, this chapter demonstrates how women's reproductive related experiences are shaped and influenced by their histories of mental illness. It details findings relevant to the following research question: To what extent and in what ways does a personal or family history of SMI influence women's reproductive-related experiences and experiences of stigma? Although women's experiences of stigma are addressed in greater detail in the next chapter.

The chapter aims to build a rich and nuanced picture of how SMI shapes, impacts and influences the reproductive lives of women. The chapter is organised temporally, by reproductive 'stage'. This is done in part as it made analytical sense from a narrative perspective, but also for clarity. First, I focus on the preconception period where women reflected on and made decisions about whether or not to have children. The next section focusses on pregnancy and birth, and the final sections focus on women's postpartum experiences and motherhood beyond this period. The chapter provides an overview of the situations within which my participants approached reproductive decision making, experienced pregnancy and motherhood as women affected by SMI. This provides important context for more theoretically-grounded chapters which follow.

Reproductive decision making

In this section I illustrate how women's histories of SMI affect their decisions about having children, as well as their thinking about *how* they will or can become parents.

Trauma and reproductive decision making

Early childhood adversity and trauma are associated with higher risk of SMI and there is a strong evidence base for higher rates of experiences of trauma amongst people with SMI compared with the general population (Jorgensen and Dixon, 2022). As illustrated in Chapter 2, there is emerging evidence concerning early life trauma, adverse experiences and an increased risk of developing perinatal SMI (Hazelgrove *et al.,* 2021). Around half of the women interviewed disclosed histories of significant trauma in their lives. This included experiencing sexual abuse in both childhood and adulthood, domestic violence and other traumatic events.

Several women who did not have children at the time of interview explained their histories of trauma were significant factors in their not becoming mothers. Asma did not wish to have children because of the trauma caused by domestic abuse perpetrated by her family of origin (i.e., the family in which people are raised). This had fundamentally influenced how she thought about kinship and family. For Sofia, the partner with whom she was actively planning to have children died suddenly. This caused her whole life to change. The emotional and material consequences of this traumatic event were described by Sofia as significant contributing factors in her not having had children.

Bella and Alice had both experienced trauma in childhood. Alice had not had children at the time of interview and Bella had made the decision to not have children. Bella and Alice were both concerned about intergenerational trauma and expressed fears about the different manifestations of their mental health conditions affecting potential future children. As women with histories of sexual abuse, they also expressed concern about how this might influence particular aspects of maternity. Alice talked about how the abuse she had experienced and the resulting mental health condition this caused (an eating disorder) impacted her fears around pregnancy:

> *"I think that's quite common for people who've had experience with eating disorders and the idea of losing control of my body and your body changing: like your body changes after child birth, your breasts are different sizes, your hips are different sizes That not being in my control feels really terrifying and my understanding of the routes of my eating disorder are around childhood sexual trauma, and so, I'm aware through a lot of therapy, I've reflected on it a lot that the sort of feminine aspects or female aspects of my body are what I obsess about more when I'm in a difficult place eating disorder-wise so the idea of breasts and hips and stomach and the sort of more female aspects of me becoming more enhanced because that's what pregnancy does, as is obviously biologically necessary, that terrifies me."* **Alice**

The relationship to her body that has been altered through the trauma of sexual abuse was something echoed by Bella. For Bella it manifested as concerns in relation to maternity care:

> *"The idea of going into hospitals, giving birth and having doctors poking around in my nether regions did not appeal. That was quite a source of anxiety. The idea of giving birth, going for medical exams with [a] history of trauma (long pause)[…] All those exams and stuff […] I don't know, it feels like women's bodies feel like they're public property, and I'm quite boundaried about my body […] I do think I'm more uncomfortable than the average person around things like the medical exam due to my mental health and the C-PTSD and stuff, I think I would think I would find it quite triggering and invasive probably."* **Bella**

Bella was not the only participant who was concerned about maternity care. Cammi also described similar fears and experienced difficulties in relation to the maternity care she received because of previous trauma (discussed in more detail later in the chapter).

Women's histories of trauma also generated practical concerns in relation to motherhood. Many participants described relational disruption as a result of childhood trauma or different forms of abuse rupturing family ties. Not having family support to assist with childcare was also something women with a history of trauma were concerned about, as Bella explains here:

> *"I've got [a] very splintered family, do you know what I mean? [explains family history] so not having a lot of family, and my husband not having a lot of family has played into decisions about whether to have children because there's just no suppo- I mean we've got lovely friends, amazing friends but you haven't got that support system to look after the children that many people might have."* **Bella**

Several women who did have children explained how their histories of trauma had contributed to them feeling differently about motherhood at earlier points in their reproductive lives. Despite these histories and an initial hesitancy to have children, they later decided to become mothers. One of these women was Isa, who understood her mental health difficulties as rooted in adverse childhood experiences:

> *"I think for a long time in my twenties I was like I should not have children, this would be a really bad idea. I was really unwell a lot of the time and I was like I don't think I can sustain a relationship, I don't think I should have children because there's also like [describes family history], so clearly there's some sort of hereditary genetic aspect here as well and then I think I got older, I stabilised a lot, I met my now husband and I was like oh actually, maybe I could do this (laughs) in terms of a relationship and then I think, like, yeah, once I was into my thirties I was like actually I really do want to have a child and so things stabilised a lot for me, I wasn't using any mental health services, working, married and so actually I did do it."* **Isa**

In this quote, in parallel to the difficulties she has experienced as a result of trauma, she talks about her concerns about a family history and the potential risk of genetic transmission of mental health difficulties to her future children. Many women interviewed, including Katie, Fee, Mae and Anna shared concerns about the transmission of mental illness genetically. Others such as Alice and Bella were also concerned about the transmission of trauma intergenerationally. This shows the complexity of the decisions that women with both personal and family histories of SMI are having to make in relation to parenthood. For Isa, a shift in decision making about becoming a mother occurred because of her experiences of prolonged periods of wellness, being in a strong and loving relationship and having secure employment.

Cammi, who also disclosed a history of trauma, spoke about how she felt earlier in her life about becoming a mother:

> *"There's something about me that's broken there's something about me that's wrong and so I had a real fear of motherhood […]. I was afraid of becoming a mum because I was afraid of passing on what was broken in me to my children. I kind of felt like somehow, I don't know if I was thinking in terms of genetics, I was more thinking in terms of I don't function well. I am going to teach my children not to function well […], it's probably more in terms of stuff in my thinking isn't sorted out, stuff in my emotional processing isn't sorted out, stuff in my life, I don't know how to do life, I'm broken. I'm going to raise a broken child. I now, at [age], yeah, we're all broken mate (laughs). And no, parents don't break their children. Actually, we all do our best and we all break a little bit and you just do your best to pass on the good things and say sorry for the bad things and muddle through."* **Cammi**

Cammi's quote illustrates the shift in her thinking between the earlier years of her life and at the time of interview. Isa, Cammi and the experiences of other women interviewed illustrate how women's thinking about whether to have children or not is not static but dynamic and fluctuates in relation to both external (e.g., stable work opportunities) and internal factors (e.g., psychological healing or new perspectives).

Whilst trauma did influence many women's thoughts and decisions about having children at different points in their lives, this wasn't the case for all women who disclosed a history of trauma. Grace said:

> *"Even when I was a child, a teenager at school, my friend told me years later, she said you always told me you wanted children. You want a lot of children but you don't want no man. And I said, why would I say that? But now looking back, because of the abuse in my childhood that [would] be why I don't want a man around. I always wanted lots of children, I wanted all different kinds of children, all being in my house. I didn't know how I was going to get them but that's what I wanted. I've always loved children because I wanted children to have love, and I wanted to be loved. I wanted*

> *them to be loved the way I wanted to be loved. And I wasn't loved. I wasn't loved the way that I should've been loved. So that's what I wanted for them. Always."* **Grace**

Grace's experience of abuse gave her a positive orientation, a vision for her own motherhood which stands in contrast to her own experiences in childhood; one where she sought to build something more hopeful and positive. Her experience illustrates the ways in which trauma does not always create concerns or hesitancy to negatively influence women's reproductive-related positions or experiences.

Before concluding this sub-section, it is important that that I exercise reflexive practice in relation to these findings on trauma. As discussed briefly in Chapter 4 on methods, I was open with women (before the interviews began) about my experience working on women's health and sexual violence. It is likely that this decision has influenced the data in that it may have meant some women may have felt more comfortable disclosing histories of trauma, particularly gender-based abuse. However, the ubiquity of trauma in many women's accounts is also not surprising as there are well established links between the experiencing of traumatic events or abuse and it's consequences on mental health (Jorgensen and Dixon, 2022; Hazelgrove *et al.,* 2021; Kim *et al.*, 2021).

Risk of SMI relapse

Several women who had experienced SMI perinatally stated that the *risk* of becoming unwell again during a future pregnancy/postpartum period was a significant factor in their decision to not have any more children. This included women whose history of mental illness pre-dated their perinatal experiences as well as women who did not have any history of mental illness prior to pregnancy/postpartum.

Cammi decided not to have any more children because of the risk of becoming unwell again and the impact this could have on her family. After having become unwell due to side effects of fertility treatment, Cammi said:

> *"That's too much of a risk to my mental health and too much of a risk for [child] so I probably can't have another baby and that is quite sad but that is about weighing up the risks to my mental health and to my current family."* **Cammi**

For Fay, who had no history of mental health difficulties prior to experiencing postpartum psychosis, the significantly higher risk of becoming unwell again if she were to have another baby was a crucial influence on her reproductive decision making. She said:

> *"It was a conversation that [Partner] and I had started a lot of times and I'd stopped it because I couldn't cope with it and then during [year], I can remember where we were when we said it out loud that we weren't going to have any more children and I said it. [Partner] was there way before me, he was like you don't have to put yourself through this again, and this is because I know there's a 50% chance that I get sick again […] I felt like it was all on me. It was my mental health, there was nothing wrong with [baby], and we had no problems conceiving. It was my age and my mental health that were the factors and I felt that quite acutely as a pressure."* ***Fay***

In both Cammi's and Fay's accounts their emotion conveys the significance of these decisions as well as the struggles women face in relation to reproductive decision-making in the context of their mental health histories. Fay's account also illustrates the sense of personal responsibility she feels to maintain her wellness, knowing there is a high risk she will become unwell again. She also makes reference to her age, a concern which women

without histories of SMI share. This shows the multiple layers of factors women with histories of SMI are having to consider.

Jeanette was advised by professionals that to have more children she would have to change the medication she was using to maintain her mental health. She described the difficulty of identifying the right combination of drugs to keep her well and the prospect of potential periods of illness occurring whilst making changes to her treatment were not appealing. Anna did not to want to have any more children because she knew she was likely to become ill again. She did not wish to go through what she had been through postnatally before: hospitalisation and subsequent social services intervention. She wished to maintain her wellness to gain parental responsibility for her existing children. Jeanette's and Anna's experiences illustrate that the risk of relapse intertwines with the *consequences of* SMI to influence women's decisions to have more children. For Jeanette, the consequences were the complexities of having to take medication to maintain her mental health, and in Anna's case a consequence of her illness was having her children removed from her care.

Alternative paths to parenthood

Several women had contemplated alternative paths to motherhood including adoption, fostering or surrogacy. For some women, contemplation of these paths was in part due to concerns about fertility as well as fears about how pregnancy and postpartum might exacerbate their existing mental health conditions. In discussing alternative paths to parenthood, women expressed different concerns or attachments to these routes. Katie was aware she had a higher risk of experiencing postpartum psychosis, if she were to become pregnant. Here she talks about her thoughts about the different paths to motherhood and her openness to alternative means to becoming a mother:

> *"I don't feel strongly that I need them [future children] to be like genetically mine, or like carry them myself. I don't really mind either way whether it's me or it's adopting… or yeah, if I'm- for whatever reason can't get pregnant or don't want to get pregnant myself, you know, IVF or anything like that. I'm quite open to that kind of thing. So I don't feel like Oh, I must be the biological mother, like birthing a child but I definitely want to have a child."* ***Katie***

Katie didn't express any concerns about barriers to adoption because of her history of SMI. However, Alice and Cammi had concerns about their mental health posing a barrier to this alternative route:

> *"Because of my mental health history, with various sectioning and stuff, adoption just wouldn't, like they wouldn't consider (laughs) there's no way that someone with my mental health record would be allowed to adopt. So, yeah, if I can't have them biologically, and I can't adopt, it may just be off the table anyway."* **Alice**

> *"I always expected we would adopt but (exhales) that's one area where I think I'd be an amazing [mum]… I could do it again, of course I could, but would my mental health go against us? Would I have to fight that? Would I have to get a load of people to stand up and go she's an amazing mum. Even thought she's got this diagnosis, that diagnosis. So I kind of feel like that might go against us."* **Cammi**

Cammi and Alice both perceive they would not be adjudicated by authorities as good candidates for motherhood via the route of adoption, with Cammi feeling that she would have to in some way prove her suitability. They felt they would be viewed negatively rather than empowered to undertake the role of an adoptive parent. This illustrates a potential path

through which reproduction for women with histories of SMI is stratified (Ginsberg & Rapp, 1995). Alice also talked about surrogacy during the interview, although she did not want to choose this option. She felt she had not had a strong bond with her mother, and thought this informed how she felt about the importance of the bond between birth mother and child.

Mae envisaged a large, blended family in her future: a number of her own children, later looking into adoption or fostering. However, she was concerned that having experienced eating disorders from a young age may have impacted her fertility. When asked about how her vision for her future family sat alongside her fears about her fertility she said:

> *"There's always the thing with adoption and fostering that they're not your genes and that makes me sad. I think particularly because my boyfriend and mum have sort of mentioned the fact that it's not you, you know and my mum in particular always says there's something about giving birth yourself, you don't understand, you know and that makes it hard… but yeah I do hope that even if the worse comes to the worst and I can't have kids, there are options."* **Mae**

Concerns about fertility related to SMI therefore meant that Mae, like Katie, was hopeful routes such as adoption and fostering would be available. Participants reflections illustrate how women's histories of mental illness influence thinking about the feasibility of both normative and non-normative paths to motherhood. They demonstrate the complexities and tensions that exist in relation to SMI and alternative routes to parenthood, particularly with regards to highly regulated processes such as adoption. Women may wish to pursue an alternative path to motherhood because the corporeal or biological processes involved in pregnancy and the postpartum may pose serious risks to their mental health and wellbeing. However, there also exists a paradox at this juncture in their perceptions that they may be excluded from this path to parenthood too.

Multiple factors influencing decision making

As I have shown, for many of the women interviewed, mental health was a key factor influencing their thoughts and decisions about whether or not to have children. However, it was not the sole factor. There were multiple factors influencing women's decision making and many of these echoed broader concerns for women considering pregnancy in the UK today that have been reported elsewhere in the literature (see for example, Locke & Budds, 2013).

For Sofia, who had not had children, stability and independence, in addition to emotional considerations, were important factors in her thinking around becoming a mother:

> *"I was quite scared to get pregnant because I just thought I had to be settled in my studies and emotionally more stable to bring a human in the world. I thought it was such a huge issue to bring another human being, how I could give the best of me?[…] I think I always had a level of instability and anxiety that was running through me. So yes, I have struggled since I was young with different conditions and emotional conditions and physical as well."* ***Sofia***

For Stephanie, who was pregnant at the time of interview, the life-stage of both herself and her husband, their work, concerns about fertility, as well as her mental health status were all important factors in their reproductive planning and decision making:

> *"For us it kind of coincided nicely with the realisation that we [had] probably just about grown out of having those last big nights out. So, then over the course of [year], I secured the role I'm in now. We felt we had kind of regular consistency in my work and*

his, so over the course of [year] we discussed if and when we would begin trying to have a child. A large part of that for me was feeling that it wouldn't be quick or successful immediately and then considering […] how I wanted to strike a balance with my mental health and particularly the medication that I was taking and how I felt in general with my hormones and moods really." **Stephanie**

Mental health often sits alongside many other factors when women are reflecting on whether to become a parent or not. Their reproductive decisions and positions are informed by many other factors in their lives. Interviews with Stephanie, Sofia and the other participants revealed these parallel considerations included thinking around work and employment, educational goals, age and life-stage, physical health, migration status and their intimate relationship status.

Pregnancy and birth

Many of the pregnancies of the women interviewed were planned. Some were unplanned and some women had both planned and unplanned pregnancies at different points in their lives. For some women the dichotomy between planned and unplanned pregnancy was not clear-cut when placed in the context of their rich and complex life-narratives. Some women simply did not disclose if their pregnancies were planned or unplanned.

Comparing the experiences of women who had a history of SMI prior to the perinatal period with women who first experienced SMI perinatally: there was clear heterogeneity in terms of women having both planned and unplanned pregnancies within both groups.

Feeling well

Before discussing the ways in which SMI complicated women's experiences of pregnancy and birth, it is important to highlight that not all of the women interviewed who were mothers struggled with their mental health antenatally. Women both with and without histories of mental illness prior to the perinatal period also talked about positive experiences of pregnancy. Several women had multiple pregnancies and had different mental health-related experiences in each one. Fay, Melanie, Stephanie, Elton and Anna described experiencing a pregnancy as a time of feeling well; a time they practised self-care and felt in tune with themselves, their bodies and their pregnancies. Many women attributed this wellness to protective factors such as continued use of medication, relational and financial stability, being part of maternal communities and feeling prepared because they had knowledge about motherhood and mental health. Their collective experiences illustrate that difficult antenatal experiences are not universal for women with histories of SMI.

Maternity care

For several women, their mental health had a significant influence on how they experienced maternity care. For some women, such as Stephanie and Kimberly, it meant increased monitoring and contact time with their midwives. For women like Jeanette and Laura, the ways in which their mental health conditions manifested (i.e., their specific symptoms) had a significant influence on how they experienced care.

Laura did not have a history of SMI prior to her perinatal experiences. She sought help for her mental health postnatally where she'd experienced an escalation of symptoms of anxiety which she had had throughout her pregnancy but was not identified as in need of intervention by professionals. She said:

> *"I was kind of very anxious through the pregnancy, yeah, needing lots of reassurance, having private scans to help with the reassurance and erm (pauses) reading a lot and being worried about the baby's movements and was [baby] moving and had I felt enough movement and worrying about everything you could possibly worry about basically."* **Laura**

Laura's anxiety meant she was not assured by standard antenatal care. In addition to the research she did in relation to her pregnancy, she also felt the need to seek additional care, outside of the NHS, in the form of extra ultrasound appointments.

Jeanette had a history of mental illness and was unwell throughout her pregnancy. She did not seek help for her mental health, and she was not identified as someone in need of more support by professionals until the postnatal period. She experienced paranoia and delusions as a result of her mental health condition. Here she describes a routine maternity appointment:

> *"I went to see a consultant before I had [child], they called us back into the room because they'd looked at my blood test […] I was a bit scared [thinking] Oh my God, they're going to tell me I've got AIDS or something. But luckily, it wasn't anything like that. They told me [explains results of blood test] and that later had an impact on me because I was thinking my parents weren't my parents and have my children been swapped and all sorts of things."* **Jeanette**

Like Laura, Jeanette's symptoms are an important lens through which she experienced maternity care. The tests many women are subject to during pregnancy may provoke anxiety or unease in many women, regardless of their mental health status. However, for Jeanette, because of her condition which includes symptoms of paranoia and delusions, these tests are not simply tests. They influenced her thinking in such a way that she questions the foundations of both her family of origin and her family of procreation (i.e., the family she has created through having children).

In contrast to Jeanette and Laura, Cammi was well during pregnancy. However, her concerns about her mental health, and protecting it as much as possible, still influenced her experience of maternity care, particularly in the latter stages of her pregnancy. She described how she felt her decisions were not fully understood by maternity staff:

> *"I've got to do everything I can to keep myself mentally healthy, like not having medication and not having more intervention than is required because I know I'm going to have to deal with the trauma of that afterwards. They don't know what that means for me."* **Cammi**

She described elsewhere in the interview how she rejected particular interventions (pain relief and interventions to initiate labour) because of her fearfulness about their effect on her mental health; specifically, the triggering of dissociation and other PTSD-related symptoms.

The purpose of antenatal care is often articulated as to ensure that woman and baby are well (Tommys, 2023). Cammi's, Jeanette's and Laura's experiences illustrate the different ways that the various interventions deployed in maternity care - scans, tests, physical and pharmaceutical intervention - can be sources of distress for women, because of their histories of SMI. They also illustrate the phenomenological differences that are brought about by the specific manifestations of different mental health conditions: altering memory, bodily experiences, feelings of security and safety.

Work and employment

Work and employment featured in many women's narratives in relation to their experiences of mental health and illness during pregnancy (and featured in narratives presented earlier in this chapter around reproductive decision making). Several women implicated work as a precipitating factor in the deterioration of their mental health during pregnancy. Isa, who had a history of SMI prior to pregnancy said:

> *"Somewhere in the second trimester my mental health just started to really dip and I was just like, yeah, really struggling to function and increasingly sort of depressed and anxious and I think I was (pauses), I think I hadn't realised how vulnerable being pregnant would make me feel in terms of my work, if that makes sense? I was finding it very stressful to do that type of work whilst pregnant, which I think hadn't crossed my mind."* **Isa**

Melanie, who had a history of SMI prior to pregnancy, but not during her previous pregnancies also experienced stress and distress related to work which impacted her mental health during pregnancy. She says:

> *"By the time I was pregnant with [child] I was really unwell and I think part of that was the job. It was really stressful, the environment I'd ended up working in [describes work/environment in detail]. […] Whereas before, you know, it had been all self-care and everything. I just was not looking after myself and I was in a really bad way and I'd convinced myself that I was a terrible person. That I was a huge failure and I took an overdose whilst I was pregnant."* ***Melanie***

Melanie's suicide attempt brought her to the attention of social services and the rest of her pregnancy was subsequently very closely monitored. She was also monitored closely by services postnatally.

Laura did not have a history of SMI prior to her perinatal episode. She was pregnant during the pandemic, which had a significant impact on her work. Laura saw the disruption to her work as well as the nature of what she does for a living (working with children) as important factors influencing her escalating anxiety during pregnancy. This sat alongside other factors such as the disruption the pandemic caused to maternity care delivery and the social isolation of lockdowns. Laura also described how professionals had dismissed and minimised her symptoms of anxiety and had not identified it as in need of intervention because of the nature of her work (working with children):

> *"I wonder why shouldn't my anxiety have been picked up sooner, you know actually, I remember it got pooh-pooh-ed a lot because of where I work, like "ohhh, you're just anxious because of where you work [describes professionals perceptions of her job]."* ***Laura***

Work and employment is not randomly allocated and it is worth highlighting some of the socio-economic characteristics of participants and commonalities in relation to their work, whilst also being mindful of confidentiality. Isa, Melanie and Laura had different class origins, and worked in different sectors but were all educated to graduate level. Whilst the industries and roles they worked in were distinct, what they share is that they are professions/sectors that are female dominated.

Fay's baby was born a few weeks earlier than expected, and she had not yet started maternity leave when she went in to labour. She'd had a positive experience of pregnancy,

she said ‘I loved being pregnant, I felt really well’. She also had no history of mental illness prior to her perinatal experiences. She says:

> *“I had no time between stopping one part of my life as “Fay” and starting a new part of my life as mum. [describes going into labour at work]. […] So I had, I had no gap between that, and in my head I had this two weeks where I was gonna prepare and I was gonna think about the change that was happening from leaving work and leaving a job that I really liked… To… being a mum, and I didn’t have that time at all. And I feel, I feel that impacted sort of how I was.”* **Fay**

By ‘how I was’, Fay is referring to her mental health postnatally. Fay’s experience illustrates how identity and role shifts can impact women’s mental health perinatally. It also underlines the importance of maternity leave antenatally as well as postnatally, as it can provide women with the space and time to prepare for these role shifts. As highlighted in the previous chapter, work was an important part of many of the participants’ identities. This was as true for women who had histories of SMI prior to the perinatal period, as it was for women who had not. Several women interviewed (e.g., Elton, Kimberly and Jeanette) had given up work for reasons connected to their mental health, and during interviews many of the women who were not in employment still talked about their previous work and the importance of this to their identities and sense of self. Despite the significance of work and employment shaping the transition to motherhood and its’ influence on poor mental health, to date this topic has not often been explored in the existing perinatal SMI literature.

Birth

For some women who were unwell antenatally, their experiences of illness profoundly influenced their births and experiences in the immediate postpartum. Jeanette was unwell throughout her second pregnancy. Her symptoms of SMI, particularly paranoia, feature heavily in her narrative of the birth of her second baby:

> *“[Maternity staff] monitored me in a room, and my husband asked if he could use the toilet in there. And there was somebody else's blood in the toilet. I didn't see it myself, but just hearing about it contributed to paranoid theories. Because I was just thinking, well, obviously they're not ready for me to go into the room was they doing something secretive, you know what I mean, it all like fed into my paranoid theory. I had a TENS machine on to start with and staff had to check me to see that I was in labour as they thought I would be in more pain with the contractions. But the monitor was showing and that not being believed stuck with me because I questioned whether I'd had a false pregnancy and then been given somebody else's baby. It's like, it all sort of fed into the theories.”* **Jeanette**

Jeanette’s experience illustrates how symptoms of SMI can influence how women experience and interpret routine encounters and interventions within maternity care.

Anna was acutely unwell during the latter stages of her second pregnancy, both mentally and physically. Whilst talking about her first delivery, it was clear that experiencing a vaginal delivery with little intervention or pain relief was important to Anna. When delivering her second child, an application was made to the courts to request a caesarean section be performed on Anna. She describes the days around when she gave birth as ‘a really dark time’ and goes on to explain:

> *“[Husband] had to do something to ask the court to get the OK to give us a caesarean and when I gave birth I don’t remember it at all because I was all drugged up and I felt like such a bad mother I can’t remember giving birth but I had a*

caesarean […] I thought I lost my baby because I can't see my baby around I thought I lost my baby, like I didn't have a baby, like where's my baby." **Anna**

Whilst these cases are rare (as Brione, 2021 details), Anna's experience illustrates how reproductive agency can be removed from women who are acutely unwell, resulting in the loss of something she perceived as an important and integral part of the maternal experience, memories of the birth of your child, with the embodied process of birth being important to Anna. This contributed to Anna feeling she was a 'bad' mother. As illustrated in the following section of this chapter, the disruption of normative maternal experiences and practices by mental illness was something experienced by women postnatally too.

Postpartum and early motherhood

Just over half of the women interviewed reported experiencing some form of mental illness or distress postnatally. Some reported receiving interventions from professionals and were given specific perinatal diagnoses, for example, Fay, Laura, Willa, Anna, Grace. Others received care but did not report receiving a specific diagnosis, such as Melanie, Isa, Cammi, Kimberly and Masi. A small number did not receive care or a diagnosis but self-identified how they felt postnatally as a form of postnatal mental illness, for example, Fee and Jeanette (during her first postnatal episode).

Formal diagnoses reported by women included postpartum psychosis, severe postnatal anxiety and depression, relapses of existing long term conditions such as bipolar or schizophrenia. Women who did not have a particular diagnosis to label their perinatal experiences described their distress manifesting as suicidal action and ideation, hallucinations, dissociation, panic and intrusive thoughts. Women who had self-identified their distress and not sought help labelled their distress as postnatal depression.

For many women, their experiences of SMI postnatally interrupted their motherhood. These interruptions were felt in different ways.

Physical Separation

Anna and Grace were both separated from their children postnatally whilst they received treatment for their mental health as inpatients. Grace says of this time in hospital:

"My daughter was 4 months when she was taken away from me and it wasn't until 13 months that we got reunited properly. 9 months, the same amount of time as being pregnant, away from her. So it was hard to be separated. I was still lactating and all that." **Grace**

Grace underscores the difficulty of the lengthy separation from her baby, which she emphasised was as long as her pregnancy. Despite the separation, her body forces her to confront her interrupted motherhood as she continued to lactate. Elsewhere in the interview she talked about the visits eventually granted which enabled her to see her children. She describes hugging and kissing her children but perceived a fearfulness in the baby whom she hadn't seen for months, emphasising their disrupted bond. Anna was treated initially in an MBU and later in a general psychiatric unit postnatally, where she was separated from her baby. Social services planned for her baby to be taken into care; however, Anna's family intervened. Anna says of this time:

"I was in hospital for quite a long time, from giving birth to going to hospital to when I got discharged […] I had to take a long time to recover from coming out of hospital so

> *my mum was really more hands-on with my daughter at first and then for years and years it was a bit of a struggle because the connection, everything, the bonding. […]It was a bit hard because my mum was like the second mum but at least she was my mum, you know?"* **Anna**

Anna's separation from her baby during her inpatient treatment and the lengthy recovery after discharge resulted in a feeling of distance within the relationship with her daughter. Her struggles to connect with her daughter persisted even after they were physically reunited, and she described the years it took to build a strong relationship with her daughter. She also alludes to but was not explicit about the effect this had on her relationship with her own mother, illustrating a pathway through which perinatal SMI can disrupt intergenerational relationships within families in the context of new parenthood.

Both of their experiences show the effects on both women and children of treatment in particular inpatient settings. It shows the impact the lengthy separations can have on the mother-child relationship, both in the short and longer term. Anna's experience in particular illustrates both the time and intense activity required to reconnect and restore mother-child relationships.

Disrupting early motherhood

Other women interviewed who were not physically separated from their children also talked about the ways in which their experiences of motherhood were disrupted as a result of interventions deployed in response to their mental illness postnatally.

Following a suicide attempt during pregnancy, Melanie was closely monitored by health and social care professionals. Whilst her children remained in her care, services decided she could not look after her children independently. She explained how that made her feel:

> *"I wasn't allowed to look after them on my own because of what had happened previously and, you know, they [social services] were very happy for everyone to stay at home but someone had to be with me but that had huge pressure because we were constantly having to ask childminder, family, friends to come and like babysit me, which had destroyed my self-esteem and it didn't feel like it was going anywhere in terms of me getting any help to get out of that hole. So it was just getting worse and worse, this kind of like not having an identity anymore, not working, not even being able to properly mum because someone always had to be there."* **Melanie**

This intervention by services, which resulted in her caregiving being supervised, eroded Melanie's sense of identity as a mother, despite still being physically with her children. Whilst Melanie did not explicitly articulate what 'good' motherhood meant to her, in the frictions which arose as a result of this intervention, Melanie implied that the freedom to look after her children independently was an important aspect of motherhood to her, and she felt she had lost her status as a mother. As highlighted in Chapter 3, status loss is a mechanism through which stigmatisation occurs (Link & Phelan, 2001). She also talks about not being able to work during this time, which as highlighted in chapter 2, relates to a contemporary norm of 'good' motherhood (Schmidt *et al.,* 2023).

Laura talked about the difficulties she experienced in relation to breastfeeding whilst taking medication for her mental health:

> *"There were very few "sedative-y" type medications that I could be on and breastfeed and so that was a very, very difficult thing [describes course of illness and efforts to breastfeed]. I reached the point where I just had to accept that it was going to be a*

longer journey; it wasn't going to be a short term fix and I had, I just had to stop breastfeeding. Which was dreadful (laughs). Yeah, it was massively, massively traumatic and sad and I was absolutely devastated about that and I still am and I find that really hard, that I wasn't able to carry on and especially because I had worked so bloody hard to do it in the first place […] I know breastfeeding isn't easy for anybody but you know, [describes experience of breastfeeding]… It was gutting." **Laura**

For Laura, having to cease breastfeeding – an important postnatal practice to her – was a difficult and painful experience. Despite the time that elapsed between these events and the interview, it was clear that this remained a (in her own words) traumatic memory of her postpartum period. Elsewhere in the interview she explained how ceasing breastfeeding negatively impacted how she felt in public spaces as a mother. She described how she would conceal the bottles she was feeding her daughter with when out in public because she felt like she was being judged. She clarified she never experienced anybody saying or doing anything that would indicate judgement, it was more "*me and where I was coming from"*; indicating she was self-stigmatising.

Postnatally, Fay spent time being treated on an MBU. The interventions she received as a result of experiencing SMI postnatally ruptured her ability to engage in postnatal experiences that are anticipated by, and of, new mothers:

"Going to these [mother and baby] groups […] I was like, none of you get it. Like you've been at home, you've been with your partner, you've been… I feel cheated out of my maternity leave, I've been in hospital, I've had my freedom taken away from me, and I can't talk about those first nights where I was sharing the feeds because I wasn't; the nurses were doing it. And [partner] is a dad who had a brilliant night's sleep for the first six months […] I felt like I had a big red spot over my head as well – like 'she's different." ***Fay***

Whilst holding patients under the Mental Health Act is not something undertaken lightly by professionals, Fay's experience illustrates how this highly restrictive intervention has impacted her experience of motherhood, not only in terms of when she was in hospital but also in more long-lasting and nuanced ways. It left her feeling isolated, not 'seen' and othered in maternal spaces, leading to self-stigmatisation where she felt physically marked as different.

Fay's, Laura's and Melanie's narratives demonstrate that it is not solely the experience of illness itself that causes women distress postnatally, but also the interventions deployed in response to women's mental health difficulties. In the case of Fay, Laura and Melanie, the effect these interventions have on women is on their self-perception, specifically in relation to motherhood and their mothering roles. These interventions are all different and (partially) illustrate the heterogeneity of professional responses to women's distress postnatally. Yet, however different they may be, these interventions do share a commonality. Whilst all deemed professionally necessary, their unintended consequence is the disruption they cause to women's experiences of and expectations of motherhood and contribute to processes of self-stigmatisation.

During interviews, women talked about the importance that particular postnatal practices held for them and how these were entangled with their experiences of SMI. Fee suffered physical complications perinatally, which she saw as a significant factor in her experiences of antenatal and postnatal depression. The physical difficulties hindered her from being able to do certain things with her baby. This exacerbated the feelings of depression she had already begun to experience during pregnancy and in the postpartum period:

> *"I really struggled then even looking after my baby to begin with, like, I wasn't able to bath him and things like that, my mum would come round and help to do jobs like that, which in itself was really difficult just to sit and watch and not be able to participate, and I know that my depression was worse at that time as well but I couldn't really talk to anyone about it which was really hard. So yeah, there was a lot of upset and hurt around that time. Even now it, you know, to think that I never got to bath my baby just is really hard but, it's one of those things."* ***Fee***

Fay, who spent time in a mother and baby unit postnatally talks about how the memories of her daughter meeting family members in that setting are particularly difficult for her:

> *"The first place she met her niece was in hospital, which she probably won't remember, it will mean nothing, you know if I said to her now when did you meet [Daughter]. Well it doesn't matter because I know [Daughter] now, but for me, that was quite hard thinking your auntie is cuddling you in a hospital, on a horrible NHS sofa and that was really tricky."* **Fay**

Both Fee's and Fay's accounts convey a sense of isolation and loneliness in relation to these disrupted practices. For Fee she says she wasn't able to talk to anyone about her experience of depression. For Fay, the loneliness of her experience is palpable in the distance she describes between her feelings in relation to this memory and her assumptions about how her family members might feel about the same event. Their accounts also implicitly illustrate their ideas and expectations about what the postpartum period should be like. i.e., one spent in the comfort of their own home, being the primary caregiver for baby, nature of visits from family. However, these expectations were not realised and were disrupted by the nature and responses to their experiences of illness.

Mothering beyond the postpartum

Seven of the women interviewed had reported experiencing SMI beyond the postnatal period too, later in their motherhood. Their experiences and diagnoses were varied but several women described being treated as inpatients, experienced suicidal ideation and/or received intervention in the community from crisis teams.

Feeling harmful

Several women described that when they were most unwell, they felt like a harmful force or figure within the context of their families and their parenting roles. Melanie talked about how during her most vulnerable moments psychologically, she felt 'misguided and deluded' about her role in her children's lives and the positive impact she could bring. Isa and Cammi expressed similar sentiments:

> *"I did get very fixated on the idea that I was in some way sort of toxic and dangerous, more sort of psychologically, but also just by physically being in the house to my husband and [child], and that I needed to remove, that I needed to be gone from the situation […], and I did yeah, this sort of like weird, quite distorted thinking that I was in some way dangerous and that [they] would be, that although it would, I wouldn't deny that it would be you know traumatic, but that it would in the long-term be better and safer for [child] to be raised by someone else, and obviously now that's a horrific thought- I'm like of course I don't want that! "* **Isa**

> *"I had this awful period of mental health these last [redacted] years […] all the nasty thoughts in my head were all about you've been a rubbish mother and you're doing a really bad job and [child]'s going to be really blah blah blah. That's what all my mental*

health, you know, thoughts were about. When you're unwell your thoughts can focus on any particular area of your life but that's what it was for me." **Cammi**

Melanie's, Isa's and Cammi's negative thoughts when they were experiencing distress are inextricably linked with their roles as mothers and also characterised by fearfulness about being psychologically harmful to their children. This echoes the fears of other participants, ones who had chosen not to be mothers or who had not yet become mothers, and is discussed in more detail in Chapter 8 (which examines the concept of risk). Isa, Cammi and Melanie received support from professionals during these periods of distress. Cammi and Melanie did not articulate whether the support they received addressed their thoughts and feelings about being harmful maternal figures. However, Isa described a lack of curiosity and willingness of services to engage with her thoughts around feeling harmful to her family and about her role and identity as a mother.

Positive aspects of parenting with a mental illness

It is important not to solely perpetuate deficit narratives in relation to maternal mental health. To address this, below I have included quotes from several participants which, each in different ways, talk about positive aspects of their experiences at the intersection of motherhood and mental health. These quotes illustrate the resilience, love, joy and strength that is also an important part of the experience of parenting for women with a history of SMI. Kimberly says of her daughter:

"She tests me, but she never tests me in the way that depression, deep-running depression and those two breakdowns have tested me, she's a doddle in comparison and she fulfils me and loves me in a way that gives me love, that no person, no other, no partner has ever given me. And she's fulfilled me much more than any career choice or country I visited." **Kimberly**

Talking about her daughter, Cammi said:

"She has got emotional intelligence that she wouldn't have had, had she not watched me earn it and therefore pass it on. She's got stuff that she wouldn't have had had she not been through the fire […] I know parents always try to give kids the lessons of their lives and some kids are like go away you're old! But actually, my hard won lessons, if she wants them, you know, […] She's actually seen me learn and therefore she's got that respect. Often teenagers don't tell you that to your face!" **Cammi**

Through this, Cammi's experiences of mental health and illness are rendered valuable and meaningful, not just to Cammi herself but also to her wider family. Isa explains a similar sentiment expressed by her husband:

"I think I was really worried about the impact I was having on my daughter […] I said to her 'I'm really sorry that I haven't been able to play with you and stuff so much in the last year, I've just not been very well' and she went 'don't apologise for the past, look to the future' (laughs) and I was like 'well thank you!' […] she's done really well academically and socially and stuff and it doesn't seem to have had a massive effect on her. My husband was saying 'actually, you know it's actually good for her to see that within a family bad stuff can happen, people can get ill and what we do is we support each other and we come out the other side and that's ok." **Isa**

Isa's and Cammi's quotes also illustrate the love and compassion shown to them by their children and the positive formative potential that adversity within the family unit could create for their children. This was echoed by Grace:

> *"I love my children, I rate my children, prop, I give 'em props because when I was in the hospital the first time [describes hospitalisation] my children never abandoned me […] they never abandoned me and they never ashamed of me, they never shunned me. They stuck up for me. They look out for me when [describes another period of hospitalisation]. They were the ones who put me in hospital. To get me help, even though I thought they were being bad at the time […] no matter what's thrown at us, we will, no matter how far we get thrown down and crushed we never stay down, we always get back up […] We're resilient. We have courage. We're quite strong women. Strong, principled women. Strong-headed women."* **Grace**

Finally, Melanie wished to close her interview talking about her son's recent achievements. Despite the challenges that mental health difficulties have presented, she states emphatically the joy of parenting, of being a mother:

> *"My eldest, the one that's kind of stuck with me for years of mum not always being the best, has just [describes achievements], and I'm so, so proud of him. And he's been on this journey with me the longest and I'm proud of all my kids and I love them all, but you know he's going to turn [age] this year which is a time I remember being very difficult for me. And there's something really just so amazing about being a mum. Despite having mental health problems, I've still got so much positive there and I just wouldn't change any of it - even the worst, worst bits because I'm here today and got these wonderful kids that I love so much."* **Melanie**

In this final section of this chapter, Melanie, Grace, Isa, Cammi and Kimberly describe the ways in which motherhood can generate alternative perspectives on their conditions and experiences of illness. They also demonstrate the ways women conceptualise their condition as playing a positive role in their mothering, through the cultivation of resilience by overcoming the challenges SMI can generate.

Discussion and concluding comments

This chapter has introduced the women participants affected by SMI who will feature throughout this thesis, and demonstrated the range of diagnoses and reproductive statuses represented within my sample. I have demonstrated the multitude of ways that SMI has impacted and influenced many of my participants' reproductive-related experiences, and demonstrated that women's histories of SMI affect their decisions about having children, as well as their thinking about *how* they will or can become parents. Though literature often considers this issue in relation to diagnoses of bipolar disorder or women with histories of postpartum psychosis (e.g. Dolman, Jones and Howard, 2016), I have shown that women with a range of diagnoses including eating disorders, anxiety, depression, trauma and stressor-related disorders can articulate similar emotions and concerns around reproductive decision making.

The data shows that SMI profoundly affects many different aspects of women's reproductive related experiences. This is the case for women whose history of mental illness predated any perinatal experience, as well as women whose sole experience of SMI occurred antenatally or postnatally. The data demonstrates that SMI can rupture times in women's lives that, culturally, women are socialised to expect times of happiness, joy, care, nurturing and fulfilment (Oakley, 2018). For many of the women interviewed their narratives of pregnancy, birth and motherhood were imbued with uncertainty, fear, shame, dread, loneliness and illness. However, there is a potential danger in perpetuating a solely deficit

narrative in relation to SMI and reproduction, as some literature in relation to this topic may unintentionally have done. The chapter has rendered visible the positive experiences participants had of pregnancy and parenting. This is important because an unintended consequence of such research is that it may contribute to stigmatisation and a perception of women with histories of SMI as unable to engage in 'good' motherhood. It is important that these stories are shared to challenge these potentially stigmatising narratives.

The findings in relation to planning of pregnancy are also important because they challenge assertions in the literature regarding the capacities of women with histories of SMI to plan pregnancies. Women with SMI have been framed as chaotic and not capable of forward thinking in relation to their reproductive choices (Torey, 2019). The evidence in this chapter illustrates that women with lived experience of SMI often reflect deeply on their reproductive-related decisions. We saw that the participants' histories of mental illness significantly influenced their decisions in relation to pregnancy and motherhood; however, concerns relating to mental health often sat alongside other factors. Factors, which women without histories of SMI are considering also (Locke & Budds, 2013).

A significant contribution this chapter makes is its detailed account of how trauma, SMI and reproduction intertwine to influence women's reproductive-related experiences. It demonstrates how earlier life trauma can influence women's relationships with their own bodies in ways that make not only the embodied experiences of reproduction challenging but also the ways in which their bodies are treated in medical settings and the effects this may have on their mental health and wellbeing. I have also shown that work and employment was a core feature of their narratives about their experiences of perinatal mental illness, with many explicitly attributing the deterioration of their mental health perinatally to work-related stress. This has not often been captured in existing literature on SMI and reproduction, but is an important avenue for further qualitative work.

Most crucially, this chapter has shown that perinatal mental illness, as well as the interventions deployed to treat it, can disrupt pregnancy, birth and early postpartum practices in ways women find highly distressing. This disruption can be explicit, for example through physical separation. However, it can also be more subtle or have long-lasting impacts, for example, where women feel unable to attend mother and baby groups and have difficult early memories. This disruption to normative maternal experiences can leave women feeling isolated, othered and ashamed, which in turn can contribute towards women self-stigmatising.

The chapter has also illustrated that women at different points in their reproductive lives express fear that they are, or have the potential to be, psychologically harmful to their own children (real or potential). As highlighted during the introduction and literature review chapters of the thesis, women are often framed in public health and media discourse as 'vectors of potential harm' to children. The fears of women - both those who are mothers and those who have contemplated but not embarked on motherhood - mirror this discourse of maternal harm. Their fears echo these wider discourses and potentially illuminate another path through which self-stigmatisation can occur, via the internalisation of these messages. Other forms of stigma (e.g: anticipated, experienced and 'cultural' stigma) will be discussed in more depth in the next chapter in this thesis.

Chapter 6: Sites and substance of stigma

Introduction

Chapter 5 briefly introduced stigma as an aspect of my interviewees' experiences. I demonstrated how not only the experiences of illness itself, but also the interventions deployed to address perinatal mental illness could negatively impact women's pregnancies and postpartum periods in ways that made them feel alone and othered, a process through which women may self-stigmatise. This chapter discusses other forms of stigma that featured in my participants' narratives.

As highlighted in Chapter 2, much of the literature on perinatal SMI talks about stigma but often does so in taken for-granted ways, providing little theorisation of this concept. Consequently, we have limited understanding of how women with SMI are stigmatised, why, where they are stigmatised and what effect these experiences of stigma have on them. This chapter addresses some of these gaps in knowledge by providing an in-depth examination of participants' experiences of stigma. I highlight the diverse sites in which stigma can be encountered, the lasting impacts of stigma, and its interplay with wider aspects of women's lives, thereby lending nuance to existing work on this topic. This chapter presents findings relevant to the following research questions:

- To what extent and in what ways does a personal or family history of severe mental illness influence women's reproductive-related experiences and their experiences of stigma?
- What individual, institutional or systemic factors cause inequalities in access to perinatal mental healthcare and how could these be addressed?

I used a conceptual framework drawing on several sociological understandings of stigma to address the aforementioned limitations in the perinatal mental health literature. To make sense of the data, I drew on literature which conceptualises stigma as a force which operates across multiple levels socially (micro, meso and macro) (Tyler, 2020) and that defines stigma as labelling, stereotyping, separation, status loss and discrimination that happens in contexts where power is exercised (Link and Phelan, 2001; Tyler, 2020). Using these definitions helped to draw analytical attention to the places and spaces where women experience stigma. Furthermore, these definitions also demanded attention be paid to the concealed structures, values and processes that reproduce stigma. Using definitions of stigma that differentiate between anticipated and experienced stigma (see: Scambler and Paoli, 2008) helped me to generate a detailed understanding of the relationships between women's past experiences of stigma and how this relates to their future fears about being stigmatised. Finally, the framework also draws on a definition of stigma as constituting judgements related to mental health and illness that are medically unwarranted (Scambler, 2009).

General overview of data relating to stigma

This chapter draws largely on the data from interviews with women participants. The development of the themes and sub-themes in this chapter were driven primarily by the

analysis of data from this respondent group. This reflects the focus of my research questions, but also the fact that there was less stigma-related data generated from the interviews/focus groups with professional participants. I generated two overarching themes from my analysis of the data: 'sites of stigma' and 'nature of stigma'. Women interviewed reported experiencing, anticipating and resisting stigma at the intersection of their mental health and their reproductive-related experiences. This stigma circulated in several key sites including within public services, the workplace, the family and in maternal spaces. I have chosen to structure the chapter by these sites of stigma and will detail the common substance of the stigma circulating within each of these sites. I have presented the data in this way as it made analytical sense from a narrative perspective, presenting the findings by 'setting', but also for clarity.

Social services

Of the 14 women who were mothers, 4 described, in detail, social services' intervention occurring as a result of an episode of perinatal SMI (Melanie, Anna, Grace and Kimberly). There were notable demographic differences between these women and the other women who experienced SMI perinatally, who were accessing healthcare but did not report interactions with social service. Of those receiving social care intervention, 2 were from minoritised ethnic groups, most were single parents at the time of intervention, all described themselves as being on a low income, and at the time of interview all resided in local authority housing or were renting privately. The two participants from minoritised ethnic groups were the only women interviewed who had had their children removed from their care as a result of local authority intervention. The demographic differences between the women interviewed who were and were not subject to social services intervention and who subsequently experienced child removal are in line with quantitative work which has illustrated differential patterns of removal for families of different ethnic groups (Ahmed *et al.,* 2022). My sample size means I am unable to make claims about population-level trends, but I emphasise these characteristics as they were articulated as a significant aspect of these participants' lived experiences.

Grace felt, as a Black woman she experienced discrimination from social services, who intervened following a serious incident which occurred when she was acutely unwell postnatally. Her children were taken into foster care whilst she was hospitalised. She was eventually discharged to a mother and baby home in the community, where she cared for her baby under close supervision and she was reunited with her older children much later. The process of reuniting the family after her illness had significant consequences on Grace and her family's housing situation:

> *"There was racism definitely behind all that. They [Social Services] made me give up my house, said the children didn't want to come back to the house because of terrible memories. My children weren't [age], they couldn't make a decision. They could've come back to the house, they could've supported us because they were supporting us beforehand. But they chose, what? Because my big house was too big for a Black woman, on her own? They gave us a smaller house, we had to be cramped in here."*
> **Grace**

Whether these decisions were the result of stigma in the form of (racial) discrimination as Grace perceived them to be, or well-intentioned, child-centred safeguarding-led decision making on behalf of services, the outcome is the same: serious material consequences for Grace and her family, resulting in the loss of the family home.

In the previous chapter (5), Melanie described how she came to the attention of social services following her suicide attempt during pregnancy. Her children were not removed from her care; however, services stipulated that she could not look after her children independently, that another adult would need to be present with her. She went on to describe the impact this had on her sense of self and her recovery:

> *"[It] destroyed my self-esteem and it didn't feel like it was going anywhere in terms of me getting any help to get out of that hole. So it was just getting worse and worse, this kind of like not having an identity anymore, not working, not even being able to properly mum because someone always had to be there and it's chicken and egg, you know, I'm not going to get out of that situation unless things are calm for a long time but it was really hard to get things calm for a long time because of the way we were living life."* **Melanie**

Whilst Melanie's children were not removed from her care, she still experienced stigma in the form of status-loss in relation to her mothering role, as she felt she was not able to 'properly mum'. She also described how this intervention by services hindered her recovery. In the excerpt of Melanie's quote from Chapter 5, she talked about feeling like she was being 'baby sat', inferring she felt infantilised. Grace, also talked elsewhere in her interview about feeling infantilised and underestimated by social workers supporting her following her experience of postpartum psychosis. The feelings of infantilisation illustrate another route through which stigma may be inadvertently being generated, since it can be another form of status loss.

In addition to highlighting the ways in which stigma, in the form of status loss and discrimination, can be generated in-/advertently via social care intervention, Melanie and Grace both perceived they were not getting help or support from social services to re-establish their families and family practices. This illustrates a mechanism through which reproduction may be stratified (Ginsburg & Rapp, 1995) for women with histories of SMI, particularly women with SMI who are working class (like Melanie) or from minoritised ethnic groups (like Grace).

Healthcare

14 of the 20 women interviewed disclosed experiencing and/or anticipating stigma in healthcare settings. Several participants (notably, those with personality disorder diagnoses) went as far as to say healthcare settings were the places where they perceived they had experienced the most stigma in relation to their mental health. Women reported experiencing stigma in primary care services (e.g., health visiting; general practice) or in generic secondary mental healthcare. In contrast, women reported few experiences of stigma in the context of care delivered by specialist perinatal mental health teams, in fact, it seemed the care received by a small number of women from these teams played an important role in helping them to resist self-stigma.

The nature of the stigma women experienced in this setting was often highly gendered. It was influenced by institutional factors such as team hierarchies and workload and systemically by normative ideas undergirded by patriarchy and heteronormativity.

Shaming and sexuality

Several participants who did not have children and were amongst the youngest women interviewed, discussed ways that health professionals had stigmatised them for disclosures related to sex and sexuality. Katie talked about how symptoms associated with bipolar disorder have led to her feeling stigmatised within healthcare services. She explained that when talking about sexual impulsivity to professionals she felt judged and 'slut-shamed'.

Mae described how her mental health deteriorated after she had experienced sexual violence until she was eventually hospitalised. Describing the dynamics between the staff on the ward, Mae said the lead clinician was an internationally renowned specialist and the other staff on the ward were deferential to them. She went on to describe an interaction with the doctor where Mae felt victim-blamed by the clinician. In Mae's account of the event, she resisted this stigma by expressing to nursing staff how she felt about her doctor's statement. She explained how the nursing staff tried to explain what the doctor meant and did not escalate the incident further. She said she did not receive an apology or an explanation from her doctor personally. Mae perceived that the incident "was handled really poorly and everyone just backed each other up". Mae's perception of how the incident was addressed illustrates how hierarchies within medical teams could leave stigma unchallenged. After this incident she was discharged from the hospital and at the time of interview said she was "at home, hiding from doctors", not wishing to engage further with NHS services.

Alice's experience of stigma sits at the intersection of her diagnosis, socioeconomic status and sexual orientation. She talked about how diagnostic interviews for personality disorders include discussions around sexual promiscuity and an uncertain sense of identity. She talked about how these 'traits' of personality disorder were interpreted by her therapist and how this influenced their therapeutic encounters:

> *"[Therapist] had a kind of issue with my bisexuality being like that I was unsure of my identity or it meant that I wasn't really committed to [partner]. I was like no I'm bisexual but I'm still in a monogamous relationship. Oh but are you really just scared of commitment? It's like, no, I'm committed but I'm just also bisexual. Oh so you're always looking for something else? No (laughs) like can you not understand this. Just this kind of translation error."* **Alice**

She went on to explain how after disclosing circumstances around a sexual assault, the therapist continued to make stigmatising (in the form of discriminatory, biphobic) remarks in their sessions. Despite these experiences, Alice continued to engage with this therapist for months longer than she wished, due to fears around how this might affect her future access to care:

> *"It happens a lot, like if you don't do this then you can't have this, and I was aware of this system within the NHS so I was like well, if I don't engage with them it will be written in my notes that I disengaged, and therefore if I ever ask for help again or a different type of help they'll be like oh well you didn't engage."* ***Alice***

Katie's, Mae's and Alice's experiences of stigmatisation in healthcare, relating to sex and sexuality, occurred outside of the perinatal period; however, I believe these insights still hold perinatal relevance, as illustrated by Jeanette's experiences. Jeanette reported not seeking help perinatally for exacerbation of her OCD symptoms during both of her pregnancies because of the 'taboo' nature of symptoms. She described having worries about inappropriate sexual feelings and had paranoid thoughts relating to a previous experience of abuse. Jeanette anticipated experiencing stigma from professionals in relation to how these symptoms had manifested perinatally.

Seeing this alongside the experiences of the three other women, it is easy to understand why women such as Jeanette may be reluctant to disclose these manifestations of maternal mental illness. Katie's, Mae's and Alice's experiences demonstrate how sex and sexuality is discussed and responded to in mental healthcare settings can result in stigmatisation that is (perhaps unintentionally) informed by heteronormative and patriarchal ideas and practices. Their experiences also illustrate that the relationship between experiencing and anticipating stigma and the effect on access to care is not straightforward. Mae experienced stigma and Jeanette anticipated stigma which led them to be healthcare avoidant, whereas Alice, despite experiencing stigma and biphobia felt she was unable to withdraw from care for fear of the effects this would have on her future access to mental healthcare.

It is important to exercise reflexive practice when interpreting findings on highly sensitive subjects to understand the limitations of the data. Jeanette was reluctant to talk in-depth about the manifestation of her symptoms during the interview, so it is unclear if her anticipation of stigma was due to previous experiences in a healthcare setting, or if it had another basis. It is also possible that other participants who were mothers may have experienced or anticipated sexuality-based stigma in a healthcare setting but felt unable to disclose this during interviews because of the highly sensitive nature of discussions related to sexuality.

Transgressing gendered family roles

Some women's experiences of stigmatisation in healthcare were centered around normative expectations of gendered family roles.

Laura talked about her experience of speaking to a counsellor about her postnatal period, which included experiencing severe postnatal anxiety. She was not seeking counselling as a primary treatment for illness, but rather to process what she described as the trauma of being unwell perinatally:

> *"She [the counsellor] doesn't have any experience or expertise from a perinatal point of view and I've found that tricky. […] I've had to explain my experiences to her and I can tell she's never really spoke to anybody about this. I explained to her about how I'd not been able to be in the bedroom with [baby] overnight for a long time and she raised her eyebrows. And I remember – earlier you asked me about stigma – I took that as real like, god, I've just told you something that is such a hard thing for me to have expressed, something that I am embarrassed and mortified and feel such shame about and you've kind of gone "uhhhhhh" (laughs) you know, raised your eyebrows."* **Laura**

Laura's experience underscores the importance of support from specialist professionals who are familiar with the manifestations of perinatal distress and how this may affect women's postnatal experiences, including interactions with their child. Laura sought help from a counsellor via her workplace benefits programme, because she was no longer eligible for support from the specialist perinatal mental health team in her local area, who she reported could only support women for up to a year postpartum. Although Laura was in a relatively privileged position to be able to access therapy via her employment benefits, her experience illustrates how the organisation of care, particularly service cutoffs and thresholds indirectly influenced her experience of stigma.

Following a suicide attempt, Melanie also felt shamed by healthcare professionals in relation to her mothering role. Melanie attempted suicide during pregnancy and at a later point in her motherhood. She talked about a conversation with healthcare professionals upon discharge from hospital after her later suicide attempt in which she reported mental healthcare workers

asking her if she knew about the damaging effects of parental suicide on children. Melanie's experience of stigma in a healthcare setting also echoes that of Katie (who is not a mother), who whilst being treated for self-harm was reminded of her role as a daughter:

> *"I remember when I used to self-harm a bit and then I was telling, I think it was a nurse about it or something and she was saying oh do you really want to do that to your family, you're making them see that, how could you do that to your parents, why weren't you thinking of them?"* **Katie**

In Melanie's and Katie's reports of these encounters, they are not being 'seen' as individuals. They are seen instead as someone else's mother, someone else's daughter rather than women in their own right. Their distress is seen as incongruent with expectations of these gendered roles. Particularly in relation to Melanie and Laura's experiences, this illustrates how ideas about mental illness not being part of the 'ideal' of motherhood can be perpetuated through institutions such as healthcare.

Future motherhood

Two of the four women who experienced postpartum psychosis talked about interactions within healthcare where they experienced status-loss by not being seen as candidates for future motherhood. Fay described her experience whilst attending a GP appointment:

> *"She just really flippantly, was just looking at my records, not at me, and went 'Yeah, so you're not having any more children' and it's like, we have never had that conversation, you are making an assumption. I wasn't at a place when she said that where I'd accepted that and I can remember just going 'yeah that's right' and thinking I just need to not be in your presence […] I was just so shocked that she'd said it and afterwards I was questioning myself kind of thing like, well of course she's thinking that because… and I was like no, no, no, that's not OK what she said and the way she said it."* ***Fay***

I asked Fay what she thought the GPs assumption was based on. She explained:

> *"I assume it's because I was so seriously mentally ill. I assume, because while I was [age] I would've been [age] I wasn't kind of 50 and therefore it was completely written off, and I was asking her for the pill that was part of my prescription so I was clearly still considering birth control was a thing that needed to happen, so yeah, I assume it was because I was so ill."* **Fay**

Another woman who was acutely unwell postnatally was Anna. She reported being told by healthcare professionals to take contraception and "just don't get pregnant again". In Anna's and Fay's cases, their perception of the judgements made by professionals relating to their mental health history and their reproductive futures can be interpreted as a form of stigma. Specifically through the definition of stigma as a judgement related to mental illness that is medically unwarranted (Scambler, 2009). Through these perceived judgements, women also experience a form of status loss (as a candidate for future motherhood). Their experiences are in line with other women's reported in the literature (see Dolman, Jones and Howard, 2016, for example). These experiences illustrate another mechanism through which reproduction may be experienced as stratified for women with histories of SMI.

Whilst both women felt subject to similar judgements, there were significant differences in their responses. In discussing how they responded to these interactions, it is pertinent to highlight the variations in their mental health histories, ethnicities and socioeconomic positioning. Postpartum psychosis was Fay's first experience of SMI. She is a White British

woman, university-educated, owns her own home and works in a professional role. Fay's initial internal response was one of shock and wishing to leave the appointment as swiftly as possible, and she recalls afterwards experiencing both an internalisation and a resistance to the stigma she experienced. Fay's ethnicity and socioeconomic position mean it is unlikely her legitimacy as a 'good' candidate for motherhood had been called in to question before this encounter with the GP. Anna's history of SMI predates her first pregnancy and she belongs to a racially minoritised group. She has completed some further education, lives in local authority housing and at the time of interview was not in employment. Anna was asked how she felt during this healthcare interaction. She said:

> *"Erm it was OK 'cos I know myself, that when I give birth I get really sick. So erm… For me now, as a [age] year old lady who's single, I'm not trying to have any more children. I don't want to go through what I've been through... I've got a daughter and a son, and they both don't live with me and I can't think about having another baby […] I don't wanna, I got a girl and a boy and that's lovely already. I wanna focus on the children I have already instead of having another baby. But if I did meet someone. You know, maybe I might meet someone, dunno, some companionship, someone that's compatible with me on certain things. If they had children I'd love them as my own so… I'm alright with that. I'd tell them straight out that I'm sorry but if you wanna be with me I'm just telling you straight out that I'm not having no more children. Like if he's got children of his own I'll accept them as my own."* ***Anna***

Whilst her legitimacy as a 'good' candidate for future motherhood is denied by healthcare professionals because of her history of mental illness, this status-loss is resisted by Anna in interesting ways. Firstly, she utilises the language of personal responsibility ("I know myself"). In the latter part of her response, she resists stigmatisation by asserting her claims to motherhood both present and future by foregrounding her wish to focus on the children she already has and regaining care of them. Furthermore, she asserts that her maternal love would extend to the existing children of potential future partners. Their experiences illustrate that women respond to stigma in complex and dynamic ways, and should not be seen as passive 'victims'.

The methodology of this work means it is not possible to understand the rationale of the professionals speaking to Fay and Anna. It is worth highlighting that no professional participant expressed similar sentiments to those Fay and Anna reported encountering during their appointments. Psychiatrist 1 and 3, who worked in specialist perinatal mental health teams, both expressed how the work they do in the preconception period, where they are supporting women with SMI contemplating future pregnancies, was a part of their job they highly valued. Psychiatrist 1 said: "*it's one of the joys of my job. I'd love to just see women for pregnancy planning support because it's such a nice thing to be able to do for women and give them that time and space to empower them to make decisions about what they want to do..".* Preconception care is discussed in more detail in the next chapter.

Ticking boxes

Many women alluded to the mental health-focussed parts of maternity-related appointments as feeling like a formality, or a "tickbox exercise". Melanie articulated how this made her feel, illustrating how the structure of healthcare appointments and the wider conditions healthcare professionals are working within impacts individual patients. Melanie said:

> *"They've got a tick list of questions and I got the very real feeling that they just expect you to say no and they can go "any mental health- no, any involvement of social services -no" and they're just ready to just tick all the no's and then obviously here I*

am sitting there in front of them and actually it's a bit messy and it's a bit complicated... You know, then having to justify and explain myself instead of just going actually I'm a bit vulnerable and I could do with a little bit extra help please. It more feels like here I am having to apologise for everything that's ever happened. No, you can judge me for it and make me feel small and rubbish. Instead of how can we go past that and work to a more positive time this time round." **Melanie**

Health Visitor 2 provides an insight in to this from a professional perspective. Talking about their experiences in MDT meetings, they described how often it appeared women had chose to disclose their distress to their GP rather than their health visitor. Health Visitor 2 said:

> *"[Patient had] not mentioned it to the health visitor. Why is that? I think like that kind of checklist of all the things you've got to do is a deterrent, really, for people to kind of speak up and say how they're feeling because you look busy and you sound busy and you're in a rush and you can, you know, like.. And I remember being that health visitor, like I've been that health visitor, just so busy all the time […] when they come to me and [do] VIG[15] and say no one's ever listened to me. I think that speaks volumes about like how, how it does make them feel."* **Health Visitor 2**

Health Visitor 2 works in a specialist role now, delivering video-based (and other) interventions to women who are struggling postnatally. The fact that Health Visitor 2's patients reported feeling heard again illustrates the value and importance of specialist care for women postnatally. The other part of the quote highlights the strains on others working within the profession.

Midwives and health visitors are increasingly expected to cover more and more topics in their time-limited appointment and are operating within stretched systems characterised by significant workforce-related challenges (which are discussed in more detail in chapters 7 and 8) which impact on patient interactions. The unintended consequence of this is women feeling, like Melanie, these appointments are more a bureaucratic process than a place of care and that they are judged for their histories disrupting the expected 'flow' of these processes, inadvertently stigmatising women and in turn influencing their seeking help.

"Recursivity" and the anticipation of stigma

As outlined in Chapter 3, 'recursivity' is a concept used to understand inequity in access to healthcare. It describes how past experiences of healthcare can inform future healthcare seeking (Liberati et al., 2022; Kovandžić et al. 2011). Midwife 1 alludes to the concept when discussing different factors which act as barriers to care:

> *"It could be that they've had bad experience with previous diagnosis of mental health, but also could be the fear of children being removed from them due to mental illness. So, that could be another big prevention of them asking for help."* **Midwife1**

Earlier in this chapter, I showed how Mae's past experience of stigmatisation in a mental healthcare setting influenced her perceptions of healthcare to such an extent that she no longer sought care but 'hid from doctors' instead. This was true of other participants such as Asma who experienced stigma in the form of racial discrimination whilst in an inpatient setting and subsequently felt this affected how she interacted with professionals. I also illustrated how Alice's experience of stigmatisation in a mental healthcare setting complicated her access to care: she anticipated she might be labelled as an obstructive

[15] VIG = Video Interaction Guidance, an intervention where women reflect on recording of their interactions with their babies with the guidance of a healthcare professional

patient and believed her future access to care might be made more challenging because of this labelling.

Alice was not a parent at the time of interview. She was also one of several participants who described healthcare as the setting within which she had experienced the most stigma relating to her mental health. Later in Alice's interview she went on to describe one of her concerns about accessing future perinatal mental healthcare:

> *"What would really, really worry me is if I were pregnant and went to the GP about a genuine physical health concern and then it was written off as oh well she's got BPD, it's probably nothing, or if I went with a completely new health condition i.e. like if I developed postnatal psychosis and then people were like oh she's got BPD, she's a time waster it's not real and then something awful happened, that's always been my fear, and to the point where I end up getting, my team are more aware of it now so they're much better at it, but I tend to get worse into crisis than I should get because I'm so scared of asking for any help until I absolutely need it because I'm so scared of someone turning around and being like oh she's got BPD, she's a time waster, so I don't ask for any help until it gets to serious crisis point, by that point it's usually quite a dangerous situation."* **Alice**

Alice's quote demonstrates how past experiences of mental health-related stigma in healthcare settings - outside of the perinatal period - can generate anticipated stigma. For Alice, this generated fears about her safety in the perinatal period, as due to past experiences she believed that genuine health concerns could be perceived as her 'wasting time' because of stereotypes about her diagnosis circulating within healthcare.

In contrast to Alice, Kimberley had largely positive experiences of mental healthcare both prior to her pregnancy and perinatally. Despite these positive interactions, she talked about the residual fearfulness she felt as a single mum interacting with professionals in a healthcare setting:

> *"There's still a little underlying fear of don't use that [single parent status] against me. I'm still a competent person. There is just one of me, but I'm, I'm trying my best, you know? And I suppose, despite how well I've been looked after on two occasions, one with a breakdown and one during my pregnancy. Erm, maybe I am still a little bit frightened that maybe that, those teams could turn against me and say, I'm not a good enough mother."* **Kimberley**

Kimberley's fear about being judged by professionals as a 'bad' mother is related to her status as a single parent rather than explicitly with her mental health history, showing that women may anticipate stigma in relation to other aspects of their experience or identity, including their parental status. It also illustrates that the relationship between positive past experiences and the anticipation of stigma may be complicated by other aspects of women's identities.

Professional perspectives on stigma and healthcare

Many of the professionals interviewed saw stigma as a significant barrier to women accessing mental healthcare. They perceived stigma as arising from different sources. Midwife 1's statement below summarises the concerns different professional participants discussed in relation to the stigma experienced by women with histories of SMI. Talking about their role as a specialist midwife, in which they are responsible for upskilling other professionals' knowledge in relation to perinatal mental health, Midwife 1 said:

> *“One thing that I highlight to professionals [is] that we need to be aware of stigma. We need to educate women about perinatal mental health and explain about how stigma can prevent women accessing care. So that could be stigma from being ashamed for, obviously mental health is something that some women are ashamed of and again it could be cultural [explains other factors] But definitely the biggest one for us is the cultural stigma and the language when it comes to mental health.”* ***Midwife 1***

Midwife 1 perceives education (of both women and professionals) as key to decreasing stigma-related barriers to accessing care, as other professional participants interviewed did. The quote above illustrates that Midwife 1 perceived self-stigma and ‘cultural stigma’ (i.e., stigma circulating within minoritised ethnic groups influenced by certain religious, spiritual or cultural beliefs (Kapadia, 2023)) as the dominant forms of stigma complicating and generating inequalities in access to care. As highlighted in Chapter 2, these are also common narratives in the perinatal mental healthcare literature.

Interviews with women participants illustrated how stigma can be embedded in processes of ‘recursivity’, both in terms of the anticipation of stigma but also in terms of stigma circulating within healthcare. Social Worker 1, who worked within a Specialist Perinatal Mental Health Team, asserted that stigma within healthcare didn’t necessarily affect access to a service but instead impacted the nature of the care or the kinds of interventions women were offered. They described this stigma as distinctly socioeconomically and diagnostically patterned:

> *“it feels like there is a massive class difference between the women that we see who might develop postpartum psychosis and then go to an MBU, recover, do really well. And who might tend to be quite middle class. Have a lot of family resources, a lot of family support, might have income that they can rely on and kind of typically recover and that's it […] To women who might present, who [are] often labelled with a PD [personality disorder] diagnosis, or just “mental health difficulties” and have had involvement from services for a long time and you know that they'll be kind of in the system after as well. Sometimes that doesn’t necessarily act as a barrier to them accessing the support, but definitely accessing appropriate and non-judgmental, non-oppressive support. […] Sometimes our own biases kind of stop, or might prevent us from offering the support that they need because of [capacity and workforce pressures]. We might not give them the attention that they need and might see others as more deserving. You know, I hope it's something that doesn't happen, but I know (hesitant speech) I think, it does. We know it does and I think we're probably all been guilty of it, sometimes it's easier to put resources into someone who you know you’re going to get a good outcome for then sometimes women who you just think it's going to be going on forever.”* ***Social Worker 1***

Social Worker 1 indicates that women with particular diagnoses or from particular social backgrounds may be treated differently because of perceptions about their “ability” to recover. This illustrates another route through which reproduction is stratified for women with SMI. Social Worker 1 also indicates there may be further stratification depending on women’s diagnostic histories and class backgrounds, whereby women with lengthy mental health histories or highly stigmatised diagnoses are not provided with the same level of support as other women who are unwell perinatally. Social Worker 1 also highlights the ways that the wider institutional and structural conditions in which healthcare professionals are practising, conditions characterised by stress and scarcity, may exacerbate the effects of stigma, thereby connecting individually mediated stigmatising practices to the broader structural conditions they are occurring in.

Health Visitor 1 explained that classed attitudes and stereotypes circulate in healthcare in relation to women from more affluent backgrounds too:

> *"I used to work in [area of high deprivation] and then I moved to [affluent area] and a lot of professionals were like "Awwww, a lot of worried well you'll be dealing with, right?" But we say in training, attention seeking is attention needing. You're not worried well if you're consistently accessing the service about maybe what we'd call infant regulation problems. It's really about looking sort of beyond and beneath. So I think there's also that unconscious bias at the other end of the spectrum as well."*
> ***Health Visitor 1***

In contrast to Social Worker 1, whilst Health Visitor 1 highlights the presence of these stereotypes, they do not make clear whether there are any consequences of this stereotyping for women from these class backgrounds. For example, it is not clear if the classification of these women as 'worried well' results in them not being offered particular interventions.

*

Before concluding this section on stigma in public services, it is important to highlight that, whilst experiences of stigma in healthcare settings were common in women's narratives, not all participants reported such experiences. In highlighting this, it is worth noting some shared characteristics of the women who did not report experiencing stigma in this power-setting and exercising reflexive practice.

Elton, Willa and Masi did not report experiencing any stigma in this setting, Masi was explicit about this saying emphatically: *"No. I didn't have the stigma".* Asked directly, they did not feel like they were treated differently because of any aspects of their identity or report any negative experiences of care perinatally: they are women of Black African origin and first generation migrants to the UK. Whilst it may be that they did not experience any stigma, it is important to be mindful of researcher-participant positionality and the broader contexts of participants' lives here in the UK. It is important to be mindful of the 'hostile environment' politically and socially in the UK (Taylor, 2018), characterised by increasing anti-immigration sentiment. Especially following the COVID-19 pandemic, the period within which these interviews took place, critique of the NHS is difficult and some scholars have argued its fervent defence has nationalist overtones (Cowan, 2020). Considering these broader contexts, it may be possible that these participants are reluctant to share experiences of racism and poor care with a White British researcher and instead may have felt more comfortable presenting as a 'good immigrant'.

Secondly, whilst this study used a self-identified definition of SMI, two participants (Masi and Stephanie) described their mental illness experiences and diagnoses more in line with common mental disorders (CMD). This is not to say that women who experience CMD are not also subject to mental-health related stigma. However, there is evidence in the broader literature that those with SMI are more likely to experience stigma (Hazell *et al.,* 2022). Participants in this study from both respondent groups also alluded to a hierarchy of stigma in relation to different diagnoses.

Family

Around half of the women interviewed described experiencing or anticipating stigma within the context of their families. However, different family members played different roles in

relation to stigma. It was more common for participants to discuss their partners as having played a role in helping them to resist self-stigma. For example, when Laura says:

> *"I often feel like I was weak, that I wasn't strong enough to cope with the challenges of having a baby and that's why this happened and as I say that I know that [partner] would go mad if he heard me talking like that (laughs). As would my perinatal mental health team and [CPN.]"* ***Laura***

Where women had experienced mental health-related stigma from partners, they were ex-partners at the time of interview. One of these women was Fee, whose ex-husband's views on mental health and illness had a significant influence on her care seeking perinatally:

> *"I didn't really talk to anyone about it because of the way I knew my husband felt about depression, it was like I had to just keep it to myself… I suppose I could've talked to my mum but I think I just felt like I needed to keep it to myself because of the way my husband was… it was, I dunno, the relationship, he was quite controlling as well, so it was a difficult situation really and I think it was like I knew I'd come off the antidepressants so I felt a bit like I'd made my bed so I had to lie in it."* ***Fee***

Fee explained earlier in the interview how prior to pregnancy, her husband had said they could only start trying for a baby if she was to stop taking the medication she took for her mental health. A decision she regretted, but felt she couldn't seek help to address. She described her husband as having mixed views about mental illness and, despite there being a history of different mental illnesses within the family, she said he believed that some were 'real' (schizophrenia) and others (depression) were not, illustrating heterogeneity in attitudes towards mental illness.

Of the women interviewed who had children, none expressed any anticipated or experienced stigma from their children in relation to their mental health. Although one participant was concerned about courtesy stigma (i.e., stigma experienced by people associated with a person who has a mental illness (Kapadia, 2023) affecting their child. This is discussed more towards the end of this chapter.

Women more commonly reported experiencing mental health-related stigma from their own parents, siblings and wider family members. Participants more commonly described having experienced or anticipated stigma from female family members than from male family members. This does not necessarily mean they are experiencing more stigma from female family members, but perhaps that it is more memorable, or powerful a memory when perpetrated by a family member of the same gender. Below I present three key areas in which my participants experienced stigma in the family: medication use, around expected family roles and with regards to concealment.

(Resisting) resistance to medication use

Fay and Stephanie experienced stigmatising attitudes from their parents regarding the use of medication to manage and maintain their mental health. Fay continued to take antidepressants following her episodes of perinatal SMI a few years earlier. She described an interaction with her mother regarding her use of medication:

> *"I was talking to my mum about having my medication reduced and she said 'ah, that's good', and I challenged her and said 'well, it is… if I no longer need the medication, but if I was asthmatic you wouldn't say oh I've been on an inhaler for quite a long time. Like if this keeps me sane and a healthy human being, able to be a good parent to my daughter, I will take it until the day I die. That's fine, I do not care".*

> *Whereas for my mum she was like, well, you should come off your medication. I should come off it if I'm well enough to and if it's appropriate not because you think I shouldn't still be taking medication, so I feel like there is a stigma around that as well."* **Fay**

Stephanie had a history of anxiety starting several years prior to her pregnancy, but described feeling well throughout the antenatal period. When asked about stigma during our interview she described a time when her father had queried her use of medication whilst she was pregnant:

> *"I had to explain that yes, because I felt it was too risky especially at that point, you know [describes pregnancy timelines]. Too risky to have come off of it ... So there was a definite sense of what I would say the biggest, the overriding emotion from him was surprise. I think also because the idea of someone who is mentally unwell or takes medication for mental health… [it] just did not line up with his idea of who his daughter was."* ***Stephanie***

Both Fay and Stephanie's experiences illustrate how it is not always the illness itself that is stigmatised by family members, but rather the interventions they are using to manage their mental health. In addition to highlighting specific aspects of women's illness experiences that are stigmatised, both these excerpts illustrate ways in which participants resisted stigma. In the case of Stephanie and Fay, they utilise notions of risk and what it means to be a good parent. In Fay's account, she also draws on common anti-stigma messages which circulate in media and common discourse, making comparisons between physical and mental health disorders to invoke a parity of esteem between the two.

Failure to meet expectations of family norms and roles

The quote above from Stephanie also illustrates how the nature of stigma circulating within their families is characterised by a sense of failing to inhabit their family members' expectations of them as a 'good' mother, sister or daughter. It is not only within the healthcare setting that the nature of the stigma women are experiencing related to their gendered family roles. Melanie talked about the effects of her sister's stigmatising views:

> *"My sister used to really judge me, I think she was probably the most outspoken critic, and we didn't talk for a long time because she thought I was a complete waste of space because I've got these wonderful children and I just refuse to be well, and I'm just lazy and selfish. [describes reconciliation] but when even your own sister can have that judgement about you it's hard to feel a lot of self-esteem because she knows what's happened in my past and what I went through."* **Melanie**

Melanie's history of SMI is inextricably linked to her history of trauma. She was upset that her sister, despite knowing about the trauma she'd experienced, had seen her distress as manifestations of laziness and selfishness. These descriptions indicate that Melanie's distress is being perceived as a moral issue rather than illness, as something she has control over, rather than something beyond her control. Grace described a similar stigmatising interaction with a female relative whereupon she was told to "pull herself together", a common English idiom but one which implies Grace's distress (psychosis) could be ameliorated if she could just control her emotions.

As highlighted in Chapter 5, Mae's experience of SMI had potentially impacted her fertility. She talked about how anxieties about her fertility were not solely personal troubles:

> *"I just feel a lot of pressure from my mum. My mum dreams of having a family, so there's all this 'oh we're never gonna have grandchildren, you've ruined, it's your dream, you've ruined your life', she doesn't say ruined, but, 'the only one who has done anything, who has caused this, is you."* **Mae**

The perception of SMI as something within women's control rather than illness is both a manifestation of stereotyping and a judgement that is medically unwarranted (Scambler, 2009). Melanie's, Grace's and Mae's relatives positioned their distress as a choice, one which was disrupting their ability to fulfil their gendered family roles as mothers, or in Mae's case, as a potential mother.

Similar to Mae, Kimberly's family expressed anxieties about her not having children, but this manifested slightly differently. Kimberly described her family's classed attitudes towards motherhood and womanhood:

> *"All my family are Northerners. Very, very working class Northerners. The common question I would get when I was home [was] when are you going to get a house? When are you actually going to stop what you doing, stop messing around and get set up [redacted], get yourself a fella and have a child, cos you gettin' on… cos all of us were younger, and we're all young pretty mums now… Little did they know I was bloody working and it was hard, but those were all experiences I couldn't kind of relate with them and explain to them, so I just never did. And the process of bottling things started."* ***Kimberly***

Kimberly perceived her work-related life and identity was not acknowledged or legitimised by her family, within which motherhood is more highly valued than her professional achievements. As such, she experienced a status-loss for not fulfilling this role within 'normative' timeframes. This led to feelings of isolation and disconnection from her family-of-origin, which she perceived as an important aetiological factor in the development of coping strategies and which were ultimately detrimental to her mental health.

Mae's, Kimberly's, Grace's and Melanie's narratives all illustrate varied manifestations of stigmatising attitudes towards women with SMI experienced in relation to their reproductive roles within their own families. More specifically, they demonstrate how, in the eyes of their families, their mental health condition contributed to their failure to inhabit the gendered norms and expectations of their roles as women within the family unit.

Concealment and "cultural" stigma

As highlighted in earlier in this chapter, professionals interviewed saw stigma as a significant barrier to accessing care, particularly for women from minoritised ethnic groups. This included practitioners who were practising in highly ethnically diverse areas as well as those who were not, but were aware of ethnic inequalities in access to perinatal mental healthcare through engagement with influential research and advocacy, referencing studies such as ESMI-II (Howard *et al.,*2022) and MMBRACE (MBRRACE-UK, 2024) by name.

Talking about their perceptions of stigma circulating in minority ethnic communities, one professional working in a specialist team said:

> *"Mental health isn't spoken about in a lot of cultures and it's still very much kind of brushed under the carpet, so to speak, and not spoken about. I think a lot of people are fearful in how their families are going to react and what their thoughts are and what other members of their community will also think, because a lot of maybe Asian communities are really close knit, and, you know, they're all kind of very close*

together. So, it's then thinking about what will other people think? And, particularly if people having hallucinations or are experiencing an episode of psychosis, the stigma that's attached to that is quite significant, which again stops people from coming forward or speaking about it." ***Nurse 1***

Nurse 1 described stigma within minoritised ethnic groups manifesting as silence or concealment, and reported that those struggling with their mental health may anticipate stigma from family or wider community members. Nurse 1 also saw particular forms of illness and distress such as hallucinations and psychosis as more heavily stigmatised.

Several participants discussed concealment, silence or euphemistic ways of talking about mental illness within the context of their own families. Fay, who is White British, talked about how conversations about mental health within her family started only after her own episode of postnatal mental illness. Following this, her family talked about other family members' histories of postnatal distress; something which had not been discussed or disclosed before. She said:

"I remember […] my cousin struggling, I don't remember it having a label and particularly not when talking about it with my aunt, so mum spoke to me about it, she wouldn't label it as postnatal depression and I think that's probably to do with the stigma. How she felt that would be perceived if she put a label on it." ***Fay***

Concealment of mental illness within families was discussed by participants of both White British and other ethnic backgrounds. Asma and Fee, who were both of South Asian heritage, described in detail the dynamics of concealment of mental illness within their families of origin, which they perceived as informed by their families' cultural histories. Specifically, they described these dynamics as driven by cultural beliefs about the nature and causes of mental distress and the high cultural value placed on marriage and family.

Asma's decision to not have children (informed by trauma she'd experienced) was discussed in Chapter 5. In terms of experiences of stigma, Asma described how her family concealed her distress (which manifested as OCD) from wider family members by physically separating her from others during family gatherings:

"Many times when the relatives used to visit they would hide me away because they didn't want the others to know I had mental illness and abnormal behaviour." ***Asma***

Fee had a significant and multigenerational family history of SMI. Prior to trying for a baby, she discussed her family history of illness with her husband, specifically the risk of her and her future children inheriting the condition. She said that these kinds conversations and the openness about mental illness were unusual within her family. When asked about why she thought there were differences between the ways that she and others in her family thought about mental health, she said:

"I don't know whether it's the fact that I'm more Western than the rest of my family. As I say, my mum was born here so when you compare my family unit to the rest of my dad's family and my dad had a big family, we were very Western and they were still very Asian culture and within the Asian culture you don't talk about mental health, it's not, it's like… it's still very taboo. Only now my family are accepting that it's actually a mental illness, is an actual illness you know, is a real thing, as real as breaking your leg." **Fee**

Fee's response shows the complex dynamics within families of South Asian heritage that may influence attitudes towards mental health and illness. Generational differences as well

as processes of cultural assimilation mean attitudes and beliefs in relation to mental health are not fixed and that heterogenous views within the same broader family unit co-exist.

Workplace

As discussed in chapter 5, many women's interviews included extensive discussions about work and employment. In chapter 4, I highlighted that most of the women interviewed talked about work or their occupation (current or former) as a key part of their identity. In chapter 5 I demonstrated work and employment was a core feature in women's illness narratives. The workplace was also identified as a significant site of stigmatisation.

Both Melanie and Cammi talked about the unique intersection of their experience as a working mother with a history of mental illness and what this has meant for their experiences of stigma in the workplace:

> *"I've had stigma for wanting to work and having mental health issues, and I also get stigma for wanting to work and having four children. It's like "you've got four children and mental health issues, no I don't think you should work!" I've had people say that to me. I've had jobs where it's been pretty much obvious that you know once I've kind of had to disclose about my mental health issues because I've had a relapse and I've had to take some time off and I'm doing the whole back to work thing. And they're like well you've got kids AND mental health, you know, it's almost that sort of why did we ever employ you, you know, you're just too complicated."* **Melanie**

> *"I think as a person with mental health problems [you're] being questioned, that you've not got the capacity to deliver or bring it through or you're not reliable or you're going to let the team down or you… That sense of bad worker, bad mother, bad person, thing going on with mental health… When I [describes work success], my bosses boss took me aside and she said "see! You <u>can</u> deliver" and I was like "What did you say?!""* **Cammi**

The nature of the stigma they describe in the workplace as a woman and mother with a history of SMI is multifaceted. Cammi and Melanie's extracts show that their abilities are underestimated. Assumptions were made about their reliability and their status as 'good workers' is called into question. Women are often marginalised and discriminated against within the workplace because of their maternal status (Adams *et al.,* 2016). However, these mothers' place in the workplace is rendered more precarious because of their mental health history.

Work & employment-related stigmatisation at the maternal/mental health juncture was not only a concern for the women interviewed who were mothers. Bella, who decided not to have children, talked about how work and employment are often used against women who are child-free, describing how the term 'Career Woman' is often used as a slur towards women in relation to childlessness. Bella also talked about the exclusion from workplace practices that express care and solace when being off work for mental illness compared to physical illness:

> *"If someone else is off with a broken leg or something, they get a get well card and people welcome back and ask how they are doing. I went off with a mental health problem, then you know, you don't get no cards. There's no big welcome back. It's kind of like, let's pretend it didn't happen. So like, it's just being treated differently."* ***Bella***

One participant disclosed a serious incident of workplace-related discrimination where a reference was withheld for another role because of her history of suicide, demonstrating that the stigma experienced by women with SMI in the workplace has both psychological and material consequences for women and their families. My participants' narratives illustrate how women can experience exclusion both from and within the workplace with implications for their self-esteem, their sense of self and also their economic stability.

Maternal Spaces

Female spaces and relationships such as mother and baby groups, voluntary sector facilitated support groups, peer support and female friendships were commonly mentioned by participants when discussing stigma.

In comparison to the other spaces and settings described in the preceding sections of this chapter, there was less evidence of women experiencing stigma in these places. There was more evidence of women anticipating stigma and of the role these spaces and interactions provide in protecting women from or enabling women to resist mental health-related stigma.

Most of the professionals interviewed did not discuss maternal spaces or relationships in connection to stigma. Only Health Visitor 4 tentatively alluded to anticipated stigma when hypothesising why women from lower socioeconomic backgrounds utilised support groups in lower numbers than mothers from more affluent areas, saying: *"Potentially they [mums from less affluent backgrounds] wonder, you know, maybe that they're going to be looked at as bad parents. I don't know. But potentially."*

Formal settings

Just one participant described experiencing stigma in the context in a formalised maternal space. Jeanette was referred to attend a local mother and baby group by her Health Visitor, who had concerns about her mental health:

> *"She suggested I go to a mother and baby class at the clinic. But most of the other mums were quite rude to myself and another mum because our children were older, and they said they felt uncomfortable breastfeeding around us because our babies are older and they arranged to meet somewhere else a lot of them did… And so that was a big rejection."* **Jeanette**

Whilst Jeanette did not perceive this exclusion, where she was separated from the other mothers, as related to her mental health, this rejection had a significant impact on her subsequent willingness to engage with services. Following the birth of her second child she experienced more severe perinatal mental health difficulties. The Health Visitor advised she attend the same service but Jeanette resisted, anticipating a similar stigmatising experience.

Fay and Kimberley both described feeling uneasy at mother and baby groups. Fay's experience was highlighted in Chapter 5, but is included again in this chapter as it illustrates mechanisms through which women can feel excluded in these spaces:

> *"Going to these groups, particularly the ones where there wasn't anything to do and you were just chatting. I was like, none of you get it! Like, you've been at home, you've been with your partner, you've been (pauses)… I feel cheated out of my maternity leave, I've been in hospital, I've had my freedom taken away from me and I can't talk about those first nights where I was sharing the feeds because I wasn't, the nurses were doing it. And [partner is] a dad who had a brilliant night's sleep for the*

first six months of childhood because… It's just, I felt like, I felt like I had a big red spot over my head." **Fay**

In contrast to Jeanette, Fay does not describe the actions of other group members as being exclusionary. Rather, her sense of exclusion and separation from other mothers occurs from her feeling unable to participate in discussions about the normative experiences of early motherhood. Despite her distress and difference likely being invisible to the group she is in, she describes feeling a metaphorical physical marking of herself as different. She also says she found unstructured sessions as particularly challenging. Elsewhere in her interview, she described feeling much more comfortable in groups where there were activities which generated more focus on the babies. Later in her recovery she described the value of attending groups which were for women who had exclusively experienced postpartum psychosis:

"it's so nice to talk to somebody and say I had a difficult start to motherhood and they know what you mean, and they have a similar and shared common experience. So I've spoken to some women from there about am I going to have a second child, and I know somebody who did and I know somebody who didn't and I know their experiences, and that's really helped me and just yeah, being in a community where I don't feel othered in. Because the bit that I find difficult in other groups of women isn't there, because we all feel different until we're together, and then we don't feel different, we feel the same and that's really helped." **Fay**

Earlier in this chapter, Fay's experience of stigmatisation (in the form of assumptions made by her GP about her candidacy for future motherhood) was discussed. Through these formal maternal settings, outside of the healthcare system, Fay found sources of support and advice. These helped her resist stigma, as well as provided access to information about future reproductive decision making, an important part of her reproductive-related experience as a woman with a history of SMI.

Kimberly's unease in maternal spaces relates to her anticipation of stigma, not just in relation to her mental health condition but also in relation to her status as a single mum who is not in employment. Here she describes the probing from other mums regarding her occupation and future work plans, which she has had to give up because of her mental health difficulties:

"I must admit, there's always a little knot in my tummy going is somebody going to work out, single parent and I'm not at work. Or I'm not going back to work... it's already come up in mum classes. When are you going back to work? Oh shit, I'm not going back to work. You know, I can't do my job anymore. I can't be a [profession] anymore. I'm not on the ball in the same way. So I'll say career change, which bemuses a lot of people, or I'm in between jobs, or I'm, I'm taking my time to decide what I'm going to do. When they get to know you a bit better, it's like, how can you afford to do that then? You know? And so those questions come again. And it all comes back to explaining this hiatus period where I'm just in no man's land being mental." **Kimberly**

The probing by other mums regarding how she can afford to not work is particularly pertinent to the socioeconomic context Kimberly and other mums in her area are living in. She described the area she lives and is attending the groups within as a 'deprived working class area'. It also illustrates how the stigma women anticipate is multifaceted and intersectional.

Formalised parental spaces were not sources of (experienced or anticipated) stigma for all women interviewed. Elton, Willa and Isa described the positive interactions they had in such spaces.

> *"It made me feel like I had people going through the same as I am going through, and I am not alone at that moment, which I didn't know earlier on. I thought maybe it was something strange which was happening to me and it was the first case and it made me feel that I am not alone in this, and it made me feel encouraged, and the fact that I also opened up and I talked and they could help where they were able to. It made me feel at ease."* ***Willa***

> *"Pretty much all the stigma and discrimination I have experienced has come from within health services. It has not come from other parents… I used to go to this [name of group] sometimes people would be there and like literally sitting there crying, and it was just very much you know like actually, everybody you know, everyone has difficult stuff happen and yeah, just generally like whenever anyone was open about anything mental health-related other people would be like 'thank you for sharing' or 'I'm going through something really similar' or 'I have' or 'I'm really glad that you were still able to come and do this with us', and you know, so from other parents, really nothing, very much a kind of like 'shit happens and we're trying to get through this and let's see and can we help each other'."* **Isa**

Willa's and Isa's quotes illustrate how interactions in formalised spaces can be protective against the isolation which can occur as a result of maternal mental illness, and the self-stigmatisation which can occur as a result. They show the ways in which these formal spaces and the relationships that are formed within them helped women feel less alone and detached from "normative" maternal experiences as they found common ground with others.

Informal connection

Social connections which were fostered via informal means (i.e., existing friendships, or women coming in to contact not because of organised activities) were also discussed by women in relation to stigma. Women described the importance of non-judgemental, affirming, inter-maternal friendships for the recovery and maintenance of their mental health. Melanie also describes these as important for affirming and resisting the stigma she had experienced:

> *"Once I started to feel like I had some allies and some understanding that wasn't just coming from my partner and my mum, but actually from other women who were living this, I felt so much like I'm not alone and some of the treatment and prejudice and the discrimination and the judgements, actually I'm not the only one who's feeling this, I'm not the only one who's seeing this happening. And it made me realise this isn't just my low self-esteem, this isn't just me deserving to be treated badly, this is happening and it's a reality for people."* **Melanie**

Similar to the experiences of Isa and Willa described above, connecting with women who have similar experiences affirmed these for Melanie. She also no longer felt alone both in her experience of illness but also in the experiences of discrimination and stigmatisation in relation to her mental health condition. Through these connections Melanie is able to see their external rather than internal cause, or experienced stigma rather than self-stigma.

Whilst friendships were largely reported as positive, some women described existing friendships and relationships becoming strained in ways which engendered stigma. As mentioned earlier in this chapter, in the section on 'family', just one participant reported their family members experiencing courtesy stigma (i.e., where the isolation, status loss, discrimination etc. that a stigmatised person experiences is also experienced by those associated with them (Kapadia, 2023)). Talking about the impact of her illness on the social life of the family, Cammi said:

> *"The impact [illness] has had on us as a family and especially on my mothering has been that [child] has lost out because those mothers - particularly the mothers that didn't understand - withdrew and therefore (pauses). I wasn't… when I was unwell, able to do what the other mums were doing in terms of relating to the other mums and booking in playdates or you know, organising things for my daughter, or for us to socialise as a family or couples. Or socialise as mums and kids, so my daughter lost out […] that just makes you feel rubbish as a mum because she hasn't got what she would have. "* **Cammi**

The separation Cammi and her child experienced from other families, which she perceived was a result of her illness, illustrates how experienced stigma can be internalised and transformed in to self-stigmatisation. As illustrated in Chapter 2, aspects of 'good' mothers are those perceived to be those who secure their child's successful development and are 'in control' (Schmidt *et al.,* 2023)). She is not able to control arranging social interactions (which are important for child development) but she internalised this as something she is to blame for, feeling 'rubbish as a mum'.

Friendships were also discussed by women who had not had children in relation to stigma. Sofia, whose decision to not have children was described in Chapter 5, talked about the dynamics of relationships with friends who were also parents and how this can be upsetting and affecting:

> *"It's about not being included in things rather than what people say. Like not calling you back or not asking how you are. It's the action speaking louder than words… I do take pleasure in looking after peoples' kids and offering my help, because it's not easy to raise kids. You feel like you are missing the friendship, or the time, and your friends is and friendship are leaving you. And you are not included anymore in things, you think 'what's happening? What I'm not bringing to the relationship?'. So yes, it's painful."* ***Sofia***

Despite helping with childcare and spending time affirming and supporting the motherhood of others, she perceived herself excluded, rejected, separated from friends on the basis of her not having children. Sofia's pleasure in these tasks is notable and shared by other participants who had no children at the time of being interviewed. With the exception of one participant, all of the women interviewed who had no children expressed how much they loved children during their interviews and many of these participants worked with or had aspirations to work with children in a professional capacity. It is important to exercise reflexive practice regarding this observation. It is possible the women who were childfree may have anticipated stigma in relation to their reproductive identities and foregrounded their fondness of children during the interviews to resist stigma, to guard against stereotyping of them as women incapable of loving children.

Discussion and concluding comments

Chapter 4 introduced women's experiences of reproductive decision making, pregnancy and motherhood in the context of SMI. Part of this illustrated the nature of and the mechanisms through which women's self-stigmatisation can occur. This chapter builds upon this by drawing attention to other forms of stigma present in the lives of women with a history of SMI. It not only demonstrates the stigma that women are experiencing and anticipating at the intersection of their mental health and reproductive-related experiences, it also shows the ways in which women are resisting this stigma. Demonstrating they are not just 'passive

victims' as those with mental illness are sometimes portrayed (Scambler, 2012; Link and Phelan, 2001). It also highlights the concerns professionals have about how stigma operates in the lives of their patients. More specifically, this chapter outlines the different sites stigma is circulating in, in the lives of women with a history of SMI: these sites include within public services, the family, the workplace and in maternal spaces. I have also shown institutional factors contributing to the generation of stigma. The main contribution of this chapter is to nuance existing literature on stigma, SMI and reproduction by showing its complexity, its multi-sitedness and its temporality through an in-depth exploration of women's and professionals' accounts, facilitated by applying sociological lenses.

This chapter demonstrated that professionals are concerned about the impact stigma may have on help-seeking. Their concerns mirror some of those posited in the perinatal mental health literature and include factors such as self-stigma and 'cultural stigma' ((Tripathy, 2020; Bains *et al.,* 2023; Sambrook Smith *et al.* 2019). In the women's dataset, there was limited (although not entirely absent) evidence of these forms of stigma influencing women's help-seeking, potentially complicating this narrative. Instead, through analysis of the data, several mechanisms through which stigma influenced participants' access to care were identified. This included through processes of 'recursivity', whereby past stigmatising experiences in healthcare settings complicated women's future help-seeking practices, including through the generation of anticipated stigma. There was some evidence, albeit limited, that family attitudes towards mental illness may impact help seeking; however, there was also evidence that women resist stigmatisation in their families towards particular interventions to treat mental illness by utilising risk discourses and the ideology of 'good' motherhood.

The findings also illuminated paths through which reproduction may be stratified for women with histories of SMI. In Chapter 5 this came in the form of women's perceptions that they would be disadvantaged in adoption processes because of their mental health histories. In this chapter, this came in the form of women's perceptions that social services were not providing the support they could have to enable their families to recover in the aftermath of periods of acute illness or distress. Some women also perceived their histories of perinatal SMI had influenced professionals' assumptions and advice they gave about future parenthood. These participants were not signposted by professionals to further help and support which exists to enable women to make informed and empowered reproductive choices. There was evidence from professional data which indicated there may be further intra-group stratification of reproduction for women with perinatal SMI which is determined by diagnosis and socioeconomic influences.

As highlighted in Chapter 2, leaders of the perinatal mental health field have called for research investigating social determinants (Howard and Khalifeh, 2020). This chapter makes a valuable contribution in this regard. An important social determinant of mental health is employment. In Chapter 5, work and employment was shown to be a notable feature in women's narratives of perinatal mental illness. This chapter has built on these findings by demonstrating that the workplace is a significant site of stigma for women in relation to motherhood and mental health. This stigmatisation has consequences on factors such as women's sense of selves, their comfort and inclusion in the workplace but also on their material conditions. Despite being an important aspect of my participants' experiences, this topic has not been explored in existing literature.

Placing some of these findings in the context of the wider literature, it is often asserted within mental health research that there is *more* mental health-related stigma circulating in racially minoritised communities (as highlighted by Kapadia, 2023). This research illustrates that mental health-related stigma does not solely exist within racially minoritised families and that

processes of silence or concealment are utilised within both minority and majority ethnic families. Several perinatal mental health-focussed studies have identified stigma present in healthcare (Wan, Moulton and Abel, 2008; Sambrook Smith *et al.* 2019; Edwards and Timmons, 2005). My study confirms and builds on the work of others by demonstrating in detail the nature of the stigma circulating in this domain as well as institutional and structural forces which influence stigma in healthcare. This is the value that sociological lenses can lend, allowing us to see the connections between “personal troubles” and socio-structural issues (Mills, 1959).

Through the analysis presented in this chapter, a rich picture of the nature of stigma in the lives of women with a history of SMI has been assembled. One which has illuminated some of the connections between stigmatisation and how it may influence women’s help-seeking practices and the access to care they are granted. The next chapter of the thesis moves to examine the healthcare setting in greater detail and more specifically additional factors which hinder or enable access to and delivery of services in an equitable manner.

Chapter 7: Access to care – navigating a complex system

Introduction

As highlighted in Chapters 1 and 2, inequalities in access to perinatal mental health care exist within the UK, particularly for women from some minoritised ethnic groups and women living in areas of high deprivation (Langan Martin *et al.*, 2017; Jankovic *et al.,* 2020; Redshaw and Henderson, 2016; Prady *et al.*, 2021). As described in Chapter 3, much of the literature on understanding inequalities in access to care is based on a narrow use of 'utilisation' as a measure of equity of access (Dixon-Woods *et al.*, 2006), and literature on perinatal mental healthcare is not an exception. Much of the qualitative literature on this issue has focussed on understanding the interpersonal or individual-level factors that influence access to care. Gaps exist in understandings of multi-level, particularly structural, influences on access to care (Sambrook Smith *et al*., 2019).

To address these limitations and explore the issue of access to care through a different lens, in this thesis a conceptual framework comprised of sociologically-grounded approaches to understanding access to healthcare has guided the analysis of relevant data from both participant groups. This framework includes sociological concepts such as candidacy (Dixon-Wood *et al.*, 2006), cultural health capital (Shim, 2010) and recursivity (Kovandžić *et al.*, 2011). Using understandings of access to care that are relational and sociological can help illuminate the ways in which social processes and social categories (e.g., 'race', class, ethnicity) influence healthcare encounters. In addition, they broaden the frame of analysis beyond the level of interpersonal interactions between patient and professionals. As a consequence, they bring into view and demand attention be paid to the institutional and structural factors that are influencing inequity in relation to perinatal mental healthcare; factors often under-researched in qualitative studies relating to access to care.

With this in mind, this chapter presents data relevant to the following research question: what individual, institutional or systemic factors cause inequalities in access to perinatal mental health care and how could these be addressed?

This chapter draws on data from both respondent groups. In contrast to the previous chapter, where there was more data on stigma arising from the women's interviews, there was rich and voluminous access-related data from both respondent groups. Therefore, the development of the themes and sub-themes presented in this chapter was driven by the analysis of both datasets in parallel.

Before sharing the key findings, it is important to outline a potential limitation of the data. It is important to include this at the start of this chapter to inform readers' interpretations of the findings about access to care. Many of the women participants whilst being interviewed clearly stated they had gaps in their memories around the time they were seeking help and accessing care for their mental health perinatally, many reported being acutely unwell by the time they accessed care. I mention this not to dispute their accounts or to call into question their ability to reliably narrate their experiences, but rather to highlight that there may be limits to what we can know about access to care using talk-based methods. I will discuss this and the methodological limitations of the research overall in more detail in Chapter 9.

Nevertheless, in this chapter I strive to provide as rich and detailed an account as possible of patient and professionals' perceptions of the barriers and facilitators to perinatal mental healthcare for women with histories of SMI.

Overview of data relating to access

14 of my participants affected by SMI were mothers or mothers-to-be. Of these, 13 described experiencing some form of mental illness or distress during one or more of their pregnancies or the proceeding postpartum period. These 13 participants described accessing care and support for their mental health during this period from the NHS via specialist perinatal mental health teams and from more generic mental health services. A small number of participants also described receiving support via private healthcare provision (i.e., workplace employee assistance benefits or from long-term therapists they had employed privately). Others accessed support via charitable organisations.

Just one participant, despite self-identifying as being unwell perinatally, did not seek or receive any help for her mental health during pregnancy or the postpartum. Whilst most women did receive some form of intervention, several participants only accessed care or came to the attention of services after serious incidents (i.e., they had harmed themselves or others or were in a state of crisis). It is important to note some demographic characteristics of the women who did not access care or did not access it before a serious incident. These participants were largely women from minoritised ethnic groups and/or women from low socioeconomic groups, echoing findings of Jankovic *et al.,* (2020).

All 14 of the professional participants expressed concerns about patients struggling to access support for their mental health perinatally, with some expressing particular concern for certain demographic groups. This included younger mothers, LGBTQ+ parents, fathers, women living in socioeconomically deprived areas. Most commonly, professional participants expressed concerns about women from minoritised ethnic groups struggling to access care. Precisely which ethnic groups professionals were concerned about not accessing care depended on the region the professionals worked in and the demographic dynamics and histories of their places of practice. For example, a clinician working in an area of high Black ethnic density described being not as concerned about the access of women from Black ethnic groups compared with other ethnic groups in the area. Another clinician described their concerns in the context of working in an area of dispersal (i.e., local authority areas where asylum seekers are moved to owing to the Home Office's dispersal policies).

Chapter 5 illustrated the ways in which perinatal mental illness can profoundly influence how women experience healthcare. It also demonstrated that it is not just the experience of mental illness that can impact women's reproductive-related experiences but also the interventions, often administered in healthcare settings, which can disrupt their expectations and experiences of pregnancy and motherhood. In terms of *why* women may be struggling to access care, the previous chapter demonstrated that professionals perceived self-stigma and "cultural" stigma as factors influencing women's willingness to access care. They also perceived women's fears about child removal as an important factor influencing women's help-seeking practices. In Chapter 6, healthcare was demonstrated to be a place that women had experienced, or anticipated experiencing stigma within, which complicated their help-seeking and perceptions of different parts of the healthcare system. Whilst many participants did describe healthcare as a significant site of stigmatisation, there were parts of the health service which were not described as stigmatising. Specialist perinatal mental health teams in particular were not widely reported by participants as sources of stigma, it was clear that the care some women received by staff working in specialist teams helped them to *resist* self-stigma.

This chapter sheds further light on the issue of access to perinatal mental healthcare, thinking beyond the role of stigma. Analysis of the data generated from both participant groups on the topic of access to perinatal mental healthcare led to the generation of three higher order themes: 'Interaction', 'Organisation of Care' and 'Systems and Structures'. The chapter is structured according to these themes and concludes with a discussion and summary of the findings of the chapter and their connections to chapters of the thesis presented so far.

Interaction

Two sociological concepts have informed my analysis of the data presented below; candidacy (Dixon-Woods *et al.,* 2006) and cultural health capital (Shim, 2010). The concept of candidacy argues that patients' eligibility for intervention in medical settings is jointly negotiated between individuals and services through processes that are highly interactional (Dixon Woods *et al.,* 2006). By conceptualising access to care as a highly interactional process, three key aspects of interaction were identified through analysis of the data as important facilitators of access to care. These are language/verbal communication, specialised knowledge and visual perception. I have articulated these as "saying", "knowing" and "seeing". Whilst these will be presented separately, as can be seen from the data presented, they are not separate and they often are deployed simultaneously in interactions. Whilst these aspects were often spoken about as individualised skills or presentations (by both patients and professionals), the sociological lenses I am using compel us to consider if the distribution of these skills is structurally influenced or socially patterned.

The concept of cultural health capital takes the stance that a significant factor contributing to persistent inequality in access to healthcare is the differential distribution of the skills and resources required to engage with and communicate with healthcare professionals (Shim, 2010). These skills and resources include verbal and non-verbal competencies and interaction styles. More specifically, these can look like "linguistic skills, pro-activity towards accumulating knowledge, the ability to understand and use biomedical information" (Shim, 2010, p.2) and the "ability to communicate social privilege and resources that can act as cues of favourable social and economic status and consumer savvy" (Shim, 2010, p.4).

Using the analytical lenses of cultural health capital and candidacy, this section of the chapter will discuss verbal communication, specialised knowledge and visually-based perception as important barriers and/or enablers to mental healthcare for women with SMI.

"Saying"

Verbal "competency"

Several individuals from both participant groups emphasised the importance of 'talk' and verbal competency in relation to accessing care. Laura experienced anxiety of increasing severity whilst she was pregnant and postnatally. Earlier in her postpartum period she visited the GP to ask for medication to treat her escalating anxiety. A GP prescribed her medication but Laura reported she was not followed up by the GP. Her symptoms continued to worsen. She said her Health Visitor, with whom she had repeated contact, noticed her escalating symptoms and advised involvement of the local specialist perinatal mental health team. She was then treated by this team for a number of months. When asked about her experience of care she explained:

> *"[I] think the thing is, as an educated person I know we, and that's me and my partner and my family, we know how to ask for help. I don't know whether this is just me, I felt more confident to ring them and to be saying, look, I need this and I need this and I*

> *need this. And I rang the mental health nurse so many times, I never questioned that, that was just something that I did and I don't know if that's because I'm a [profession] or because I'm an educated. I don't want to sound non-PC […] or you know, my background or whatever. I know how to access services I suppose but I didn't know the perinatal mental health team existed, so I wouldn't have known to contact them."* ***Laura***

She emphasises she was not aware of the specialist services available locally, it was her Health Visitor's observations and knowledge that helped to facilitate her initial access to the specialist service. However, she perceived her confidence in verbally asserting her needs to be instrumental in continuing to access the interventions and support she needed over the months she was under the care of the specialist team. She says that being able to 'ask for help' is something her family knows how to do too, and suggests her 'background' (described at the start of the interview as middle class) may be a contributing factor. She also suggests her proactive orientation to seeking help may be influenced by her education, which enabled her to enter the professional role she now occupies. Access to higher education and the skilled professions it leads to is socially patterned, often socioeconomically (Farquahrson, McNally & Tahir, 2022).

Stephanie was labelled a "high risk" pregnancy because of her mental health history but was not under the care of a specialist perinatal mental health team. Before maternity appointments she described doing her own research and preparing detailed documents to take with her. The documents included research she did about the medication she takes for her mental health. She said:

> *"I can prepare myself better to speak and maybe that's why I'm comfortable at those appointments because I'm rarely kind of totally blindsided. And also just my general personality and the education level I have and the intersection with some of the health terms means that I've been able to create documents that at least are in my language if how [professionals] put it to me, isn't."* **Stephanie**

Stephanie explained the purpose of her extensive preparation for appointments was so she could articulate her needs more effectively. It illustrates her pro-active orientation to accumulating knowledge about her condition, a feature of cultural health capital (Shim, 2010). Echoing Laura above, Stephanie alludes to her education. She was university educated and her degree subject afforded her opportunities to develop research skills, a familiarity with health-related literature, strengthening her knowledge of language used in relation to mental health. There is significant specialised labour that Stephanie performs to bridge the gap in understanding between patient and professional in her appointments. Labour that requires skills learned in advanced educational settings, access to which is socially patterned.

Psychiatrist 2 talked about the value of verbal competency and women advocating for themselves within healthcare more generally:

> *"It's just that lack of agency and not really being able, to, you know, being young, being vulnerable, maybe not being highly educated, not really being able to assert oneself. And to seek help from various channels and to, to advocate for oneself because sadly, the NHS is increasingly like that, is actually like you need to sometimes have a bit of a fight to access services."* ***Psychiatrist 2***

They imply that it is a skill that is becoming increasingly more valuable and vital to women being able to access the care that they need in light of the institutional and structural strains

on the health service (which will be discussed in more detail in subsequent sections of this chapter). Later in their group discussion, Psychiatrist 2 continued to discuss advocacy and assertiveness, how this is contributing to inequality in relation to a particular aspect of perinatal mental healthcare:

> *"You're much more likely to be admitted to a mother and baby unit if you're quite well, quite educated able to speak up for yourself. You're much more likely to end up on an acute female impatient ward versus a mother and baby unit if you are black, and yeah, it's really quite bad and it is really quite stark and [we] really need to address that."* **Psychiatrist 2**

Whilst other professional participants were concerned about ethnic and socioeconomic inequalities in relation to access to perinatal mental healthcare, none of the other professionals alluded to this particular manifestation or process; however, this was likely due to the fact most professional participants were working in community-based teams. Whilst there was no data from other professional participants to support this claim, it tentatively indicates that this is another route through which reproduction may inadvertently be stratified for some women with SMI.

Not all participants agreed that the relationship between education and the ability to advocate for oneself and access to care was positive and linear. The perspectives of Psychiatrist 2, Stephanie and Laura are complicated by that of Cammi and Isa (whose experience is discussed later in the chapter), who reported that in accessing mental healthcare their verbal competency and ability to advocate for themselves sometimes meant that their distress was minimised by professionals:

> *"being kind of, an intelligent, White British, middle class person that's not at the very poverty end of the spectrum. You're dressed too well, and you-, do you know what I mean? I'm [university] educated, of course I can argue. I spent 3 years being taught how to argue and explain myself, of course I can. So there's that sort of aspect."* ***Cammi***

It is important to note that whilst Cammi and Isa described these struggles to have their distress or histories of distress identified by professionals as in need of intervention or monitoring, both were able to successfully advocate for themselves and access care perinatally.

Translation

Oral translation was a challenge described by many of the professional participants; one they perceived as a significant barrier affecting the care of women from minoritised ethnic groups who were unable to speak English.

Staff described challenges this could present with both initial referral or triaging to a service, as well as with the interventions that were used to support women (for example, forms of talk-based or talking therapies). They also had concerns about assessment, worrying that tools such as the Edinburgh Postnatal Depression Scale (EPDS) may be rendered less effective when communicated via a translator, resulting in poorer screening sensitivity.

Professional participants outlined how companies' Trusts contracted to provide translational services may not provide language services for less commonly spoken languages. Professionals talked about how male interpreters may be provided and how this may often be inappropriate due to the gendered nature of women's difficulties. They also described practical challenges, for example consistency and reliability of interpreters to turn up on time

for in-person appointments, which complicated access for patients who may already be reluctant to speak about their mental health.

Health Visitor 2 described how Video Interaction Guidance (VIG), an intervention where women reflect on recordings of their interactions with their babies with the guidance of a healthcare professional, is very challenging for some women from minoritised ethnic groups:

> *"She needs loads more time... the usual is three to four cycles of VIG, we're talking about double like six to eight cycles of VIG for them, for that understanding all via translator. Lots of the things is, like, very personal, often brings up stuff about your own childhood, about, you know, how that how it really feels for you. You know, in some cultures that are really struggling to kind of... Speak about mental illness, so then ask them to speak about it in this really vulnerable space with an interpreter that often, you know, like for some languages, like I know from, [east Africa], for example, where I work, right, when they.. In the community they all know each other, including the interpreter. So it's like it's not… Even if you think you're getting an interpreter that's kind of. What's the word? Independent. it's not really cause they know them, they know them from the church, they know them from... Yeah."* ***Health Visitor 2***

Health Visitor 2 highlights that several factors interact to make perinatal talk-based therapies particularly challenging for patients with limited English. Firstly, the deeply personal nature of the intervention and the discussions it can provoke. These coupled with potential issues of confidentiality, particularly in areas where there are few speakers of the patient's language. Finally, women are required to engage over a much longer period of time, which may influence women's ability to continue to engage in the programme.

Midwife 2 explained how, even when interpreters are present and engendered a lot of trust, these mediated interactions with patients can be difficult. They described a woman who had recently attended an appointment which was arranged because of concerns the patient's husband raised about her mental health. The woman attended a face-to-face appointment with an in-person interpreter who was also a woman. Midwife 2 was left frustrated by this encounter as the woman answered no to every question. Midwife 2 explained that unless there were safeguarding concerns, patients who do not disclose a need for help cannot be treated. She went on to explain:

> *"Was her husband just trying to control her and get her help that maybe she didn't want? Or was he genuinely concerned, and wanted to get her help? Was she, did she need help and she was hiding it? Or was she genuinely sat there thinking, I don't know why I'm here? So, really tricky, really tricky to get to the bottom of it. And, all you can do is give her contact details and hope she will come back if she, if she does need it."* ***Midwife 2***

Midwife 2 highlights the complex dynamics of interactions with patients, specifically if there are more people involved in the clinical encounters than the traditional patient-professional dyad. Which may often be patients whose English language skills are limited.

Translation and language-related difficulties were not discussed by the women interviewed who were from minoritised ethnic groups. However, this omission may be a methodological artefact. Interviews were conducted in English due to my own language limitations as a researcher and the resources available to me as a PhD researcher (i.e., I did not have the funds or expertise to employ the services of a translator to enable participation of women who spoke languages other than English).

“Knowing”

Shim’s concept of Cultural Health Capital invites us to examine the dynamics of patient’s knowledge accumulation and argues this is important for accessing care. Analysis of data from both respondent groups revealed that patients’ *and* professionals’ knowledge about perinatal mental health is an important factor in relation to accessing care. The first aspect of the concept of candidacy is how patients *themselves* recognise their symptoms as something requiring intervention. In this data, more patient participants described the role of others in identifying their need for care and facilitating their access to services (e.g., Fay, Melanie, Willa, Isa, Jeanette, Grace, Kimberly) than those who self-identified their distress as in need of intervention (e.g., Cammi, Anna, Masi, Elton).

Isa worked throughout her pregnancy. The nature of her work was emotionally demanding. She described not anticipating how vulnerable being pregnant might make her feel, which was difficult at work. As her pregnancy continued the stress of the work impacted her mental health. Here Isa describes an encounter at work with a colleague:

> *“I turned up to [job] and she just took one look at me went 'you shouldn’t be here, go home' and in the end I was just like, I just felt so unsafe that I went to the [hospital].” **Isa***

Isa sought help from professionals after her colleague identified her distress. After reflecting on her own perinatal experiences, she said she would incorporate a risk assessment for staff members who may be pregnant in future to ensure they were safeguarded whilst conducting the emotionally demanding work their jobs entail.

When Willa was pregnant with her second child, she felt detached, did not want to see people and did not feel happy or excited about her baby’s arrival. She explains she felt there was a detachment between her and her baby, she felt guilt over this. This persisted postpartum, where she also experienced suicidal thoughts, until one evening:

> *“I remember one night I just woke up, took the baby, and I put the baby in the car and that was midnight, and I really don't know what was running in my mind at that time. I took the baby, I put him in the car, and I started driving… And I just drove to the petrol station at that time. And when I reached the petrol station, I started crying, and I really cried….I remember at that point is when I called my friend at midnight. She didn't pick the call for the first two calls and I continued trying, but thank God she took, she received the call and we really talked and talked and I was just crying and crying… That's when I realised I was going through, I don't know if it was perinatal or postnatal depression or something of the sort, but I knew I wasn't okay.” **Willa***

Willa explained later in the interview it was her friend who helped her to identify that her distress was something which required intervention. Subsequently, her friend connected Willa to someone in her own social network, who was also a mental health professional, and Willa was eventually able to access the care and support she needed. Her friend’s networks helped Willa get the support she needed. Networks are not an explicit part of Shim’s formulation of cultural health capital. However, they feature in Bourdieu’s theories of capital (upon which Shim’s formulation of cultural health capital is based) in the form of social capital: the collective resources that exists within networks of individuals (Bourdieu, 1986). Willa’s and Isa’s routes into care illustrate how the mental health-related knowledge of others within women’s networks could facilitate their access to treatment. Collectively my participants’ experiences demonstrate it is not only women themselves and professionals involved in their maternity care that facilitate access. It is also their support networks, if they

have relevant knowledge of services and the signs of illness/distress as something requiring intervention, which can help women to recognise the need to access care.

Preconception counselling is a part of the perinatal mental healthcare pathway that women with histories of SMI are able to access to discuss with specialists the planning of a pregnancy. None of the women interviewed had accessed preconception counselling from specialist perinatal mental health teams, as outlined in the NHS Perinatal Mental Healthcare Pathways (see Appendix 1). Several professional participants working in specialist teams, who are responsible for delivering this intervention, described their concerns about the under-utilisation of preconception counselling in their services and the social patterning they observe in relation to who is accessing this pathway.

Psychiatrist 1 talked about changes their service had recently implemented to make this pathway more accessible, as they had identified they were not seeing enough women. This included accepting self-referrals, developing advertising materials which were explicit about whom the service was for and changing the name of the service. They explained:

> *"[Geographical area] has [a] huge amount of socioeconomic-deprivation. We realised when we spoke in some of our groups there, they didn't know what preconception counselling even meant, to ask for it. They didn't understand what the term preconception meant. Counselling sounded like it was therapy. So we thought, actually, yeah, how can we expect people to ask for something which is such a medicalised term? Only people from quite medical backgrounds themselves would think to ask for it. So we've changed it to be called pregnancy planning support."* ***Psychiatrist 1***

Psychiatrist 1's perception that their preconception service was often only accessed by women who were particularly health-literate illustrates that cultural health capital in the form of knowledge of medical topics and vocabulary (Shim, 2010) is required to access this form of perinatal mental healthcare. In this case, women must possess enough knowledge of medically and psychologically framed language in order to tell what a service actually delivers and to differentiate it from other forms of mental healthcare. Having a 'medical background' requires access to and engagement with specialist education, which I have argued earlier in this chapter is socioeconomically patterned.

Similar to Psychiatrist 1 (and Clinical Lead 1 and Psychologist 1 who are not directly quoted here), Psychiatrist 2, who works in a different part of the country to the other professionals quoted, also described socio-economic patterning in their service:

> *"The type of people who come in looking for preconception counselling are sometimes from GPs, not even from community mental health teams. So, not even always from secondary services. And they're often middle class pregnancy planners. Not always, but there is a huge element of that."* ***Psychiatrist 2***

In addition to talking about patient-related factors, Psychiatrist 2 highlights the role that intermediary services such as primary care and secondary mental healthcare play in referring women to preconception counselling. Psychiatrist 3 perceived preconception counselling in their service to be relatively well utilised compared with neighbouring areas. They attributed this to knowledge that professionals outside of the service had of the pathway, highlighting that when patients were discharged they would include information about preconception care in their correspondence. This highlights the importance of healthcare professionals who are not perinatal specialists having enough knowledge of

perinatal mental health more generally, as well as the services that are available, in order to better support women with histories of SMI.

Several professional participants talked about both the importance of and the barriers to training for staff who are not perinatal specialists, which are institutionally or structurally mediated. Midwife 1 described barriers to perinatal mental health training for midwifery staff that exist through the Family Hubs programme. Local Authorities have been provided funding via the Family Hubs programme, and part of this provides training for staff in service of the Hub's aims to improve parental and infant mental health. Midwife 1 said:

> *"Unless they [are] able to provide not just training, but they have to provide a funding for [cover]. If you want to attend as a midwife they [Hubs] need to pay for a replacement midwife. For example, so, if the midwife needs to attend training, someone else has to be there to cover the work. […] We haven't got enough midwives to replace, or just cover us while we go for training. It's ridiculous. So there is training, but we can't go there because we haven't got enough. So, unless midwives are happy to do it in their own time, which of course, you know, it's a lot to ask, then they can't."* **Midwife 1**

Midwife 1's experience illustrates how both short-comings in local funding packages and workforce-related challenges act as barriers to midwives taking up specialist training. To improve their knowledge of perinatal mental health, they also perceived the time allocated in annual mandatory training for doctors and midwives as insufficient to impart detailed enough knowledge about this complex area of practice. Workload was also described by professional participants as a factor influencing staff ability to engage effectively with training. Nurse 1 alluded to how training could be deprioritised in times of heavy workload and Health Visitor 2 reflected:

> *"[After the conference I] came back, launched straight into work. I haven't even had any time to process what happened at that conference, what we talked about. I didn't get to talk about that with my colleagues. [I've] just been on the wheel ever since. And it's like that. That's where it's, you know, for all this information, it's all good doing the training for people. If they don't have time, if they're basically trying to do the training whilst also replying to email, and then working, they're not taking it in. There's no good giving them the training"* ***Health Visitor 2***

These experiences illustrate that making training and other learning & development opportunities available for staff is not enough. Staff require time and space to engage in it fully and critically reflect on what they have learned in order for training to be valuable and translate into effective practice that has positive patient benefits.

"Seeing"

Despite mental illness sometimes described as an "invisible" illness (The Disability Unit, 2020), several participants talked about 'looking' or appearing mentally (un)well. For example, Kimberly experienced side effects of the medication she was given whilst she was acutely unwell during pregnancy. She described how this made her rock *"furiously"* so she *"physically looked mentally unwell".* Other participants described how their distress wasn't responded to by professionals because of how they presented to services, not 'looking' mentally ill. Katie, who is not a mother, who described her experiences of mental healthcare as positive and said this was likely influenced by her positionality as a White woman, highlighted how she perceived her distress had not been seen by professionals because of her physical presentation:

"I think sometimes [healthcare professionals] don't sort of, like, pay enough attention to it because they're like oh she, she looks fine, you know, she's dressed and presentable and she can't be that depressed if she's you know, here and she's talking well and she's, you know, she doesn't look like she's suicidal and she doesn't look like she's at a really sort of bad place, so I think sometimes when you're adept at kind of masking things or like you come across as not whatever mentally ill looks like […] I've also noticed that I think that I have to get to like a point where I'm like quite bad before like they'll do something about it sometimes I've found because I don't always present as like severely depressed." **Katie**

A similar sentiment was echoed by Isa who had a history of SMI prior to pregnancy. She described herself as increasingly depressed and anxious during pregnancy. She reported feeling better towards the end of her pregnancy and in the early postpartum period but became more unwell again after returning to work from maternity leave. She said:

"*I was in a pretty dire state but I was still managing to work and look after my child and stuff like that and therefore people just don't see it as that drastic* […] *This is a major problem for me with any mental health services right, that I appear functioning and less catatonic, I'm reasonably articulate and therefore there can't actually be that much wrong if that makes sense and so it took quite a lot of, like I was like 'no I really think that I should probably you know , that [mental health history] should be considered as well from the midwife."* **Isa**

Cammi talked about the struggles she had encountered at a later point in her motherhood in accessing mental healthcare:

"To be seen by secondary care psychiatry as a very lucid, brainy woman who looks alright on the outside, I had to annotate the NICE[16] guidelines and say you have to see me. They bounced me back to primary care. Primary care (inaudible) me and said she's not ill enough and so I literally sent them - I was hypomanic at the time so I had plenty of energy - I annotated the NICE guidelines and said you have to see me, this is what the NICE guidelines say and they saw. It took [months] to see somebody. Which I think is fairly normal actually (exhales), and my [GP] then said she said she sees this with women all the time that are able to explain themselves, who are actually really unwell, but don't look like they're in the right social bracket or, they were functioning too well to actually get any help". **Cammi**

Cammi's experience illustrates how a combination of the factors discussed in this part of the chapter (verbal competency and specialist knowledge of mental health and healthcare) interact to influence how distress is perceived and interpreted by services, and crucially, responded to.

Following a previous mental health breakdown Grace remained under the care of a psychiatrist and her family were supported by a social worker. When Grace became pregnant, she was told by her psychiatrist she was at high risk of becoming unwell again. She became unwell during pregnancy but reports not seeing her social worker or psychiatrist during this time. Grace asserts that had the professionals followed up with her:

"*They would've picked up the signs. I was still going to work, I was still studying. The children were still going to school. Even the school could've picked up on whatever, the children saying oh mum's behaving differently. We're worried about her.*

[16] NICE = National Institute for Health and Care Excellence

Neighbours, friends. All of that. But they weren't interested […] because they just didn't care. They didn't care." **Grace**

Isa, Cammi and Grace all talk about the ways in which they are continuing to 'function', despite being acutely unwell (collectively experiencing symptoms of psychosis, dissociation and hypomania). As they were fulfilling their roles as mothers and as workers, their distress was not 'seen' by others as requiring intervention. Whilst all were eventually able to access care for their mental health perinatally, it required significant labour and self-advocacy on behalf of Cammi and Isa, and a serious incident occurring for Grace, to finally access care.

The data in this section has indicated that knowledge, perception and verbal communication were important factors influencing and complicating my participants' access to care. I have argued that these factors are often seen as individual-level barriers, but when looked at through a sociological lens can be seen as structurally influenced. The next sections of this chapter continues with this structural gaze, turning to the institutional and system-level factors influencing access to perinatal mental healthcare which, as argued in earlier sections of this thesis, have received less attention in the literature.

Organisation of Care

In the UK there are a multitude of places women with a mental health problem in the perinatal period can receive care. Appendix [1] illustrates how NHS-delivered perinatal mental healthcare is organised.[17]

Women interviewed in this study widely reported receiving support for their mental health perinatally from NHS services. This included from specialist, multidisciplinary perinatal mental health teams operating in both community and inpatient settings. Women also reported receiving support from midwives and health visitors and from non-specialist secondary mental healthcare teams too (in both community and inpatient settings). Women interviewed did not solely access support via the NHS. Some participants also reported engaging the services of therapists in the private sector and utilising services provided by local and national-level community and voluntary sector organisations. This illustrates there is a wider ecosystem of formalised support women are accessing for their mental health perinatally which exists outside of the NHS. However, this section of the chapter focusses solely on the organisation of care within the NHS.

To return to the conceptual framework underpinning the analysis of the data presented in this chapter, an important component of the concept of candidacy is 'permeability'. Permeability is how well services are organised to meet the needs of those with mental health difficulties (Liberati et al, 2022). It also refers to the criteria services use to configure and organise their services. In relation to this latter point, I wish to briefly touch upon a finding which will be given more space in the final results chapter on risk. Interviews with staff participants indicated that risk is a key criteria within the context of perinatal mental healthcare that is used to configure and organise services. Professionals' perceptions and assessments of risk in relation to maternal mental health are one of the most significant factors determining what kind of mental healthcare women are able to access perinatally. In the next chapter I

[17] This document illustrates that care is inclusive of the preconception period and states the perinatal period as ceasing 12 months after birth (NCCMH, 2018). However, as highlighted in Chapters 1 and 2, national policy aims for teams to be striving to extend their support to women to up to 2 years postpartum (although the implementation of this has been patchy (Maternal Mental Health Alliance, 2023b))

illustrate how professionals' risk-concerns and services' risk-capacities reciprocally shape the organisation of care as well as women's access to it.

Returning to the findings in this chapter, this section explains how the ways in which services are organised can either support or hinder women's access to care: this will be discussed via the presentation of the two sub-themes of trauma-informed care and relational continuity

(Re)organisation of trauma-informed care

As demonstrated in Chapter 5, women with histories of SMI consider mental health alongside a multitude of other factors when they are contemplating pregnancy and motherhood. In this chapter I also demonstrated how histories of trauma had influenced some participants' reproductive decision making. I also showed that previous experiences of trauma influenced their how they anticipated or experienced maternity-related care which had consequences on their mental health perinatally.

Bella had decided to not have children. Her reproductive decision making was influenced in different ways by her history of mental health and concerns about the transmission of intergenerational trauma. She says of conversations with professionals about reproductive decision making and mental health:

> *"The bigger questions about what it means to the person, it doesn't feel like it's factored in at all. It's just about like, oh what might you have to come off if you're going to get pregnant? What meds might you have to not take? And that's just a little bit of the conversation, you know? I don't blame them as individuals at all. That's their job. But that's what happens when you've got health care that's just based on symptoms, rather than - I think it's just because its healthcare based on managing and treating symptoms rather than people."* ***Bella***

Bella highlights that conversations with professionals are often centred around what medication women should or should not take if they get pregnant and alludes to the limitations of this highly medicalised model. She infers that this is incompatible with what she would want from services, which is a conversation which is holistic in scope. Alice also talked about how these more holistic discussions with professionals (in her case, about identity and motherhood) would be valuable. It was something she had discussed within the context of private talking therapies but had not encountered within NHS settings. Alice specifically sought out private therapy because she found trauma-informed care within the NHS difficult to access. Bella's view echoed that of professionals who also perceived preconception conversations as historically narrow in scope. Two of the psychiatrists interviewed talked about their frustration with the nature of preconception counselling and its narrow biomedical, traditionally psychiatry-led focus and how their services – in different parts of the country – were seeking to address these limitations.

> *"This is something [that] bothers me so much about how we deliver this particular intervention. It's a very medicalised conversation. It's mostly the doctors and the team that deliver it but as part of our [service redevelopment]. it might not just be a doctor. It might be a psychologist if you've got a past history of trauma. It might be an occupational therapist if there is a functional issue. It might be one of our peer support workers, who can augment the whole pregnancy planning support conversation."* ***Psychiatrist 1***

> *"Historically [preconception care] been medically driven and tended to be around medication and balancing the risks for women who've got a history of […] severe*

mental health problems and might be on tablets and the focus has really been around that. But that doesn't really cover everything. So the ask is really to pull it away from just that quite narrow medical view and be starting to think about a multidisciplinary approach to PCA [Preconception Advice] as well, so for instance… [in a recent appointment the] medication part of it was tiny. But what was really, really clearly important was that her experience of what sounded like quite [a] harsh critical context growing up has left her with great difficulty managing difficult feelings and some risk associated with that. So in my mind it would have been great to have a psychologist next to me to help think about that and so I'd really like to kind of broaden up and it not just be about what meds they're on and thinking more broadly about everything that might trip someone up through the perinatal period. So background context, trauma and relationships, support, personality style. Everything. Rather than just about meds." **Psychiatrist 3**

Participants from both groups perceived there to be limitations in preconception care for women with SMI who also have histories of trauma; the limitation being the narrow, biomedicalised focus and organisation of the service not leaving space for broader discussions important to patients. The professional participants were mindful of this and wanted to reconfigure their services.

These trauma-related limitations were perceived by participants in other parts of the pathway too, beyond preconception. Whilst SPNMHT were perceived by both women and professional participants as providers of high quality, relevant care for women with histories of SMI, some members of specialist teams talked about the limitations of their services, particularly for women with histories of trauma. Social Worker 1 talked about ambitions to create a specialist pathway for women with personality disorder (within the perinatal mental health team). However, progress on developing and implementing this had been slowed by capacity issues, meaning it may not be operational for a few years despite the service seeing an increased demand for care with this patient group. Nurse 1 talked about the limitations of the service for addressing the impact of various forms of relational trauma:

"We get a lot of people through the doors that are having relationship issues or both partners may have experienced some form of trauma in their childhood or may have been brought up, you know, very differently and [been] parented very differently, and so then obviously then that feeds into their relationship, which then perhaps in turn, you know, impacts children, particularly if they're, like, witnessing things. So I think that's something that we could really do with, because, otherwise, you know, you're referring them to [Charity] but to have to pay or, you know, go in private, which costs an absolute fortune. And it's just not feasible for a lot of people [...] especially people that, you know, maybe unemployed or on maternity, they're not going to be able to access that." **Nurse 1**

Nurse 1 highlights the role of the community and voluntary sector in providing highly specialised care for families perinatally that NHS may not be providing, but also the entrenched inequity in the current model where only those with the financial resources can access this form of talking therapy.

Isa described the processes of seeking care for her mental health during pregnancy. She did not feel that the care she was offered (which was not from a specialist team) was trauma informed or anticipated her needs as a mother-to-be. She described being offered interventions which did not meet her needs:

> *“with the timescales, by the time I get to the point of [intervention] being available, I'm gonna have a newborn baby and they were like 'oh you're being obstructive' and I'm like how am I supposed to do a group like (laughs), you know it's like 2-3 times a week, individual therapy and group skills (laughs) with a tiny little baby that I'm intending to breastfeed' so like this complete schism and this was seen as me being obstructive as opposed to being practical and I'm like 'I don't think anyone else would feel comfortable if I bring my baby into this type of group. I wouldn't feel comfortable exposing my baby vicariously to other people's trauma' because you know, we don't even know the extent of how you know, babies are impacted by that stuff!”* **Isa**

The care Isa was offered did not meet her needs and she was concerned about the risks that this intervention could pose to her baby. However, she recalled that in declining treatment, she was labelled as obstructive, something experienced and anticipated by other participants interviewed with her diagnosis within the mental healthcare system (for example, see Alice’s narrative in Chapter 6). Isa’s awareness of vicarious trauma, a concept from the field of psychology, and her resulting concern about the impact of this on her child is an example of how cultural health capital (in the form of the accumulation of biomedical knowledge) may also inhibit access to care through the reticence to take up the intervention.

It is not only the availability of services that influences access. As I have shown here it is also their suitability and specification which affects access, particularly in relation to trauma. If services are not meeting patient need, they are likely to go unused.

Relational continuity

Both participant groups talked about the value of patient-clinician relationships for facilitating access to care. Several women participants talked about the relationships they had with various health professionals who facilitated their access to more specialist mental healthcare perinatally or were instrumental in providing support themselves. For Fay, it was her midwife. For Laura, Isa and Jeanette, their health visitors played pivotal roles. For Elton, this was a therapist she had been seeing prior to her pregnancy.

Continuity of carer is a model of care delivery whereby patients have a relationship with the same clinician or small group of clinicians over time, allowing trust to be built and knowledge about the patient to be accumulated (Fraser and Clarke, 2023; Smith, 2024). Whilst continuity of carer is relationally mediated, there are ‘local operating conditions’ (i.e., the availability of/pressures on resources) that influence its implementation as others utilising the concept of candidacy have demonstrated (Hinton *et al.,* 2023).

In the context of perinatal mental health, as highlighted in the literature review, particularly pregnant or postpartum women are likely to come in to contact with many different parts of the healthcare system. Continuity in relation to midwifery care was discussed by Fay and Laura, who had contrasting experiences of continuity:

> *“When I was pregnant […] I saw the same person [Midwife] every time, which I didn’t know until much, much later was not normal. Erm, and that helped them to realise I was ill very quickly because they knew me […] knew what was normal and when I was saying one thing and [partner] was saying the other and knew which one of us to believe was, yeah, I guess, lifesaving for me. And I don’t say that lightly, but yeah, it really was.”* **Fay**

> *“I suppose that thinking, antenatally [midwives] ask you about mental health don’t they and again, it’s a tickbox isn’t it. And I’m not criticising them, I think the problem is that they [midwives] don’t get the opportunity to get to know you. I saw a different*

> *midwife antenatally and obviously they have to ask you about mental health, mental health history and how you're feeling and yeah, you see different ones every time, they don't build a relationship with you, they don't, well, perhaps they don't get the opportunity to build a relationship with you and so I wonder, why shouldn't my anxiety have been picked up sooner, you know."* ***Laura***

Both Fay and Laura had no history of SMI prior to their perinatal experiences. Fay became unwell rapidly postnatally and was diagnosed with postpartum psychosis. Laura's experience of severe perinatal anxiety started in pregnancy and escalated postnatally. Fay perceives the pre-existing relationship she had with her midwife, something she later learned from other women in her social network to be rare, as instrumental to her distress being recognised postnatally and being rapidly admitted to an MBU. Laura had a different experience to Fay in that she didn't have continuity with her midwife and speculates whether this may have meant that her distress was not recognised as requiring intervention sooner. Laura's distress was identified as requiring further specialist intervention by her health visitor, with whom she had had continuity. Jeanette also had continuity with her health visitor and was referred on for specialist support by this professional. Their experiences illustrate how the accumulation of knowledge about patients, via repeated encounters, can be crucial in identifying and differentiating between distress perinatally that does or does not require intervention.

By contrast, Anna and Grace did have pre-existing histories of mental illness. Their experiences of continuity were more complicated and underscored the roles and the expectations they had of professionals working in secondary mental healthcare which were not realised. Earlier in the chapter, Grace reported her psychiatrist (who had treated her for a number of years) informed her she was at higher risk of relapse whilst pregnant but did not follow up or monitor her. She was increasingly unwell throughout pregnancy, labour and postpartum but her distress was not identified by professionals. Her admission to hospital postnatally occurred only after a serious incident. During Anna's second pregnancy she recognised in herself a deterioration of her mental health and sought help for this from the secondary mental health team she had been under the care of for a number of years. Her medication was adjusted but she was not followed up as expected by her community psychiatric nurse (CPN), who was relatively newly assigned to Anna. Anna described having a strong, trusting relationship with her previous CPN (who had moved to a new area). Despite her medication being adjusted her mental health continued to deteriorate and she was hospitalised postnatally. Whilst on the ward, Anna discussed her path to admission with staff. She said: *"they said, the nurses at the hospital said to me if there's a relationship with [CPN], then you wouldn't be here".* Anna also described being visited by her CPN whilst in hospital:

> *"She came to the [ward] and saw me and she was really awkward, she was making me feel very uncomfortable. She was putting her hand under my wardrobe and everything. I said excuse me, I told you I was getting ill. You knew I was going to give birth and was going to move house which was a massive stress and strain and an ordeal. Why did you not come and visit me? Oh, I don't work weekends she said to me. "* **Anna**

Anna's treatment team at the hospital underscored the importance of the relationship with her community treatment team implying that had she received earlier intervention or closer monitoring, she may not have needed to be admitted to hospital. Her experience also illustrates the complexity of providing continuity to patients both in terms of the practicalities (i.e., working patterns, managing team changes) but also the minutiae of interpersonal

frictions which can occur between patients and professionals and which can complicate relationship building, especially when patients are acutely unwell.

Psychiatrist 1 also alluded to these difficulties whilst describing a recent encounter with a patient:

> *"The person who was [patient] mental health practitioner had gone off sick and then someone else stepped in, but then that trust and that relationship she had with him couldn't really be mirrored at the point when she was unwell with someone else. So that became quite challenging because she needed a lot of reassurance, she needed a lot of time and you needed to really be patient with her. And even though we were resourced well to do it, she didn't have those relationships with that new practitioner who stepped in."* **Psychiatrist 1**

Psychiatrist 1 highlights that even within teams which are well-resourced and there is a well-defined plan in place for patients, a lack of continuity can result in patients requiring more intensive input than was anticipated, which may in turn, in Psychiatrist 1's own words, make "things unravel a little bit" and affect the wider capacity of the team.

Most professional participants perceived continuity had benefits for all women with histories of SMI. Some professional participants underscored the value specifically for those who may be mistrustful of services. Talking about families who are social care experienced in particular, Health Visitor 5 said:

> *"They need that face that they know. They do, because they're very suspicious, they're very, they don't like letting new people in. They find it, they've got mental health issues already. So they, they find it hard to then trust. We have a lot of trust issues. A lot of, you know, believing, you know, you have to build that trust, because if you don't, they don't let anybody [in]. We have a lot of, like, you know, disengagement because they don't want you coming in cause they don't know who you are. So once we build that relationship, it's really beneficial because they'll just constantly kind of get in touch with us and stuff like that. So it works really well."* **Health Visitor 5**

Whilst most professionals valued continuity, it was described by some professional participants as challenging to deliver. The contexts of delivering continuity and the consequences of not being able to operate this model of care were described in detail by many of the health visitor participants. Health Visitor 1 described how in their team, health visitors would review women's records and triage who should be prioritised for antenatal visits, to build trust and rapport to support disclosure. However, capacity constraints in teams due to leave, sickness, an increase in more complex cases (e.g., involving child protection) was said to constrain their ability to review notes early and attend initial appointments. Health Visitor 2 also alluded to capacity constraints that put pressure on the workforce affects not only services' ability to provide continuity as a model of care but patient encounters more generally:

> *"If there are more [staff], people feel less pressured, people ask the questions they need to ask in the way that they are, and know that they are able to deal with what comes up. Cause that's the thing at the moment, is that we're not able to do that, I don't think, as health visitors. I feel like we'd get that continuity as well, because they'd be enough of us to do the work, and therefore you can see the same person multiple times and check in on them about their mental health. And, I think that it would reduce burnout so that people would have time to be empathetic. Like, I think sometimes people aren't as empathetic as they could be because they're just, like, busy, they're just busy, and they're*

tired and they're, you know, they have enough stuff of their own going on. Yeah, that's basically the bottom line for me is that we need more people in all of the professions." **Health Visitor 2**

In addition to the impacts that workforce pressures place on the ability of services to provide continuity to patients, Health Visitor 2 also talks about the effects of these pressures on the mental health and wellbeing of practitioners. They perceive burnout staff experience due to the stresses of working within a stretched system as eroding clinicians' capacity for empathy. This illustrates a potential route through which stigma could unintentionally be produced and highlights a broader structural condition (workforce pressures) which could generate stigma that is transmitted interpersonally.

In contrast to others, Health Visitor 3 worked in a service where the continuity model of care was often able to be delivered. They described how leadership in their local area had enabled their team to prioritise providing continuity to women and families:

> *"I think having commissioners that really understand what we do, and we've actually got really, really good commissioners in [Place]. So they understand the importance of the things like relationships. So it's not about KPIs and ticking a box that that child has had that universal contact within the time frame. They understand that what we want to do is offer that continuity of care from the same health visitor."* **Health Visitor 3**

Health Visitor 3 contrasted this approach to that of a neighbouring district whose services were now delivered by a private-sector contractor, commissioned by the NHS to deliver community health services. In that district, time-based KPIs were prioritised over continuity. Health Visitor 3 described how this had impacted negatively on staff retention in the adjacent area but positively on their ability to attract staff to work in their area.

Women's experiences illustrate both the importance of and the complexity of continuity in relation to accessing perinatal mental healthcare. These were echoed by professional participants who recognised the value of relationships in engendering trust, an important patient need. The professional participants' insights also illustrated the interconnectedness between interpersonal relations (between patient and professional) and the institutional and structural forces that influence which models of care which can be organised and prioritised.

To summarise, this section illustrates, from the perspective of both patients and professionals, how services are organised and? are not always meeting the needs of those with mental health difficulties, who also have histories of trauma. Finally, it demonstrates both the importance and complexity of relational continuity between patient and professionals for facilitating access to care. Furthermore, it illustrates the institutional and structural forces such as workforce shortages and provider priorities, which are important 'operating conditions' influencing access to care (Dixon Woods *et al*., 2006).

Systems and structures

The final tenet of the concept of candidacy is that wider structural conditions (e.g., resource pressures or policies) can influence patients' access to care. As highlighted in Chapter 2, perinatal mental healthcare is a highly complex area of practice, in part because compared with other psychiatric specialities, it interfaces with many more parts of the health and social care systems (Humphreys *et al.* 2016). Therefore, understanding the wider contexts and operating conditions of perinatal mental healthcare, and the broader systems it sits within, is

crucial. Also highlighted in Chapter 2 were the gaps in the literature concerning perceptions of barriers to perinatal mental healthcare that exist at this structural level (Sambrook Smith, 2019). Whilst some of the interviews with women affected alluded to systemic challenges, most of the data relating to this theme came from the professional participants' dataset.

Some professional participants talked about worsening socioeconomic conditions in the UK and the impacts this was having on service provision and, in turn, on families and communities. Health Visitor 3 and Health Visitor 1 talked about the increasing social complexity they saw in the course of their work, whereby women who had mental health difficulties may simultaneously be experiencing issues with housing, substance misuse, and domestic abuse. Health Visitor 1 talked about how these wider social contexts impacted service capacity, affecting the ability of health visitors to provide continuity of care to build trust with patients, as they were being pulled into more child protection meetings as a result of increasing social complexity.

Psychiatrist 2 and Social Worker 1 both raised concerns about strain elsewhere in the healthcare system impacting on their perinatal work. Psychiatrist 2 described patients cancelling appointments last minute to attend GP appointments instead. Social Worker 1 described how patients struggling to access primary care could impact the escalation of symptoms and in turn specialist service capacity:

> *"Community services have been decimated, so these are people who have not ever necessarily engaged with anything beyond their front door. And so, even just getting someone to feel confident enough to go to a mum and baby group […] the absolute decimation of services that started with universal services, and has had the impact on everybody's lives. The fact that people are coming to us with things that should be treated by their GP, but they can't get in and it's got so bad now that they're now in a secondary mental health team."* **Social Worker 1**

Professional participants perceived specialist perinatal mental health services to be *relatively* well funded compared with other services in their areas, but still perceived there to be stress on these teams due to high demand. Participants from each of the professional subgroups (health visitor, midwifery and specialist teams) advocated for strengthening of primary care services to reduce demand on specialist services, illustrating the importance of understanding the wider healthcare system context if examining the problems of capacity and access in relation to perinatal mental healthcare.

The organisation of healthcare in England is a complex system comprised of hundreds of organisations operating at different levels, with different purposes and providing different forms of care (NHS England, 2024b). These organisational structures, through which funding is distributed, were reported by several professionals to impact on patients' access to care. Midwife 1, Health Visitor 2, Health Visitor 3 and Psychiatrist 1 all explained the challenges of delivering care in the context of strict organisational boundaries. Midwife 1 spoke of wanting to 'remove that postcode [lottery]' so women could choose where to access perinatal mental healthcare services: providing them with as much freedom of choice as they have when they choose where to give birth. Health Visitor 3 described a local housing estate in their patch, where women in one part were not eligible for the same services their neighbours in the other part of the estate were. Psychiatrist 1 said:

> *"even when your team has a case load that's manageable, all it takes is one or two tricky cases whereby they live in a border town so they fall between two systems, they have a health visitor on one side of the patch but they have a GP on the other and just navigating that and advocating for patients can be hard and sometimes,*

particularly our newer staff - I find it hard and I've been in the team a while, and it's particularly challenging for our staff." **Psychiatrist 1**

Psychiatrist 1 emphasises the time it takes staff to accumulate the institutional knowledge required to navigate complex systems on behalf of their patients. They also imply that the advocacy staff are required to do to get their patients access to different forms of care within the local care ecosystem can take up a lot of their time and capacity.

Another consequence of this way of systematising healthcare is the flow of patient information between the different units of organisation. Several professional participants talked about information sharing between the different Trusts and teams women may be being seen by as a particular challenge in the context of their work. Midwife 1 said:

"One of our main issues where, it's that our systems don't talk to each other. So, even though we all work together and we all provide service for the same group of families, but because we are different trusts, our systems don't really communicate [explains system dynamics and negotiations to get access] I have managed to get access to perinatal mental health team, to have access to maternity. But of course they are going to need to be within the trust. Meaning that they have to be in the hospital to be able to have that access. They can't do that remotely. But the mental health trust here, don't allow anyone outside their, within, unless you're employed by them. You can't have access to, even for read only, which is an issue." **Midwife 1**

Social Worker 1, who worked in a different part of the country, expressed similar difficulties:

"Being able to access people's records is so difficult and we've had quite a few people recently […] we're bordered by quite a few different local authorities. [describes local areas] and they might choose to have their baby in [city] but we've got no access to any of their previous notes until we seek it out, but we can't immediately look and check someone's diagnosis, check someone's history. You know, we're waiting weeks maybe for those files to come over." **Social Worker 1**

Midwife 1's and Social Worker 1's articulation of these problems illuminate how structures and policies such as information governance and the ways in which NHS trusts (as an organisational unit of the wider health service infrastructure in England) operate in ways which can impact on perinatal patient care. Others utilising the concept of candidacy to understand women's access to maternity care have also highlighted technology systems as a local operating condition which can influence care delivery (Hinton *et al.,* 2023).

Whilst staff are waiting for further information about the women in their care, they are reliant on patients' narrations of their mental health histories and their ability to express their needs; something which may be impaired by women's symptom severity. Or as illustrated in earlier sections of this chapter, may disadvantage patients who are less able to articulate their needs or who do not have detailed knowledge of their conditions (i.e., those with less cultural health capital). Having timely access to patient notes can counteract some of the interactional disadvantage that some patients may have, especially those whose histories may be more complex.

Discussion and concluding comments

The main contribution of this chapter has been the attention it has paid to the institutional and structural forces that can influence access to perinatal mental healthcare. Taking a sociological approach has also foregrounded access to healthcare as a highly relational and interactional process between individuals and health services. My in-depth interviews have

allowed a nuanced understanding of the influences on access from the perspectives of both patients and professionals. It has illustrated the interplay between individual, institutional and structural factors.

Sambrook Smith *et al.*, (2019) systematic review of multi-level barriers to perinatal mental healthcare identified women's and professionals' awareness of perinatal mental illness as a commonly cited barrier in the literature. The findings from my study confirm but also extend these findings by considering this barrier to care through a sociological lens. Whilst Sambrook Smith *et al*., (2019) conceptualised the issue of patient-professional knowledge at the level of the individual, I have highlighted institutional and structural forces influence both women's and professionals' knowledge of perinatal mental health and illness. This includes the workforce-related dynamics inhibiting professionals' participation in training. I also demonstrate the significant labour women participants performed to access services, drawing on highly specialised skills and knowledge that their education had afforded them, education which not all women will have access to as access to higher education is socially patterned in the UK. The sociological lens I applied to the data thus reveals the interaction between structural and individual level factors. It demonstrates how institutional strains are therefore felt unequally by women, thus contributing to inequalities in access to services. I have highlighted that strains in the wider health and social care systems in the UK impact perinatal mental healthcare. I also show how information governance policies and data protection can create challenges for professionals. I argue this can then unequally impact patients, especially those who may struggle to articulate their needs..

This chapter also demonstrates the value placed on continuity of care/r by both groups of participants. A recent review highlighted there is relatively little literature about the effects of midwife continuity of care models on outcomes related to perinatal mental health (Sandall *et al.,* 2024). Broader literature on this model of care indicates it can have more significant impacts for patients with chronic conditions, those living in areas of high deprivation and those with new or rapidly changing symptoms (Fraser and Clarke, 2023). This indicates that it could be of value to women with perinatal SMI and could reduce some of the inequity in access that is seen in perinatal mental healthcare. However, there are significant institutional and structural barriers that currently impact the ability of professionals to provide this. My participants perceived this model of care as valuable in facilitating timely access to treatment. This is in line with the findings of a recent systematic review of women's experiences of specialist perinatal mental healthcare which found that continuity of care was one of the most commonly cited barriers to care in the literature (Moran *et al.,* 2023).

With increased global mobility due to globalisation, conflict and growing environmental instability, the need for a multi-lingual health service may become an increasingly pressing challenge for health services in the UK. The professionals' concerns outlined in this chapter, including concerns about translation infrastructure and uncertainty about translation accuracy, echo those found elsewhere in the maternal health literature (Prady *et al.,* 2022).

In addition to the findings in this chapter which add to the perinatal literature, the findings also make a contribution to sociological perspectives, extending and connecting the original concepts of candidacy and cultural health capital. I demonstrate that, in the context of perinatal SMI, it is not just women but others in their personal-social networks who can identify their distress as in need of intervention perinatally and that their networks' knowledge of perinatal mental health and healthcare is also a facilitator to access to care - underscoring different relational components of candidacy and cultural health capital.

In this chapter I briefly discussed how professional concerns about risk factor into determinations of whether a woman is considered eligible for care under specialist perinatal

mental health teams. Data, which will be presented in the following chapter, indicates that these risk concerns implicitly shape and define who specialist services are for and create diagnostic hierarchies, whereby women with clearly defined diagnoses (e.g., bipolar disorder) are prioritised for care. Discussions of risk will continue in Chapter 8, the final results chapter of this thesis, where I will critically examine this concept which pervades perinatal mental health and healthcare in more detail.

Chapter 8: Conflict, affect and temporality in risk relations

Introduction

As illustrated in the literature review, the concept of risk is prevalent in discourses related to pregnancy more widely, as well as in relation to perinatal mental health. Chapter 5 demonstrated how women's risk concerns (for example, the risk of relapse) influenced their reproductive decision making. Risk is also an important concept to the many professionals encountered by women experiencing SMI perinatally. A core part of their work is the assessment, identification, treatment and management of risk. Risk is both a ubiquitous and a taken-for-granted concept in relation to health and healthcare delivery, but has been theorised and critiqued by social scientists (Lupton, 2013; Fischoff & Kadavany, 2011). Whilst these sociological perspectives have been brought to bear on the experiences of pregnancy and mental illness respectively, there has been relatively little research that seeks to critically understand risk as constructed and experienced by both women and professionals at the intersection of women's mental and reproductive health. Sociological perspectives have the potential to help us to develop a deeper understanding of women's and professionals' experiences and understandings of risk in relation to maternal mental health. One which pays attention to the organisational and professional cultures risk discourses and practices are embedded within.

This chapter provides a nuanced account of how women and healthcare professionals construct and experience risk in relation to maternal mental illness. In doing so, this chapter presents data relevant to the following research questions:

- what are the implications for women if they are identified as being at high risk of developing perinatal SMI by healthcare professionals and how does class and ethnic identity shape these processes?
- what can be learned by comparing professional and women's concepts of risk in relation to maternal mental health and illness?

This chapter draws on interview data from both respondent groups, and the development of themes presented in this chapter was driven by the analysis of both datasets in parallel. This analysis led to the generation of three high-level themes: conflict, affect and temporality. The chapter is broadly structured by these themes and concludes with a discussion and summary of the findings of the chapter and their connections to the findings presented in Chapters 5, 6 and 7.

It is important to note that in this chapter, in quotes from professionals, two women's names appear unredacted: Tana and Mary. These were the names used in the patient vignettes. As a brief reminder, vignettes were used to stimulate discussion with professional participants during interviews and focus groups. The vignettes are included as part of Appendix 11 and Chapter 4 contains detailed information about their use.

General overview of data relating to 'risk'

Both participant groups spoke about risk during data collection, in direct and indirect ways.

Women sometimes explicitly used the word risk but also referred to risk in conversations about 'worries'. Women were worried about the risks to their own health (chiefly mental and physical) that various aspects of reproduction might engender as well as the risks that their mental health could pose to their motherhood. They were also overwhelmingly concerned about the risks SMI could pose to the health and wellbeing of their (current, future or envisaged) children. Others were concerned about the risks posed by interventions used to treat their SMI and the risk of having their children removed from their care.

Professional participants used the word risk often but sometimes implicitly without articulating precisely what the risk was, who they worried was at risk and their concern about what might happen. For example, Midwife 1 when discussing non-attendance at appointments said "[if] *they're not coming for appointment of course, that's a risk for us".* Clinical Lead 1 when discussing pregnant patients with SMI who were on medication said: *"She's stable. But there is the risk postnatally"*. This illustrates the commonplace yet mercurial nature of the concept and the multiplicity of its use in clinical practice, something social scientists have identified as occurring commonly in healthcare (Kavanagh & Broom, 1998; Grant *et al*., 2019). In discussions of risk which were more clearly defined, professional participants talked largely about risk in relation to risk assessment, patients' risk of relapse, patients' risky behaviours (i.e., substance use, self-harm, self-neglect) and the risk to self, risks to baby, postnatal SMI risk factors and safeguarding. They also discussed their own, colleagues and services responsiveness to risk.

In examining participants' data, I employed constructionist, sociological lenses introduced in my literature review which sees risk as socio-culturally constructed rather than 'naturally' occurring. This allowed me to situate my participants' experiences within wider social contexts, and shed light on how risk discourse shapes experiences of SMI care and professional practice. In this chapter I will show the convergence and divergence between the risk concerns of women and professionals in relation to maternal mental health, and I will also demonstrate the ways in which risk-related complexity can impact access to care.

Before commencing with the presentation of this chapter's three core themes, I wish to present data related to a key finding briefly introduced in the previous chapter on access to care.

Interviews with staff participants indicated that professional judgements in relation to risk are one of the most significant factors in determining what kind of mental healthcare women are able to access perinatally:

> *"The importance for us in Peri[natal] is the risk of relapse postnatally. If someone has a previous diagnosis of bipolar [it] is really, really high. It's one in two. It's massive and so it's really important to have clarity around that."* ***Psychiatrist 3***

> *"I'd be really concerned if she had a diagnosis of schizophrenia or bipolar, because they're the most kind of high risk illnesses. I know [Mary's vignette] is left quite ambiguous, I'd be thinking about whether there is a first degree relative with a serious mental illness as well, cos that is a risk factor and a red flag in perinatal mental health as well, particularly on the maternal side of the family. So I'd be trying to think about family history as well and keep that in mind. I think if she had a, say, a mild depression or generalised anxiety disorder that was quite mild, I wouldn't feel as worried."* ***Nurse 1***

> *"Postpartum psychosis is always what people worry about. But yeah, the result [is] other facets of risk isn't there […] there's something that's quite unique about if there's a risk of postpartum psychosis, everybody jumps up and down. And that's definitely our population, like we're quite clear about that. But, but the slightly more social stuff around like is this just someone who's a bit vulnerable and who actually just needs a social work[er], that, that becomes a bit more, a bit more unclear.* [***…]*** *I think as soon as someone's got a diagnostic label that's quite clear and there's a clear risk and it all becomes quite biological, you know, around medication and stuff that's easy, that's clean. But I think the grey area is like, you know, does Mary have a personality disorder or something else? You know, what is Mary's diagnosis?"* ***Psychiatrist 2***

Data from professional participants showed that women with 'red-flag' risk factors (such as specific diagnoses or family histories) are often prioritised to receive care under specialist perinatal mental health services. However, women whose diagnostic histories or displays of distress do not align with these categories are not prioritised for specialist care. Diagnoses are central to the assessment of risk in perinatal mental healthcare, which guides decisions about who does and does not receive care within the context of services with limited capacities. This creates a hierarchy of diagnosis which means women with particular presentations, histories or formal classifications are prioritised for specialist care over others whose distress presents or is classified differently. This demonstrates that risk is a fundamental determinant of access to perinatal mental healthcare.

Conflict

Professional judgements in relation to risk are one of the most important factors determining what kind of mental healthcare women access perinatally. Women with histories of bipolar disorder, or who have experienced psychosis (postpartum or otherwise) are often prioritised for care by specialist teams.

As discussed in both Chapter 2 and the preceding section of this chapter, there are clearly delineated, statistically calculated risks 'known' for women who have personal or family histories of bipolar disorder or who have experienced psychosis. This was referenced by professionals during interviews/focus groups. Risk-calculations associated with particular diagnostic histories lend clarity and objectivity, which enable decisions to be made about who should be prioritised for care or monitoring within the constraints of NHS Services. This then implicitly shapes the remit of services, who they are for (and not for). A key theme in the risk-related data illustrates that the decisions professionals make in relation to maternal mental health about who to treat, with what, where and how are not always clear and 'objective'. They are messy and often contested. This section illustrates the ways in which conflict arises between different actors in relation to maternal mental health, particularly professionals.

As discussed in Chapter 2, women come into contact with many different health professionals at different stages of their pregnancy and postpartum periods. If women require intervention for their mental health during this time, they will encounter more professionals. If healthcare staff deem women's mental health difficulties a significant enough risk to the development, health and safety of children, their safeguarding responsibilities may result in social care professionals becoming part of women's lives as well (Royal College of Psychiatrists, 2021). Each professional group has different responsibilities and priorities in relation to women and families. They will also have had

different training and experiences which influence how they see the world and the situations they encounter in the course of their work.

Risk-related judgements: variability and consequences

Conflict between professional risk judgements was a common theme in the data. This was apparent in data from both participant groups, though there was more evidence in data from professional participants. Psychiatrist 3 talked about how risk management within clinical practice can have unintended adverse consequences on patient agency:

> *"When you're too focussed on the scariness and when risk is the only thing that you're thinking about, a lot of damage is done. A lot of agency is taken away. Control. And control is so important in the perinatal period, it's that, it's a real risk factor. So feeling out of control, not feeling like you have agency about decisions that you're making. [It's] Really difficult to convey some of this thinking to social care. Social care can be even more difficult to help understand things than perhaps family."*
> **Psychiatrist 3**

Psychiatrist 3 argues that in perinatal mental healthcare highly nuanced thinking in relation to risk is essential to patient care and management. They imply that there is the potential for professionals' fears about risk to generate a 'tunnel vision', where professionals are solely focussed on taking actions to manage risk which may obscure thinking about the consequences of risk management. They also explain the difficulties they experience in conveying this to professionals they encounter in social care. This illustrates that friction can arise from differences in risk perception and management between professional groups.

Kimberly's narrative of antenatal care provides a rich illustration of these variabilities in risk management, the justifications for risk-related decision making that are made and the consequences of these conflicts. Kimberly was supported by a large, multidisciplinary team throughout her pregnancy, as she was unwell both physically and mentally. Midwives, psychiatrists, support workers and a bonding team were all involved in her care. Towards the end of her pregnancy, she was assigned a health visitor. Kimberly recalled that the health visitor said after reading her notes:

> *"[Health visitor] made the monumental decision to involve the social worker much to the annoyance of all of my team who made it clear to me...it [was] translated to me by saying, we've worked hard to keep that [social services] away from you because we're controlling this situation. Somebody who hasn't met you has decided to involve a social worker, and I picked up on the anger that my midwife felt, and she told me how she was taking, she was complaining as she was taking it to her manager. She wasn't happy that [Health Visitor] had done this."* **Kimberly**

Kimberly recalls the affective consequences of this conflict on her midwife, describing the anger this situation generated. The specialists supporting Kimberly did not agree with the health visitor's' assessment that Kimberly's mental health was a significant enough safeguarding concern to warrant referral to social services. Owing to the fact that this is Kimberly's account of the situation, it is not possible to ascertain the rationale for the judgements made by these professionals. However, later in the interview, Kimberly said that her health visitor had justified her decision to involve social services by saying "but it's all about the funding". This decision generated a breakdown in trust and rapport between Kimberly and her Health Visitor, and she subsequently requested another. When she requested this, Kimberly described that the health visiting team defended their colleague's actions and Kimberly was not visited by a health visitor again. She described these experiences as damaging her view of and trust in the profession. As highlighted in the

literature review and other chapters, previous experiences of healthcare have significant implications for access to healthcare in the future (Kovandžić et al., 2011).

Health Visitor 2 also described conflict between her risk judgements and those made by staff working within secondary mental healthcare services:

> *"I've got a lady who I'm supporting who's suicidal, really suicidal, really unwell. Crisis team have said that, oh, she's OK, she's low risk. I'm like, this lady is not low risk. I do perinatal all day every day, like this lady is not low risk. She's actually [attempted suicide]. That's not low risk. They keep just discharging her back to community services. I'm worried for her, I worry for her partner. Her partner's just like, what do I do? Feel like I'm here babysitting her. Can't leave her on her own. Can't go to work. The family are now struggling financially. Like, it's a lot, you know?*" **Health Visitor 2**

The conflict arising from this risk-related judgement has affective consequences for Health Visitor 2 and significant material consequences for their patient and their family as well as influencing her access to care. Both Psychiatrist 3's and Health Visitor 2's quotes illustrate the complex nature of risk-related decision making that happens in relation to maternal mental healthcare, where women are subject to risk-related decisions from several different professional perspectives. They assert that risk-related decision making requires specialist knowledge, experience and expertise to make the 'right' call: a highly specialised and attuned clinical skill which is strengthened through direct encounters with perinatal patients.

The social science literature highlights that conflict can arise where 'lay' understandings of risk do not align with clinical perspectives (see Lupton, 2013). My data demonstrates that in the context of perinatal mental healthcare, conflict can arise from frustrations that professionals have with other professionals' understandings of risk too.

Risk, capacity and intervention thresholds

As previously discussed, risk-related decision making and access to care are inextricably linked. However, my data indicates that what is deemed high risk by antenatal and postnatal care gatekeepers (i.e., midwives and health visitors) and what those working in specialist perinatal mental health teams deem to be high risk *enough* to provide care to women are sometimes at odds. Midwife 1 explained:

> *"When we think about risk in midwifery, obviously we escalate quite early on. We know so much about what's normal and anything that's not within normal, that we consider normal, then it becomes something that we need to escalate. […] [referring to case study] I know it says that she was diagnosed with OCD in the past but OCD for us is quite significant mental illness. So that would warrant immediate referral to perinatal mental health."* **Midwife 1**

Midwife 1's quote shows how ideas of risk and what is 'normal' are integral to the processes of referral for specialist mental healthcare. A history of OCD, which is not a 'red-flag' risk factor like bipolar or psychosis, in the context of midwifery is a significant cause for concern. This is an example of how the risks associated with specific diagnoses are relative and socially defined. Whilst Midwife 1 is not explicit about what 'normal' means in midwifery, their statement implies that a history of mental health difficulties is not seen as normal within maternity care and the practice of midwifery. This illustrates a potential path through which ideas about the incompatibility of motherhood and mental illness are inadvertently transmitted and upheld.

Whilst a history of mental illness may be enough cause for concern in midwifery to warrant referral to specialist care, Social Worker 1 explains how this may not be enough for women to access care via the specialist perinatal mental health team:

> *"Where we've got the capacity issues, what we're being forced to kind of say, unless they've got the diagnosis of bipolar or psychosis or a first degree relative with psychosis, where we would take them and just monitor things. […] there are probably some women, and, somebody like Mary, who might benefit from having a bit of […] old-fashioned social work relationship building, but because we don't have the resources and the capacity to do that we would say we don't have a treatment plan for them so we can't accept them onto the team."* **Social Worker 1**

Social Worker 1 relates this to capacity-related difficulties, illustrating how risk, and the 'red-flag' risks are utilised as a way of triaging, deciding who is going to get care and support, in a resource-scarce setting. Health Visitor 5's comment illustrates how these resource constraints are perceived by other healthcare workers in their local area:

> *"In [area], we say, you have to be literally [about to commit suicide] to get under perinatal mental health. Just because they have one doctor, [name, is] brilliant. And they have a couple of other workers, I don't know what their names are, but that's it in [area], and we're a city of thousands. So they literally have to take the highest level."* **Health Visitor 5**

Briefly in this statement and more extensively elsewhere in the interview, they praise the care the specialist teams provide to the very few women amongst the many with difficulties they see who are able to access it. Health Visitor 2 talks about the difficulties that arise when referrals made by health visitors to specialist care are 'bounced back'. Speaking about a recent patient they say:

> *"She's been told [by the perinatal team] that she's not a priority and she's got all this trauma. So yeah, there is this conflict all of the time. She's sounds like she's one who's on the psychology waiting list. That could be a year! It's difficult, isn't it, because, like I personally, I'm not able to do anything about that. And this lady clearly needs help and is wanting help. And then the health visitor's feeling under pressure, like I wanna help her, but I can't help her, what, where do I go? […] Like I said, like all of these women need help, don't they?"* ***Health Visitor 2***

Looking at professionals' discussions of risk indicates that in terms of access, there is a potential gap that exists for women who do not have 'red-flag' risk factors. (i.e., personal or family histories of bipolar or psychoses), but instead have mental illness arising from significant trauma or complex mental health difficulties. That gap exists between women asking for help, or being recognised as in need of additional support and being referred by midwives and health visitors and being accepted by specialist perinatal mental health teams.

Risk conflicts and capacities across the psy-professions.

Another source of conflict in relation to risk described by professional participants arose in relation to the differences between the risk capacities of different psy-professions and services. These had significant impacts on access, even for women who were already engaged in services.

Health Visitor 3 talked about the psychology intervention service in her area which women could be referred to:

> *"With our Talking Therapies service, I know they don't like to handle any risk, so they might take somebody who maybe [has] one risk factor, but then once you start getting two plus, then, then they would probably go to our primary and intermediate mental health team, who would do some sort of stabilisation work with them. And then hopefully they might then go back to, to our Talking Therapies"* ***Health Visitor 3***

Health Visitor 3's statement demonstrates another way in which clinical decisions in relation to the concept of risk is influencing women's access to and experiences of care. They describe women being moved between services because of the capacities of different services to manage patients whose manifestations of distress are labelled as high risk. Whilst deemed clinically necessary, this is disruptive to continuity of care. As illustrated in Chapter 7, continuity of care is vital to build up trusting relationships between women and professionals. This is particularly important for women who may be mistrustful of services.

The capacity of psychology-led services to respond to different manifestations of patient distress labelled as 'risky' or high risk was also raised by Clinical Lead 1. They described a recent example where a patient later in her perinatal period did not meet the threshold for receiving care under the specialist team, so was referred for talking therapy outside the service. During a therapy session, the patient disclosed she had self-harmed, so the talking therapies service deemed the patient to be too 'high-risk' to continue accessing care with them. Clinical Lead 1 described how the patient was discharged without a discussion with the specialist team about what an alternative treatment plan for the patient could look like. Clinical Lead 1 expressed frustration at how the patient's case had been handled by the other service. Following this incident, the specialist team reassessed the patient; however, the patient's experience of a disclosure resulting in the withdrawal of care prompted a lack of confidence in services. Clinical Lead 1 also underscored the crucial therapeutic time lost, as their service is only able to offer support to women for up to one year postpartum.

Data provided some, albeit limited, insight into the source of the risk conflicts that operate in this area of care delivery (i.e: psychological therapy). Psychiatrist 2 talked about intra-professional stereotypes that exist in relation to different professions capacities for risk:

> *"This is not always the case by any means but there are different ideas about the different levels of risks that different professionals are willing to hold. And there are also stereotypes about that as well around, like the buck stopping with the psychiatrist, right? So, when it hits the fan or there's risk, like it's [the] psychiatrist that gets called in front of the coroner and if someone kills themselves, right. […]. There's a huge stereotype that psychologists are willing to hold less risk than psychiatrists."* ***Psychiatrist 2***

Psychologist 1 provides some insight into from where these ideas about the risk capacities of psychologists might have arisen:

> *"If you're digging into difficult stuff you don't want there to be a lot of risk there, I guess people need to be generally quite well and reflective and able to do that difficult stuff. I guess if someone was really sort of risky and easily rocked, then you wouldn't want to be kind of digging into difficult life experiences or I don't know, formulating their childhood trauma that would be not something we'd be looking to do […] I guess we get lots of sort of preconceived notions that we're kind of like, I guess I've heard sitting in the ivory tower or just not holding as much, but I guess that's a*

really important part of being a psychologist is the ability to have that reflective capacity or not be so stretched and so overwhelmed. And I think that's quite hard for other professions to sort of hold in mind, and sometimes it can seem like psychologists are kind of just, not do much, or have really small caseloads, but the ability to hold that reflective capacity and to be able to take that step back and think things through it's really important. Otherwise, we wouldn't be doing very good jobs." **Psychologist 1.**

Psychologist 1's assertion is that the profession's perceived 'low' capacity for engaging with patients whose manifestations of distress are labelled as high risk has arisen both out of sincere and legitimate concern for patient welfare and the nature of psychological intervention. However, as illustrated by Health Visitor 3's and Clinical Lead 1's experiences, whilst these may have ethical and patient-centred intentions, the organisation of services by risk has potential unintended consequences for patients' access to care and support.

To conclude, this section has illustrated the complexities of managing and responding to risk in the context of perinatal mental healthcare. The conflicts that exist in relation to risk management demonstrate that what is defined as a risk in perinatal mental healthcare is not always stable and objective but rather socially situated and context dependent. I have also shown that an important context shaping which risks warrant intervention is health service capacity, the organisation of services and the nature of the interventions themselves. I have also shown how concerns about risk are shaping the organisation of services, illustrating a reciprocal relationship.

Affect and system stress

A significant theme in the data generated relates to the affective dimensions of risk. Much of the professionals' risk-related data included talk about feelings and emotion. This was the worry, panic, fear and frustration that arise in the course of their practice as they are conducting risk assessments, making decisions about patient's levels of risk. It also arose when discussing the risk-related capacities and thresholds of other services. It became clear that professional participants were expending a significant amount of emotional labour and experiencing stress whilst responding to and recognising risk in relation to maternal mental health.

In the context of midwifery, specialist midwives interviewed talked about the affective consequences on non-specialist colleagues who are key referrers to specialist teams:

"As a perinatal mental health midwife I'm trying to do some training [with staff] about intrusive thoughts, how that will affect mother and baby and how we look at it. So obviously, if you've got mother who's got really severe intrusive thoughts, you know, midwives and doctors will panic (laughs), they will worry about what does that mean? But actually, just teaching them about, educating them about what is intrusive thoughts. What does that mean for mums?" ***Midwife 1***

"I'll get a call from the midwives on the ward saying they're really worried about someone. Or they go straight past me, straight to perinatal if they're really worried about someone. And then I'll go and see this person on the ward, and actually, their behaviour is what, what you might class a bit strange, but you can usually get to the bottom of it [describes recent patient encounter] […] the staff on the wards don't

always have the knowledge, they're not trained to recognise severe mental health […] So it's about just kind of helping staff to recognise what's going on and it's not always a mental health crisis, you know, we can deal with it. It's OK. So it can be quite complicated." ***Midwife 2***

Like Midwife 1, Midwife 2 perceived a knowledge gap about maternal mental health as contributing to practitioner anxiety. In Midwife 2's workplace this manifested as an over-sensitivity to risk, seen through referrals to specialist teams. As highlighted in Chapter 7, the ability for professionals to engage effectively in training, to upskill and gain greater confidence in relation to identifying women's distress as something which may or may not require intervention, is something that is contingent on upstream factors, such as workload and team capacity.

As outlined earlier, perinatal mental healthcare is a complex area of practice. If professionals have significant enough concerns to warrant a safeguarding referral to social services, there are interfaces between maternity and mental healthcare and social services. Several health professionals described extremely high thresholds for intervention by social services operating in their respective local areas. Nurse 1 talks about the worries professionals have when social services do not accept their referrals for intervention and hypothesises why thresholds are so high:

"[I feel] Really worried. And stressed. And we deal with risk all the time, but it's almost like you, you're carrying that. I don't know, it feels like almost the buck stops with you, especially as a practitioner or care coordinator, because you're kind of the lead professional. So it, it does feel really, really frustrating when you can see there's an evident and clear need there. But, putting a referral in is as far as it goes and that's it. I have asked myself numerous times how bad does it need to get before a referral's accepted? Yeah, it does make me worry. I worked in [City] previously, and I felt I didn't have as much of a fight to have a referral accepted as much as I have in [City], for some beknown reason, I don't know what it is. I don't know if it's because there's more social workers there, or maybe the provision and the funding's more. I'm not sure." ***Nurse 1***

From Nurse 1's experience practising in different areas, they have observed regional variations in how risk-concerns are prioritised and subsequently responded to by different local authorities. Nurse 1 practises in a different region to Health Visitor 3, who described encountering similar difficulties and observing significant differences in how risk is assessed and responded to in different local authorities. Health Visitor 3's observations are gained from working in a geographical area of high patient transiency. They talked about the differences in risk assessments women/families have been subject to in other areas:

"*You look at it and you think our children's services won't even pick that up. They would not be concerned about that. […] I think I worry that you get a little bit like that yourself cause you, you know, [describes safeguarding issues] […] yeah, there is that worry that you just get a little bit numb to it, I suppose, which is really bad because that's almost the norm. […] there does seem to be a difference across areas, […] I suppose it comes down to their time again, doesn't it? […] that's not to say that that family isn't, you know, suffering and has some level of risk within, but it's just not viewed the same when they move.****" Health Visitor 3***

As well as describing different affective dimensions of these interactions (worry and numbness), what their experiences also illustrate is how risk is perceived and subsequently responded to is locally contingent. This is likely dependent, as Nurse 1 tentatively suggests,

on institutional capacity and resources, which in the public sector and particularly in Local Authorities are increasingly scarce (King's Fund, 2022). As discussed in Chapter 7 on access, system-level stresses on healthcare caused by workforce-related challenges significantly impact the wellbeing of staff and affect the nature of the care these services are able to provide to women. It also illustrated the influence of strains in the broader public sector system and the impact this can have on responses to maternal mental illness. The affective consequences of system-level stresses on staff also have the potential to impact the risk-related decision making of professionals. As Psychologist 1 explains:

> *"If you're feeling really overwhelmed that's likely to increase an anxiety response. I guess you are less able to kind of take that step back and think more rationally. So, if you're operating from a place of anxiety, you're much more likely to operate from like a fight or flight response and be really triggered by any sort of threat or sense of risk. And I guess that's maybe something that I think we see in our team where practitioners are really quite pressured. So, that element of risk then rings their alarm bells cos they're so overwhelmed, they can't, I guess don't have that reflective capacity to kind of think is this high distress or is it high risk and often those two can be really difficult but different things."* ***Psychologist 1***

A similar perspective on how professionals' own affective states shaped their decision making in relation to risk was shared by Psychiatrist 3. They connect the institutional source of stress practitioners are experiencing to how perinatal risk-management training for staff is framed:

> *"It is just only designed to put the fear of God into people. And a sense of responsibility. And when you're terrified and you've got the thought of obviously, the catastrophic thing happening where mum is so poorly that she can't imagine that the world is a safe place for her baby and she kills baby and herself, it is just the thought of that in the back of everyone's mind. What the training should do is help you think about it, not make you shit scared of it so that you can't think. None. None of us. When we are put into our threat system, when we're feeling anxious are as good at thinking through complex problems as when we're calm and thoughtful and contained."* **Psychiatrist 3**

The affective dimensions of risk-related decision making and the conflicts that can arise from this are clearly present in the data. Professionals are undertaking significant emotional labour in their management of risk in perinatal mental healthcare. These perspectives again underscore the sensitivity and complexity of risk-related decision making and illustrate some of the meso and macro-level influences on micro-level decision making.

Temporality and risk-related concern

This section outlines the common risk concerns of both participant groups in relation to maternal mental health and examines the extent to which their concerns align or deviate. This is useful because sociocultural perspectives on risk argue that conflict occurs when distinct groups see dangers too differently (Lupton, 2013). By this logic, illuminating the areas of cohesion and tension between patients' and professionals' risk concerns may provide useful insights about care delivery. In this section, I illustrate that women and professionals share many risk concerns, but the temporal scope of these concerns are different, with women's concerns often being longitudinal, over their own and their children's life course. Whereas professionals risk concerns often have a shorter frame of focus.

Women's risk concerns

Women affected by SMI had many different risk concerns at the intersection of their mental health and reproductive-related experiences. Their main risk concerns were for their own health and for that of their children (or potential future children). Women were concerned about the risks of particular interventions to both their own wellbeing and the pregnancy/child. They were also concerned about the risk of being judged a 'bad' mother by professionals and the subsequent involvement of social services in family life that these judgements could precipitate. This latter concern of women represents a type of risk as a threat, or negative possibility rather than a more medically or clinically defined risk

Risks to personal health

Many of the women interviewed were fearful of the effect that pregnancy, postpartum and later motherhood could have on their health. Some of the women's concerns about risk of perinatal relapse of mental illness were described in Chapter 5. As these examples have shown, risk concerns relating to the effects of pregnancy and motherhood on their mental health influenced my participants' reproductive decision making.

Some participant's risk-related concerns about their mental health were inextricably linked with concerns about their physical health. In Chapter 5, Isa's concerns about the risk pregnancy might pose to both her mental and physical health were described. Alice was also fearful of pregnancy affecting her mental, physical and reproductive health. She was concerned about the effects pregnancy could have on her sense of bodily autonomy and control. She also described fears about the risk of miscarriage that a relapse of her eating disorder could precipitate:

> *"One of my friends that I met in [treatment] got pregnant and it was the thing that really sort of kicked her recovery into gear, but that's not the experience for everybody. For every person that's had that experience, there's been people who've had miscarriages because they haven't been able to sustain their body and the baby's body through adequate nutrition and [the risk of miscarriage is] just such a big risk."* ***Alice***

Elsewhere in the interview she describes having shared her risk concerns about being pregnant, as a woman with a history of eating disorders, with her psychotherapist. In response, the therapist suggested that pregnancy might cure her disorder, that she could "eat for the baby", which she felt as dismissive of her concerns. How her therapist responds to her fears about this risk is interesting. It is implied that the disorder can simply be cast aside. This is reminiscent of Grace's and Melanie's family members' views of their mental illnesses outlined in Chapter 6, where their illness was implicitly understood as something they could control.

Bella also described difficulties in talking with professionals about her risk concerns. Bella's decision to not have children was multi-factorial and strongly connected to her mental health. She described conversations with professionals being strongly focussed on the withdrawal of medication for her physical health condition to reduce the risk of foetal abnormalities, which did not allow space for the discussion of her concerns about other things she was concerned were a risk, such as the transmission of intergenerational trauma or how her health anxiety could complicate motherhood:

> *"Always the conversation is about like the practical stuff [medication]. Not really the- [they] just say, well, people live with, you know, people [with] mental health problems have kids all the time. I'm like, I'm aware of that, but we're not all the same. […], each*

condition is experienced differently and you know, so I struggled to get any (sighs), I guess any real conversations." **Bella**

Women's perceptions of risk are dual-edged. They feel they could be a risk to the pregnancy, but also that pregnancy could be a risk to themselves. This duality is a difficult context in which to make reproductive decisions. Bella's experience shows how difficult it can be to discuss these issues within the context of healthcare, which she felt focussed on the more medicalised aspects as opposed to broader concerns. As highlighted in Chapter 7, professionals shared concerns about the narrowness of preconception care.

Risks to children

Many of the women interviewed expressed concern about risks to the mental health and wellbeing of their existing and potential future children.

Many women were concerned about the genetic risk of future mental illness that their personal or family history may pose to their children. This included women who had decided not to have children such as Bella, those who had not yet had children such as Katie, Mae, Alice, and those who had already had children such as Fee, Isa and Anna.

Within Fee's family, there was a multi-generational history of SMI. Her concerns about the risk of heritability of this condition prompted her to discuss this with her husband prior to trying to conceive:

> *"For me it was really important that I just be upfront and honest from the off because that was the right thing to do you know, it wasn't just my child, it was [partner] child potentially that could end up having this condition, so I needed to put my cards on the table and say that this is something that could happen, and if that's like a deal breaker then fair enough because I wouldn't want to go through life keeping that a secret and then have a child with a condition like that […] it was a very difficult conversation but it was something that I knew I had to do and I was glad that I did it."* **Fee**

Despite the difficulties of having a conversation such as this with her husband, Fee deemed this the 'right' thing to do, implying there was a moral imperative behind her actions. This ethical and moral undertone was present in the narratives of several other women when discussing their concerns about genetic heritability of mental illness. Katie said:

> *"My child would have a higher likelihood of having bipolar than another member of the population and sometimes I'm like oh god do I really want to pass that on? Like I'd feel a bit like, I don't know… I'd feel a bit selfish in a way, giving that to my child, even though I do really nowadays feel like they could, you can live quite well with it"* ***Katie***

Like just over half of the women interviewed, Alice disclosed experiencing trauma earlier in her life. She connects this as a causal factor to her history of SMI. Despite the attribution of many of her difficulties with her mental health to trauma, she also expressed concern about the potential heritability of some of her conditions:

> *"I know more now that most of my mental health conditions and stuff was to do with trauma, but there still is that unknown factor of how much is genetic, particularly with anorexia there's some studies around sort of differences in the way the brain is structured and stuff, but then that could be trauma, but anyway, because there's that kind of unknown about what's genetic it's like well, would I, should I pass on these things? I don't know."* **Alice**

Similar to Alice, Mae's concerns about the genetic heritability of her conditions also cause her to question whether it is 'right' for her to have children despite her really wanting to:

> *"Although I'm desperate to have children, there is a strong part of me that is very, very concerned about how my mental health, my sort of genetics may result in kids having mental health problems. […] I'd be very scared about my genes and then them having depression, I don't want to curse them with the life I have […]. I'm proud to be [autistic], but I worry that with my autism, if my kids had autism, you are, life is a lot harder and I would worry, I would worry about that aspect and kind of like well is it even right for me to do that to kids?"* ***Mae***

Before unpacking this further, in relation to Mae's statement, it is important to be clear about autism. It is widely seen as a neurodevelopmental rather than a mental health condition. However, she spoke extensively about her autism and the impact on her mental health and also included autism in response to being asked about her different mental health diagnoses. For this reason I include what Mae has said about autism and heritability. I want to be clear that Mae also spoke extensively about the parts of her autism she has pride in. Despite her pride in her condition, she questions whether having children as a woman with multiple conditions is the "right" thing to do.

The data does not explicitly indicate where women's perceptions of the risk of genetic transmission came from, and this was not probed further during the interview, but it may be a reflection of what sociologists describe as the geneticisation of illness (Weiner *et al.*, 2017). Genetic transmission of mental illness was not articulated as a key risk concern of professionals and, in fact, heritability and genetics only arose once during interviews with professionals where Psychiatrist 1 described the typical queries which arise during preconception appointments. They said:

> *"A few times, not very often, this has been the case, but [women ask] "I've got a history of severe mental illness, what's the likelihood of my child ending up with the same problems as I do?" but that's not as common as I thought it would be when I started the job."* ***Psychiatrist 1***

The moral and ethical undertones that can be seen in some participants' concerns regarding heritability indicate that this has the potential to be a highly sensitive subject. Anna only felt able to talk about the heritability of her condition with one professional. She asked her CPN about the likelihood of her children inheriting her illness (bipolar disorder). Anna felt she could be open and was very relaxed around this professional involved in her care as they had built up a strong relationship over time.

Chapter 5 showed that many of the women interviewed who were mothers and had suffered from mental illness later in their motherhood described feeling harmful, in as much as they could be a danger or pose a risk towards their children and families when they were acutely unwell. These fears of their illnesses/behaviours being harmful were echoed by women who had not had children too.

Mae and Alice were both fearful about how their disordered eating might affect their children in the longer term. Although Alice attributes the cause of her own eating disorder to trauma, she is still concerned that through observation of her eating patterns, she could affect her children's relationship to food to such an extent that they could develop similar issues:

> *"My nightmare when I was younger and sort of thinking about children would be if I had a teenage girl who had anorexia and it was my fault, like if it felt like my fault. Yeah, because children pick up on behaviours and attitudes. So even the idea of, I don't know, if me and my partner and my child or children were sat around having dinner and every night daddy had ice cream whereas mummy had an apple, they would pick up on that."* ***Alice***

Bella's concerns centred around her manifestation of anxiety:

> *"My biggest worry would be bringing up someone to have problems. Severe mental health problems because of my mental health problems, you know? How would you grow up well if you're in an environment where someone's constantly checking if you've got health symptoms or you're dying. Or crying because one day you'll die? You know what I mean? […] passing on those anxieties and behaviours and things like that and, you know, my behaviour impacting on the wellbeing of a child. When I say behaviour, I mean, I guess my anxiety, my irritability, sometimes all of those kinds of things impacting on a child."* **Bella**

Professionals did not articulate concerns about the specific ways that women's illnesses manifest as causing long-term harm to children's mental wellbeing. Their concerns were articulated in relation to immediate risks of harm posed to children, often by mothers who were themselves acutely unwell. Many professionals expressed this fear, but Psychiatrist 2 explains this most explicitly and succinctly:

> *"That's what people get worried about that is risky for mum, it's risky for baby. That's what people worry about. I mean you don't get many infanticides with postnatal depression but you do with postpartum psychosis."* **Psychiatrist 2**

This data illustrates a temporal incongruence between women's and professionals' concerns about the risks of maternal mental illness to children. The women I interviewed did not articulate fears around posing an immediate risk of harm to their children, even whilst acutely unwell. Their fears were focussed more on the longer term, 'slow-burning' impacts that their mental health histories could pose.

Risks from interventions and the system

Women also expressed risk concerns in relation to the interventions for their mental health. These were mainly centred on women's concerns about adverse effects of their mental health treatment on their babies. Anna stopped taking her medication because she was concerned about the risks the medication could pose to her pregnancy and her baby subsequently developing a physical disability. In contrast to Anna, Stephanie continued to use medication to maintain her mental health during pregnancy. Here she talks about her concerns around this:

> *"So my concern was the [medication] and any effect on the baby but also the stability of myself to continue to be able to work and to be able to eat properly and all those things really […] [professionals] I'd consulted with didn't leave me with any impression that I should change anything if it was working for me."* ***Stephanie***

Unlike Anna, Stephanie's medication was not teratogenic. Her risk concern was the effect of the medication on the baby but also on the risks to herself to be able to continue to do all of the things that kept her feeling and being well.

Psychiatrists I interviewed shared women's risk concerns in relation to women's use of medication. Psychiatrist 3 in particular talked about the complexities of balancing the risks of harm to baby with continued use of particular drugs used to treat SMI and the risks of harm to women's mental health if they ceased taking their medication.

Cammi and Isa both had concerns about non-pharmaceutical interventions which they were offered/undertook perinatally and how these may affect their children. After her baby was born, Cammi was seen by the SPNMH team for a number of months. Whilst she was generally positive about the care she received during this time, she says:

> *“I actually felt quite annoyed that I had to go to the perinatal mental health service because [describes difficulties getting to service] and because I think I told you, I was always worried about passing on mental health stuff to my baby, and I kind of didn’t want her anywhere near it. […] But the perinatal mental health service is really about the mum and the baby’s relationship and how that’s working out and that sort of thing. But I kind of felt like, I don’t know, I don’t want this mental health thing to chase me into motherhood. I don’t want it to affect my baby and that sort of thing.”* ***Cammi***

For Isa, who was unwell during pregnancy, she expressed concern over the psychological support that she was offered to address her mental health. Briefly discussed in the previous chapter, she explained that conflict arose between her and the service when she raised concerns about the practicalities of being able to participate in the intervention that had been offered:

> *“'This was seen as me being obstructive as opposed to being practical and I'm like 'I don't think anyone else would feel comfortable if I bring my baby into this type of group. I wouldn't feel comfortable exposing my baby vicariously to other people's trauma' because you know, we don't even know the extent of how you know, babies are impacted by that stuff, even in utero, never mind once they're out.”* ***Isa***

Both women are concerned about risks to the wellbeing of their babies posed by their participation in mental healthcare. Collectively, risk concerns in this regard represent another duality where some women saw themselves as potentially risky to their children, but their participation in care was another potential risk to navigate. In addition to this, there is a clear temporal component to their concerns; they are worried about the risk of longer term impacts on their children.

Another risk described by several women participants was their concerns that engagement in mental healthcare could put them at risk of their baby being taken away. Professional participants explained women with histories of SMI are sometimes referred to social services by health professionals involved in their care perinatally. As highlighted in the literature review, much research posits that women who experience perinatal mental illness are particularly fearful of social services intervention, which may influence their help-seeking (Dolman, Jones and Howard, 2016) (Dubreucq, Lysaker and Dubreucq, 2022). Professionals interviewed also voiced these concerns:

> *“I think there's a lot of anxiety and worry that that means that baby will get taken away. It's quite hard to have that conversation [about social care input] with women sometimes*.” **Psychologist 1**

> *“I think that fear is a barrier to accessing services generally, not just peri, but all the kind of perinatal maternity stuff. I think that probably is a barrier. based on past experience but also based on cultural experiences. Friends, family.”* **Psychiatrist 2**

Whilst professionals were mindful of women’s fears, as discussed earlier in this chapter, professionals interviewed also explained that social services’ thresholds for intervention are extremely high and the referrals they make often do not elicit intervention by social services as the risk-level is not deemed to be high enough within the context of stretched systems.

Several women talked about their fears of social services intervention and the influence that this has had on disclosure and the care they received:

> *"I probably didn't get all of the support I needed because I was terrified that I would say something [to the crisis team] that would trigger a referral to social services or a bad parenting thing on my notes. Maybe it has, but I think as mothers, a lot of us probably don't get the support they need because they're trying to keep hold of their nest you know. Like, if I tell you how bad it is going on in here then I'll lose the whole thing. If people could be more open and actually know that if you say things are bad going on in here that you feel like the tribe is going to come in around you as opposed to the system coming to rip you apart."* ***Cammi***

> *"I can't tell services just how terrible I feel and that's not to say that I would conceal anything I did, you know, in behaviour terms, but certainly how bad I feel because I worry what they would respond like. You know would they […] [say] that I'm a terrible parent or... So it's like it is really bad but I can't say it's really bad. So then when something does happen, like I randomly try and kill myself, everyone's like well where'd that come from. It came from in here because I couldn't tell you how bad it was."* ***Melanie***

In contrast, Kimberly described herself as being very open with healthcare professionals and feeling like she was able to tell them 'the absolute truth' about wanting to die during the early stages of her pregnancy. Despite this, and being very well postnatally, she remained fearful of future interventions:

> *"There's still a little underlying fear of don't use that [being a single mother] against me. I'm still a competent person. There is just one of me, but I'm… I'm trying my best, you know? And I suppose, despite how well I've been looked after [by health professionals] on two occasions, one with a breakdown and one during my pregnancy. Erm, maybe I am still a little bit frightened that maybe that, those teams could turn against me and say, I'm not a good enough mother."* ***Kimberly***

Melanie's and Cammi's accounts illustrate that the perceived risk of social services' intervention influences what women disclose and when they disclose their distress. This means treatment can be delayed or intervention may not be appropriate to their level of need. Another important aspect of Cammi's, Melanie's and Kimberly's experiences is their fearfulness of being labelled or being seen by services as 'bad' or 'terrible' mothers by healthcare workers. They are not explicit in their articulation of 'good' motherhood, but what is implicit is in line with dominant norms of 'good' motherhood which emphasise mothers as happy, content and in 'control' (Schmidt *et al*., 2023).

Their statements also provide insights in relation to access to healthcare. Cammi is fearful of the risk that a 'bad' parent label could pose to the integrity of families (including her own) and sees this fear as a silencing force, influencing the care she receives. For Kimberly, despite positive experiences of care whilst being treated for her mental health both pre-perinatal and during the perinatal period, she remained fearful of professionals seeing her as an unfit parent. She felt at particular risk of her parenting being seen as falling short of what is deemed by professionals as 'good', because of her stigmatised status as a single parent.

Risk Ambivalence

Whilst many were, not all of the women interviewed had concerns about risks at the intersection of their mental health and their reproductive-related experiences. Some were indifferent, ambivalent or fatalistic rather than fearful.

Grace was one of the few women informed about her risk of perinatal relapse by professionals involved in her care during the early stages of her pregnancy. I asked Grace how she felt about being told she could become unwell again, she said:

> *"I wasn't scared. I just thought well, I'm still studying, had to pay my mortgage, I wanted to do [describes course] so I could pay my mortgage and raise my children, that's what I was going to do. […] I was still studying, I was still working. Paying the bills. The children were fed and all of that and they were at school."* **Grace**

Grace was not fearful in the face of this information about the risk of relapse. She instead talks of the multiple responsibilities and priorities that she as a woman and a mother had to balance during pregnancy and how these had to be prioritised over the risk she may become unwell again perinatally. Stephanie was labelled as a 'high-risk' pregnancy during her booking appointment because of her mental health history and continued use of medication to manage her mental health. I asked Stephanie how being labelled a 'high risk' pregnancy made her feel:

> *"I say to people or friends now that there's something about when you decide to have a baby or when you become pregnant, you are, it's a huge roll of the dice over your own health, mortality, mental health, physical health, all those things. You really just don't know how it's going to play out for you. So, I understood that that was an easy marker in the medical sense to say there's something we want to check regularly with this woman. I imagine it could have been similar if my weight was high or low and it would have been the scales would have been presented to me rather than the question presented to me each time."* ***Stephanie***

Stephanie saw pregnancy as inherently risky. She also discussed a positive orientation to the implications of being labelled high risk, which for her are the additional questions about her mood and mental state she is asked during her routine maternity appointments. She sees a parallel in the risks identified by professionals in relation to her mental health to those that other women may have identified which relate to their physical health (weight).

In contrast to many of the women whose mental health-related risk concerns influenced their reproductive decision making, Masi and Fee were more fatalistic. When asked if her previous experience of perinatal mental illness affected how she felt about future pregnancies, Masi said emphatically that they did not. When asked why, she said:

> *"Because situations are different, what is happening today is not what is happening in the future and you cannot predict the future."* ***Masi***

Fee's religion (Islam), influenced her perspectives on risk in relation to reproductive decision making.

> *"I suppose I did worry that my child or children would develop mental illness but it obviously wasn't enough to stop me from having children. I suppose it's one of those things that you're either going to have it or you're not. I know that there is the hereditary factor but I think things like that are in God's hands you know. Whether the person will, will not have it will be down to God."* **Fee**

Fee shares the concerns of many other women about the risk of genetic inheritance of mental illness and the risks this may pose to the long-term wellbeing of her child. However, unlike others who shared her concerns about genetic inheritance, she viewed and responded to this risk through the lens of her religious beliefs.

Professional concerns

Most professionals articulated their main risk concern in relation to maternal mental health the as risk of patients harming themselves or others, as Social Worker 1 describes:

> *"Essentially it's any risk to self or to others. So self-harming, self-neglect, thoughts of suicide. In terms of thoughts of suicide, there's a range of different kind of levels of that from escape fantasies to passive thoughts of I just want to die to making an active plan […]. I think sometimes what's particularly difficult is when they might not have thoughts of kind of physically harming themselves or others, but it's the self-neglect and where we assess that on the scales of whether that's somebody who is doing it bad enough, essentially to get a service, it's just a horrible way of describing it, but I can't think of a better way."* **Social Worker 1**

Social Worker 1 demonstrates how services are assessing women's displays of distress through the lens of risk. If their distress is deemed a high enough risk, women get access to the specialist service.

In addition to self-harm, suicidality and self-neglect, professionals described other risk factors related to women's mental health they would look for. These included women's levels of sleep deprivation, their personal and family history of mental illness and their risk of postpartum psychosis/postnatal relapse.

Postnatally, in relation to the baby, professionals were concerned about any strained or negative relations between mother and baby. Health Visitor 1 articulates this well:

> *"Persistent feelings of estrangement from baby and saying baby doesn't feel like mine or baby doesn't like me, baby likes Dad or kind of those negative representations. thinking Oh, baby's, just doing that to annoy me or is really naughty. That kind of thing. That would be a really significant concern, where we'd escalate to the specialist perinatal mental health team."* **Health Visitor 1**

To continue with discussions of maternal-infant relationships, Midwives, Health Visitors and members of specialist teams all discussed how issues with bonding and attachment between mother and baby was a significant risk concern. It could influence whether midwives and health visitors referred women on to secondary care, and in the case of perinatal mental health team members, could significantly influence whether women were able to access that service. As discussed earlier in this section, women's fears about the risk of social services intervention can influence disclosure of personal feelings of distress, which in turn influences women's access to care. Here, Social Worker 1 talks about how this also can extend to women's disclosure of issues with bonding and attachment:

> *"Sometimes we see these women who are like, I've got no issue with the pregnancy. I've got no issue with baby and almost do themselves out of a service because they're like it's not that, I'm just a bit depressed, but baby's fine! And sometimes that's because they've been under services so much. Particularly thinking under children services and they're so worried about disclosing any sort of (pauses) lack of bonding or lack of parenting that could flag to a practitioner that they might need social care that they don't discuss with us when they are having those kind of perinatal issues."* ***Social Worker 1***

Social Worker 1's response indicates that whilst women may disclose their personal distress to professionals, this is sometimes still not enough for them to be seen by specialist services. The disruption to the maternal-infant bond is what will engender access to the

service rather than women's distress on its own terms. This illustrates a potential mechanism through which the protection of the maternal-infant bond is, in the context of stretched systems with capacity limits for specialist services, prioritised over women's own wellbeing.

As well as having implications for understanding access to care, health professionals' concerns about bonding and attachment can also illustrate ways in which ideas about "good" motherhood and "good" pregnancy are transmitted via medical practice. Talking about bonding and attachment concerns in relation to midwifery, Midwife 1 says:

> *"We really talk about bonding at four or five weeks' pregnancy, very early on because obviously that's an indication that there could be problems later on. I mean, there could be a million and one reasons why mums will say that they can't bond with their baby because it could be their previous experience of miscarriage. And you, it's almost like a way of protecting themselves from the emotional struggle later on… but we still sort of tend to encourage parents to bond with their baby. So if there's a concern then of course, that's a risk […] we think there's potential there could be some mental health problems there."* **Midwife 1**

This quote illustrates how medical encounters contribute to upholding normative ideas about motherhood and how a woman should feel towards the pregnancy and developing foetus (i.e., nurturing and attentive (Schmidt *et al.,* 2023). Women's previous reproductive related experiences, such as miscarriage, which may have been distressing to women, are acknowledged by professionals as potentially disruptive to bonding. However, according to Midwife 1, women's strategies of self-protection for their mental wellbeing might be labelled as risky, potentially pathological. This illustrates another mode through which the protection of the maternal-infant bond is prioritised and women's own mental wellbeing is unintentionally marginalised.

In terms of women participants' experiences of the prioritisation of attachment, Cammi was aware of her high-risk status in relation to her mental health, so she sought to make an advance plan in collaboration with healthcare professionals of what to do if she was to become severely unwell postnatally:

> *"Because I have a bipolar diagnosis I was obviously more at risk of my mental health being dodgy after [child] was born. I wanted to make a sort of advance statement that said if I lose the plot, I would like [husband], who won't have lost the plot, to be the primary care giver and I was quite shocked that that was not an option. They were like "no, no you'll be sent to a mother and baby mental health unit". […] I felt that was really wrong because [child]'s got two parents right? And if one of them loses the plot then she's got another one that she could bond with rather than being in a situation where she's then being parented by a parent who hasn't necessarily got the capacity to give her the love and care that she needs. So that was difficult and I realised how little power I have, as a mother, in the system. Even to think ahead and plan for my own baby."* **Cammi**

Cammi's narrative illustrates a conflict between the priorities of Cammi, the concerns she has about the risks her mental health could pose to her child's healthy attachment and that of professionals. Her experience illustrates the primacy that's attached to the maternal infant-bond rather than a paternal or parental-infant bond by professionals.

In this section I demonstrate some tension, but much alignment between the risk concerns of women and professionals. I have shown there is a distinctly temporal dissonance between some of these concerns, where professionals are concerned about proximal and immediate

negative outcomes arising from different risk factors and women are concerned about negative outcomes over periods of months, years and decades.

Discussion and concluding comments

This chapter has built on findings from Chapter 7 to demonstrate that access to specialist perinatal mental healthcare is inextricably linked to the concept of risk. As I have shown, what professionals deem to be a risk guides referrals and subsequent acceptance or rejection from specialist services. Using a distinctly sociological lens, one which sees risk as socially situated, complex, subjective and shifting, has enabled me to identify and explore conflicts, situate risk perceptions within wider social contexts and highlight the institutional and structural forces shaping action in relation to risk.

My data illustrates that there is conflict around the perception and prioritisation of risk between health care and social services as well as between professionals working solely within healthcare. This finding contributes to sociological discussions of risk in healthcare which has often placed more emphasis on the conflict which arises between patients and professionals (see Hillman *et al.,* 2013, as an example). I have shown that the heterogeneity between professionals' different risk priorities and capacities can cause patients difficulties, for example, disrupting care. It can also generate significant affective impacts on professionals themselves. This, coupled with institutional and systemic stresses has the potential to influence the quality of the risk-related decisions that professionals are making, in turn impacting patient care.

The data demonstrated that at a high level, women and professionals share many risk concerns. Sociologists of risk assert that through an examination of risk we can understand more about what is socially valued (Fischoff & Kadavany, 2011). Many sociologists researching reproduction and risk have illustrated the ways concerns about pregnancy related risk perpetuate societal understandings of good motherhood, with protection of the unborn often privileged over maternal wellbeing (Lupton, 2012). As highlighted in the literature review, many of these studies relate to physical health, not mental health. The data generated in this study does not solidly align with this literature; both participant groups shared risk concerns for women's health and the health of their children. Although there was some evidence that the maternal-infant bond is prioritised within perinatal mental healthcare, it was this dyad and not solely the foetal/child-subject that was prioritised. Whilst women and professionals did share many risk concerns at a high-level, there are significant differences in the specificity of their concerns. A key difference is distinctly temporal, particularly in relation to the health and wellbeing of children. Professionals are often explicitly concerned about risks in the immediate future, whereas women's concerns could also encompass potential risks over a longer trajectory, and sometimes intergenerationally. This incongruence, as will be discussed in the final chapter of this thesis, illuminates a potential avenue for advancing and enhancing parts of the perinatal mental healthcare pathway.

Before concluding, I wish to highlight a specific limitation of this chapter. By taking a sociological approach, my data has shown that the ways in which risk is defined, perceived, labelled and responded to in maternal mental healthcare is mercurial, contested and context-dependent. On reflection, recruiting a higher number and broader range of professional participants could have strengthened the findings in this chapter. However, as will be discussed in the concluding chapter of the thesis, there were reasons why this was challenging within the timeframes of the PhD. I was also unable to collect sufficient data to

understand if or how class and ethnicity shape the processes by which women are identified as high risk of developing SMI perinatally and what impact this has on their care.

To briefly summarise and place this chapter's contribution into dialogue with earlier chapters, this chapter underscores the claim from Chapter 5 that women's risk-concerns can significantly influence their reproductive-related experiences in the context of SMI. These are multi-layered, incorporating concerns for their own health and wellbeing and that of their children (or future children) in complex ways. Some of these concerns are also echoed by professionals, but differed temporally. The chapter also demonstrates ways in which concerns about risk are shaped by but also reinforced normative ideas about what it means to be a 'good' mother. Finally, its key contribution is demonstrating that professional adjudications about risk are a fundamental determinant of what kind of mental healthcare women are able to access perinatally: a finding which will be discussed in greater detail in the final chapter of this thesis.

Chapter 9: Conclusion

Introduction

This thesis has aimed to provide an in-depth, sociologically informed, qualitative exploration of the reproductive related experiences of women with a history of SMI and their interactions with healthcare. As highlighted in Chapters 1 and 2, previous studies of maternal mental health have been largely dominated by disciplines such as psychology and health services research. These studies often acknowledge the importance of understanding the social in relation to mental health and illness (Howard and Khalifeh, 2020). However, they do not often employ the conceptual and methodological 'tools' to generate deeper understanding of the social lives and contexts of women, the institutions they come into contact with, and the structures that exert influence both over women's lives and the professionals who care for them. Much of the qualitative literature in relation to perinatal SMI focusses on a narrow range of diagnoses (i.e., postpartum psychosis) or women's experiences of coming into contact with healthcare whilst unwell. These are important parts of women's experiences at the intersection of their reproductive and mental health, but they are often somewhat decontextualised. They do not represent the whole story and they do not often bring into view women's broader life experiences: the times before they were mothers, their roles within their wider families, their roles outside of the home or even their earlier experiences of mental illness.

Over the course of my findings chapters, I have presented in-depth accounts of reproduction and mental health that illustrates both women's and professionals' experiences as socially situated and influenced by institutional pressures. I have highlighted the complexity, conflict and convergence in women's and professionals' concerns and experiences in relation to maternal mental health. The methods used and the literature drawn upon have generated findings which make a valuable contribution to knowledge about the reproductive lives of women with histories of SMI and their interactions with the UK healthcare system. Findings which I hope and trust will be of interest to both clinical and sociological audiences.

This chapter draws the thesis to a close; firstly by directly addressing each of the four research questions the study sought to answer and then by proceeding to outline the five key findings of the research bringing these into dialogue with existing literature. I revisit the study's conceptual framework in light of the findings of the research. A reflexive account of the study's strengths and limitations is then detailed before outlining recommendations for future research.

Addressing the research questions

The specific aim(s) of this study was to bring sociological insights into dialogue with personal accounts of mental health and healthcare in order to:

- understand how stigma operates in women's lives at the intersection of their mental health and reproductive-related experiences;

- investigate barriers and facilitators to the receipt of perinatal mental healthcare care for these women;
- provide a nuanced account of how women and health and care professionals construct and experience 'risk' in relation to maternal mental illness.

Within Chapters 5, 6, 7 and 8 of this thesis I have presented data which speaks to each of these aims. In service of these aims, the study sought to answer four research questions. Each of these questions is now addressed directly by summarising and drawing together the findings presented in the preceding four chapters.

To what extent and in what ways does a personal or family history of SMI influence women's reproductive-related experiences and experiences of stigma?

The research demonstrated that a personal or family history of SMI can profoundly influence women's experiences of pregnancy, motherhood and reproductive decision making.

Women's histories of SMI affect their decisions about having children as well as their thoughts about what paths they could take to parenthood. Whilst participants' mental health histories did influence their thinking about pregnancy and motherhood, it is important to stress that mental health was not the sole factor influencing their decisions. Their parallel concerns mirrored those of many women, those without a history of SMI. Findings also demonstrate the ways in which earlier life trauma, which many participants perceived as a precipitating factor for their SMI, meant the embodied experience of reproduction was (or was anticipated to be) uniquely challenging.

In terms of SMI's impacts on pregnancy and motherhood, the findings demonstrated that both the experience of SMI itself as well as the interventions deployed to treat it can disrupt normative expectations of these life stages. Participants' narratives of experiencing perinatal SMI were characterised by feelings of distress, shame, dread, loneliness, uncertainty and fear. The ways in which SMI and interventions disrupted normative maternal experiences (e.g., birth, breastfeeding and other forms of caregiving) contributed to processes of self-stigmatisation - just one of the forms of stigma circulating in women's lives. As specified in earlier chapters, it is important to not perpetuate a solely deficit narrative in relation to this area of women's health. Therefore, it is crucial to highlight there were also positive aspects of their experiences as a mother with SMI, including the strengthening of family bonds and the reframing of adversity.

Returning to the subject of stigma, I have demonstrated a history of SMI does influence women's experiences of stigma at the intersection of their mental health and their reproductive-related experiences. The stigma is both internal (self-stigmatisation) as well as externally experienced or anticipated. With regards to the latter, women encounter this in several domains in their lives: in health and social care services, within their families, in their workplaces and in maternal spaces. Finally, the study demonstrates that women with SMI are not 'passive victims' of stigma, there is evidence of women resisting stigma too.

What individual, institutional or systemic factors cause inequalities in access to perinatal mental healthcare and how could these be addressed?

This research found that stigma circulating within healthcare is a factor complicating women's access to care and help seeking practices. Other factors identified included knowledge and verbal competency, personal presentation, poor translation infrastructure, implicitly risk-focussed service remits, inadequate trauma-focussed care, continuity of carer, workforce and wider public sector and healthcare system stresses and information governance-related challenges.

Sociological lenses enabled the connection of participants' collective personal experiences to wider social contexts. This enabled the contextualisation of factors which have previously been conceptualised as individual-level barriers/enablers to care, consequently illuminating the upstream factors which influence them. For example, improving midwives' knowledge of perinatal mental health (through training) is assumed to facilitate better access to care for patients. The data presented in this thesis illustrates there are institutional and structural forces which make the uptake of said training challenging for professionals. In addition, patients' knowledge about perinatal mental health has previously been conceptualised individual-level factors. This analysis demonstrates that specific skills (e.g., the ability to argue, understand and advocate) are increasingly required to navigate and access care in stretched systems. However, the distribution of these skills and competencies are socially patterned, a potential path through which inequity manifests.

What can be learned by comparing professional and women's concepts of risk in relation to maternal mental health and healthcare?

Comparing the factors that women and professionals conceptualised as risks in relation to maternal mental health showed a significant alignment in their concerns. Both respondent groups were concerned about different risks to both mother and baby, risks to bonding and attachment and risks from interventions. Women were concerned about intergenerational trauma as well as the risks of their child developing their illness (through genetic, behavioural or environmental transmission). Whilst women and professionals shared many concerns, there is a distinctly temporal incongruence between women's and professionals' risk concerns. Professionals were often explicitly concerned about risks in the near future, whereas women were often concerned about risks over a much longer term trajectory, for example, over their life course, their children's life course and intergenerationally.

What are the implications for women if they are identified as being at high risk of developing perinatal SMI by healthcare professionals and how does class and ethnic identity shape these processes?

Data from professionals indicates that if women are identified as being at high risk of developing particular perinatal SMIs (i.e., postpartum psychosis) because of a personal or family history of particular SMI diagnoses, then women are prioritised for care by specialist perinatal mental health teams, thereby indicating that risk is a fundamental determinant of access to specialist care. Few women participants reported being identified by health professionals as at high risk of developing perinatal SMI, often their knowledge had been self-generated, as a consequence robust analysis and comparisons of their experiences in

this regard was not possible. Data from either respondent group did not indicate how class or ethnicity shaped processes of identification.

Key contributions

In this section I outline five key contributions of the thesis that form an addition to knowledge. I bring the findings into dialogue with broader literature and, where appropriate, I also connect the relevance of these findings to practice.

Reproductive decision-making, risk concerns and preconception care

Findings presented in Chapter 5 demonstrated that women's reproductive decision making involved considerations about their mental health conditions. One of the factors identified was the concerns women had about the risks pregnancy and the postpartum might pose for a relapse of SMI. This is in line with other studies in the literature which illustrate that women's concerns about the risk of future SMI influenced their decisions about having children (Roberston and Lyons, 2003; McGrath *et al.,* 2013). My research further contextualises these findings by demonstrating that although SMI influences women's decisions, their decision making also was influenced by factors common to the general population (Lock and Budds, 2013). In Chapter 7, I demonstrate that specialist preconception care was perceived by patients and professionals as highly medicalised in its current form. The risk-related concerns of women participants in this study align with those found by Dolman, Jones and Howard (2013); concerns about the risk of their children inheriting their illness. Findings from Chapter 8 illustrate that women and professionals often share risk concerns in relation to the health and wellbeing of women and their babies but these are often temporally distinct.

These insights combined highlight the complexity and range of factors relevant to women whilst making decisions related to conceiving. I suggest this evidence indicates a need for services which incorporate a holistic, longitudinal approach to supporting women with SMI to make decisions around parenthood. This could include developing services which draw on the expertise of different professionals who can specifically address women's concerns. For example, genetic counsellors to discuss concerns about heritability, or social workers who may be best placed to advise about the feasibility of alternative paths to parenthood. Howard, Easter and Atmore (2020) underscore the importance of 'making every clinical encounter count' (Howard, Easter and Atmore, 2020, p.4) and encourage health professionals to proactively create safe environments to discuss the reproductive ambitions of women with SMI in their care. My research indicates there may be value in these discussions focussing on a wide range of factors, not just mental health. Nevertheless, more research may be needed to confirm if this is acceptable to women since, as earlier chapters in the thesis demonstrate, discussions are highly sensitive.

Stigma and stratification

Chapters 5 and 6 make a valuable contribution to knowledge by providing a detailed analysis of the nature of stigma that women with histories of SMI experience, helping us to understand how and where stigma is experienced by women who are in need of perinatal mental healthcare. Existing literature has demonstrated that stigma stops women from

asking for help because they are afraid of being labelled a ‘bad’ mother and of social services becoming involved in their family life (Dolman, Jones and Howard, 2013).

My findings enrich this literature by demonstrating the powerful, gendered social norms which are a significant feature of women’s experiences of stigma. They show the dominant ideals of good motherhood (Schmidt *et al.,* 2023) women are expected to conform to and how SMI can disrupt this. My findings also illuminate the nature of the stigma that women encounter or are fearful of and the various settings this might be encountered in. This can include healthcare settings, which is in line with findings of others who have identified healthcare as a place in which stigma circulates (Wan, Moulton and Abel, 2008; Edwards and Timmons, 2005). Previous experiences in the family and healthcare settings specifically influenced how my participants experienced or expected to experience future healthcare. Tyler (2020) argues that within the context of austerity, stigma in systems of social provision make help-seeking a ‘desperate task’, urging us to look at other levels of power beyond the interpersonal when examining stigma. Within this thesis, I illustrate how often institutional or structural forces (e.g., structure of appointments, resource constraints, hierarchical cultures) inadvertently generate stigma.

I demonstrate the workplace and family settings are places women encounter stigma. The findings also show that many actors and spaces in women’s lives can play dual roles: perpetrating or helping women in resisting stigma too. There is evidence of women resisting stigma with ideas of ‘good’ motherhood and risk management, these findings are in line with Wiggington & Lee’s (2013) study of women who also experience marginalisation in relation to pregnancy (i.e., women who use substances).

Tyler argues that often stigma is conceived largely as ‘a social problem that can be ameliorated through education, by changing individual attitudes and by teaching the stigmatised how to better manage the stigma pinned upon them’ (Tyler, 2020, p.17). Tyler’s perspective urges us to look beyond these traditional solutions in order to address stigma. This research indicates that improving institutional and structural conditions influencing healthcare may be a good place to start in order to address the issue of stigma. Data presented in Chapter 6 illustrates a potential gap between professionals’ perceptions of the stigma circulating in women’s lives and the women’s perceptions of the stigma they experience. This gap I perceive to be widest in relation to professionals’ awareness of the stigma women experience in the workplace and anticipate in maternal settings, and indicates there may be value in communicating the study’s stigma-related findings to relevant professional audiences.

In terms of potential contributions to the sociological literature, following the analysis, I reflect on how the concept of stratified reproduction is connected to the practice of stigma. Experiencing or anticipating stigma meant some participants felt less empowered to make the decision to have children. McCormack (2005) argues that stratified reproduction is created and reinforced through public policy. Women’s perceptions they would be excluded from adoption procedures as a result of their mental health histories is a significant example of the ways in which women felt less empowered in their reproductive choices because of policies. Women who were subject to social services intervention and felt stigmatised by this, also felt they were not provided with the support from services which may have enabled a more rapid recovery.

Work & employment

The findings in relation to work and employment, particularly those highlighted in Chapters 5 and 6 make a valuable and novel contribution to knowledge.

These findings were generated largely from the analysis of women's interview data. This was not a topic I set out to explore and was not included in my interview topic guide with women affected. However it was clear that work and employment significantly shaped women's experiences of perinatal mental illness, with many explicitly attributing the deterioration of their mental health perinatally to work-related stress. The workplace was a place some women felt keenly the stigma at the intersection of their mental health and their reproductive identities. Other women talked about work and how it helped or hindered their access to care.

Because work and employment was an emerging sub-theme from women's data, I purposely included occupational information in the patient vignettes used to stimulate discussions in the interviews and focus groups with professionals. Professionals interacted with this information in an interesting way. It seemed to be used by professionals as a proxy for the patient's socioeconomic status and social standing, rather than provoking discussions about work-related stress or the reflections on the impact that the nature of the patient's work could have on their mental health. It is important to mention this here in the discussion, as work and employment is a notably absent theme or focus within the perinatal SMI research literature: others have noted the absence of perinatal mental health within sociological literature on work and employment (Wilkinson, Lennie and Duddin, 2018), although there is some emerging research focussed on understanding this in the context in of a specific workplace (police) (Wilkinson, Lennie and Duddin, 2024).

Its absence within existing perinatal SMI literature may be attributable to assumptions made about the capacity of women with SMI to work. It may also point to assumptions made about the relevance of work and employment to perinatal mental health. Under the UK's maternity leave policies, women are entitled to one year's leave from employment. However, as Schmidt *et al.*, (2023) highlights, the integration of employment and mothering is a contemporary norm expected of women. The relevance of the role of work and employment in relation to maternal mental health will arguably become more prominent as perinatal mental healthcare provision expands to up to two years postpartum. It is also important to note that the broader economic conditions in the UK are reported to be causing more women to return to work earlier (Maternity Action, 2024). It is therefore crucial that this is taken in to greater consideration by services. It is also clear that more research is needed.

Understanding institutional and structural barriers to care

Sambrook-Smith *et al.,* (2019) highlight that within the literature on access to perinatal mental healthcare, there has historically been less focus on organisational or structural level barriers. I have addressed this gap by using sociologically grounded concepts to understand experiences of care and care delivery. Sociological lenses enable the connecting of personal stories to broader sociopolitical contexts (Mills, 1959); contexts which are often under-researched in qualitative studies relating to access to care.

As I argue elsewhere, stigma is often suggested in the literature as a barrier to help-seeking (Humphreys *et al.,* 2016; Tripathy, 2020). In Chapter 6 I highlight how institutional and structural forces influence stigma circulating in healthcare, which in turn complicates women's access to care. Thereby illustrating, as Tyler (2020) has critiqued, the limitations of

awareness raising campaigns as anti-stigma interventions and suggests that if anti-stigma interventions are to be effective, institutional and structural change is needed.

The barriers to care identified in this study align with many factors Sambrook Smith *et al.,* (2019) found as part of their systematic review, including resource constraints and service organisation. The findings of Chapters 7 and 8 demonstrate how participants perceived stresses on the wider public sector, other parts of the healthcare system as well as within perinatal mental healthcare services are a major factor influencing both access to care and the quality of care received by women. This extends the findings of Sambrook Smith and colleagues. The stresses this study identified are in the form of underfunding of public services and the associated workforce-related challenges this precipitates. These factors create stress not only on the system but also on the people working with in it.

Findings presented in Chapter 7, in relation to patient and professional influencing access to care, also align with Sambrook Smith *et al.,* (2019). However, the authors had framed knowledge as an individual-level barrier. By using a sociological lens, this study lends more nuance to the findings in the literature by revealing the upstream factors which can influence women's and professionals' knowledge about maternal mental health. This analysis shows the interaction between broader contexts with factors at the level of individual patients. I demonstrate that institutional strains are not one dimensional, but can be felt unequally across patient groups, impacting some women more than others. Illustrating another potential route through which reproduction may be stratified for women from particular backgrounds who experience SMI perinatally.

Risk as a fundamental determinant of access to care

The final contribution I wish to highlight in this thesis, also relates to access to healthcare. To the best of my knowledge, in the literature on access to perinatal mental healthcare, the concept of risk has not been widely explored as an influential factor shaping women's access to care. Sociological perspectives frame risk as socially shaped and context dependent rather than an objective measure of hazard or danger. Using these perspectives allowed me to explore the tensions that can emerge in defining and responding to risk. This enabled me to see how the concept of risk can fundamentally shape and influence women's access to mental healthcare in the perinatal period.

Moth (2022) has argued that neoliberal organisational and policy mechanisms in relation to mental healthcare have resulted in a preoccupation with risk within clinical practice. Rubio *et al.*, (2021) demonstrated this within the context of perinatal mental healthcare for women with SMI and showed much risk-related conflict occurs between women and professionals as a result. Their results showed women felt fearful of disclosing their feelings to professionals in case this should precipitate their children being taken in to care. My data mirrors these findings and also extends them. My findings show there is significant risk-related conflict between professionals too, which impacts on women's care. These findings align with Easter, Howard and Sandall (2019) who found that the care and attention women receive is strongly influenced by professional cultures and the differences in understandings of risk held by the different professionals involved in their care.

Bell, McNaughton and Salmon (2009) suggest that whilst all women are subject to risk discourses during pregnancy and beyond, some women are labelled riskier than others. The data in this study indicated that women with particular diagnoses were seen as "riskier" than others. This, in turn, influenced the forms of mental healthcare or support they were able to access. Whilst this is useful, a limitation of this study is that data generated did not provide

enough insight in to how ethnicity and class could shape processes of being labelled high risk in the context of perinatal mental healthcare and could have thus shed more light on the issue of inequalities in access to care.

Revisiting the conceptual framework

In Chapter 3 I outline the conceptual framework utilised in the analysis of the data generated in the study. When applied to the care of perinatal women with SMI, my research has extended understanding of this framework in several ways.

The sections above extensively set out how my findings illustrate a strong connection between the experiences and perceptions of 'risk' and 'access' when navigating the healthcare system. In Chapter 6 I illustrate how women with histories of SMI resist stigma by utilising ideas of risk in constructing norms of 'good' motherhood. In Chapters 6 and 7, my research has illustrated the complexities that exist in the relationship between stigma and access. Whilst literature suggests that self-stigma can lead to women not seeking help for their mental health perinatally, this research illustrates how stigma circulating in healthcare settings can complicate women's access to care. Through processes of 'recursivity' (Kovandžić *et al.,* 2011), past stigmatising experiences can generate anticipated stigma in relation to the healthcare setting and can subsequently lead women to avoid care as well as feeling unable to withdraw from interventions because of the risk of future care being withdrawn. Finally, in Chapter 7, I demonstrate how my findings extend and connect the concepts of candidacy and cultural health capital. I demonstrate that in the context of perinatal SMI, it is not just women, but others in their lives who identify their distress as in need of intervention and that their family's, friends', colleagues' knowledge of perinatal mental health(care) is also a facilitator to access to care.

Figure 2: Revised conceptual framework diagram

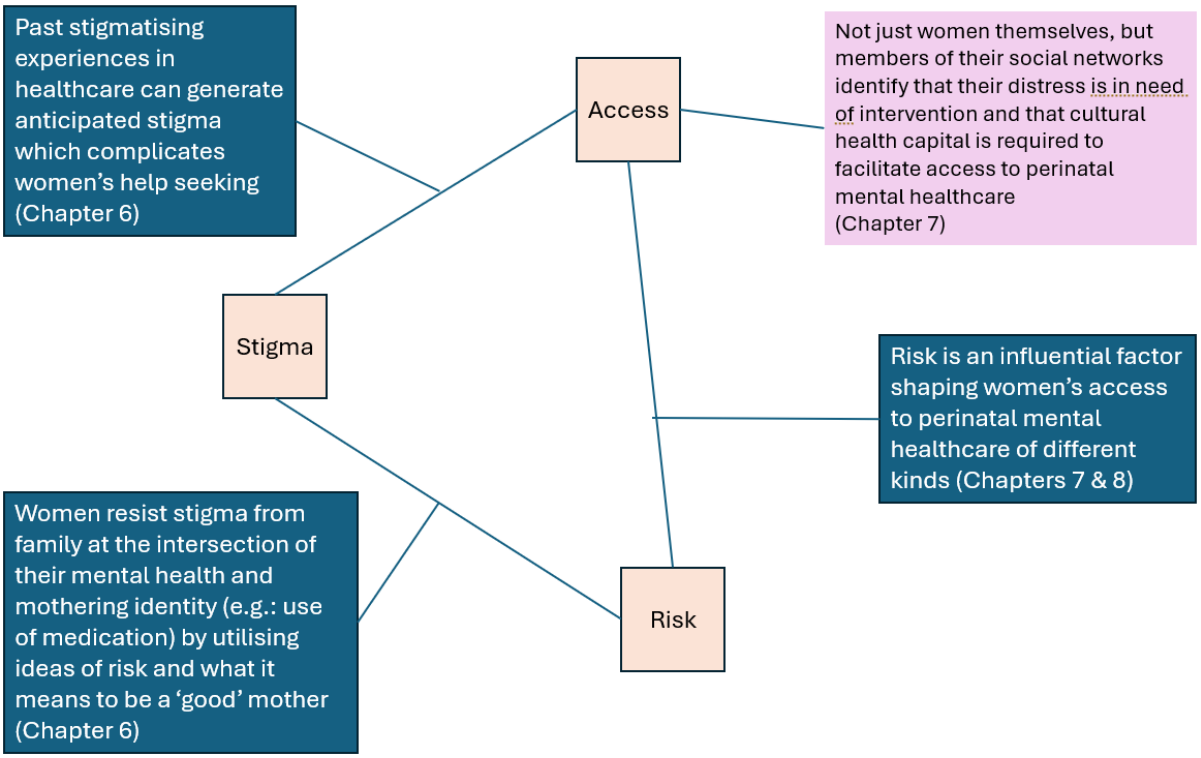

Figure 2 is a revised conceptual framework diagram. It details the relationships between the concepts that this study has illuminated.

To expand understanding of the relationships between these particular concepts, future studies could examine the role of partners and wider family networks in facilitating/complicating access to perinatal care, as these perspectives were not directly sought out in this study.

Critical reflections on the research

Strengths

This study's principal strength has been its use of a sociological, theory-driven approach to analysis. The sociological lenses have enabled institutional and structural influences on women's and professionals' experiences to be brought into view more clearly, which as is argued above, addresses gaps in the existing literature.

Qualitative approaches enable researchers to "get inside how life is experienced" (Mason, 2018). Through the use of qualitative approaches I have been able to provide a rich account of how mental and reproductive health intertwines in the lives of women with histories of SMI and those who provide care for them.

Much of the qualitative research with women who have experienced perinatal SMI utilises a semi-structured approach to interviewing, as Ford, Peters and Wittkowski (2020) systematic review highlights. Whilst this is a valid and valued method of interviewing, Glover *et al.*, (2014) highlighted some resistance from participants to more prescriptive approaches to interviewing in their study of women's experiences of postpartum psychosis. In this study, using a largely unstructured, ethnographically-informed interview technique afforded women the freedom to start their stories where they wanted and to foreground the things that were most important to them (Spradley, 1979) in relation to motherhood and mental health. It is possible work and employment may not have arisen as a strong theme had participants not had the opportunity to tell their stories in this way. This was an unexpected finding and, as presented earlier in this chapter, is a potentially significant contribution to new knowledge in relation to perinatal mental health.

With regards to the analytical approach taken, developing a shared coding framework from the data of both respondent groups enabled the integration of women's and professionals' perspectives. This was instrumental to revealing areas of tension and cohesion in their experiences, giving the analysis greater depth and richness and foregrounding the complexities at play in this area of care; for example, the findings presented in Chapter 8 related to risk.

As highlighted in Chapters 1 and 4, an overarching aim of this research was to ensure that missing voices, including those of women from minoritised ethnic groups and women living in circumstances of deprivation were accounted for within this thesis. One of the strengths of this research is the relative diversity of the sample; 45% of women interviewed were from minoritised ethnic groups. This included women who were born outside of the UK and had migrated in childhood and adulthood, women who were born in the UK to first or second generation migrant parents and women of mixed heritage. In relation to ethnicity, Kapadia (2023) has suggested that research comparing the stigma-related experiences of White British patients with those from minoritised ethnic groups would be of value in order to interrogate the assertion often made in the broader mental health literature that there is more

mental health related stigma circulating in minority ethnic families, which can account for inequalities in access to care: this positions minoritised ethnic groups as both victims and perpetrators of stigma. Owing to the small sample size in this study, a comprehensive comparative analysis was not possible, but the findings presented in Chapter 6 indicate there were similarities in the nature of the stigma circulating within ethnic minority and majority families. This finding tentatively challenges the assertions in the broader mental health literature, but more comparative research with a larger sample is warranted.

Leaders in the field have called for perinatal mental health research to widen its scope beyond postpartum depression and psychosis to develop further understanding across the diagnostic spectrum (Howard and Khalifeh, 2020). The diagnostic diversity of my sample is a strength that enabled a range of voices to be heard. This diversity adds richness to the data and illustrates the specific ways that different diagnoses, patterns of symptoms and ways of experiencing distress can affect women's reproductive-related experiences and experiences of stigma.

Limitations

Whilst there are many sample-related strengths of this research, there are also several limitations. With regards to the women participants, the sample was relatively highly educated. This is significant, especially in light of the findings from Chapter 7 which emphasised the importance of knowledge and skills gained through advanced education for accessing healthcare. Understanding the experiences of women with little or no formal education navigating the healthcare system could generate greater depth in relation to this finding.

In relation to the professional participants, the sample was limited in several ways. Firstly, relatively few midwives and community psychiatric nurses (CPNs) participated in the research. Several professionals from these groups volunteered to take part but ultimately did not participate. Scheduling proved challenging (as described in Chapter 4) due to pressures on health services, which may have been impacting nurses and midwives more acutely. With regards to midwife participants, the sample could have been enrichened by participants who worked in both specialist and non-specialist roles. Findings presented in Chapter 8 about the affective impact of risk assessment on midwives who had no specialist mental health training could have been further contextualised through the inclusion of their experiences. With regards to the inclusion of CPNs, this professional group was a prominent actor in women's illness narratives and as a result, generating insights into their practice from their perspective would have been a valuable addition to the data set.

It also would have been invaluable to have interviewed practitioners working in an inpatient (MBU) setting, as this would have probably enrichened the risk-related findings of the study. Additionally, there were some tentative insights relating to risk and inequalities in access to MBU care arising in the data from a participant who had previously worked in an inpatient setting, which I would have liked to explore further with staff working in an MBU. This participant's insights are not included in the thesis in as much as there was a scarcity of data from other participants to strengthen this claim. However, this may be an important avenue for future research to explore.

Whilst I believe the methodological approaches to data generation and analysis with women participants had several strengths, it is important to also exercise reflexive practice in relation to this. As Mason reminds us, it is important to challenge assumptions in relation to research and recognise 'the extent to which your thoughts, actions and decisions shape […]

what you see' (Mason, 2018, p.xi). I include these final reflexive comments in a separate section as these reflections do not neatly fit within the strength/limitation binary.

Reflexive considerations: talk based methods in mental health-related research

The largely unstructured interviewing technique used to generate data with women participants enabled the achievement of the overarching aim of this study (i.e., to provide in-depth qualitative insights in to the reproductive-related experiences of women with a history of serious mental illness (SMI)). Talk-based methods are dominant in qualitative research and they are highly valued as they enable researchers to generate in-depth knowledge about people, institutions and social processes (Lareau, 2021). Whilst they have significant value and are widely used within qualitative research, it is still important to be reflexive and critical about their use and to reflect on their potential unintended consequences.

Mason argues that interview methods are heavily dependent on participants' abilities to "express themselves, to observe, to narrative, to interact, to conceptualise, to analyse, to listen and understand and to remember" (Mason, 2018, p.112). I used an ethnographic interviewing technique with the aim of eliciting rich biographical narratives from women participants 'rather than brief answers or general statements' (Riessman, 2007, p.23). On reflection, this was easier with some participants than others. There are a multitude of reasons why this may have been the case. Some of these factors are practical, others more interactional. Some women were looking after young children whilst I was interviewing them, so as well as their attention and focus being elsewhere, it can be assumed they may not have wished to speak of difficult experiences in front of their children. Technical issues in a few cases hindered the flow of conversation. Differences in identity between me and the participants (particularly ethnic differences) may also have hindered the depth of discussion with some participants, although not all. Mason talks about the burden on participants to remember (Mason, 2018), several interviewees found it difficult to narrate their experiences of accessing care. Different participants explained this was due to the nature of their symptoms, or due to the time that had passed between their period of illness and the time of the interview. It is also important not to underestimate how for some participants narrating memories may have been painful, limiting the extent to which they could express themselves.

Whilst reflecting on which interviews generated the most in-depth, reflective narratives I noticed a pattern. These interviews were often with participants who disclosed having accessed talking therapies, often over significant periods of time (via both private and NHS services). Rogers and Pilgrim (2021) highlight inequalities in access to talking therapies, particularly for working class people and those from minoritised ethnic groups. Talking therapies can be seen as providing a "training" of sorts, in the kind of self-reflection and articulation that in some ways 'prime' people to be a wonderful interviewee. The depth and the richness of the data generated from interviewing women who had accessed therapy is, from the point of view of the researcher, fantastic. However, I cannot but think this may also present a problem. My final reflexive statement in this thesis is formulated as a question: Do the "tools" of the in-depth interview and the processes of analysis of the data generated in these interactions have the potential to unintentionally amplify further the voices and experiences of those who are already receiving a privileged form of mental healthcare at the expense of those who have not? I argue that whilst there is value in the methods used, there may be limits to what we can 'know' about experiences of care and inequality via qualitative interviewing. In conclusion, other qualitative approaches may be of more value to use in future studies concerned with understanding inequality and mental healthcare.

Recommendations for future research

Women's health and perinatal mental health is a significant area of policy interest. In 2022, the UK Government published the Women's Health Strategy for England, in which mental health and wellbeing is identified as a specific priority area (Department of Health & Social Care, 2022). It would not be wise make recommendations for policy and practice to healthcare practitioners, system leaders or policymakers based solely on this research, especially due to limitations in sample size. Recommendations for policy and practice would require further research and input from professionals, academics and those with lived experience. In light of this, I suggest below some areas for future research based on the findings presented in this thesis.

As outlined above, there may be limitations to what we can know about experiences of receiving (or delivering) care from interviews alone. Future qualitative research investigating perinatal mental healthcare may benefit from the use of observational or ethnographic methods, which are valued for the light they can shed on understanding everyday practices and for bridging the 'formidable gap' between rules and guidelines and their implementation in practice (Lareau, 2021, p.140). Whilst observational approaches can yield rich knowledge, it is important to note that ethnographic work in clinical settings, particularly inpatient settings, is ethically challenging (Bendall, 2019). This work may be particularly valuable to qualitatively explore the inequity seen in relation to inpatient care highlighted by Jankovic *et al.,* (2020) and Langan Martin *et al.,* (2016) which was not extensively explored in this study, in part due to the lack of professional participants working in inpatient settings.

Future qualitative research in this area should seek to ensure the experiences of women with little or no formal education are sought. A limitation of this study and of the broader qualitative perinatal SMI literature is that participants tend to be highly educated (see McGrath *et al.*, 2013, Plunkett *et al.,* 2017, for example). Therefore, it is important to understand more about the experiences of women seeking care who have fewer years of education. Particularly in light of the findings of this study that indicate specific skills often developed (for example, researching, familiarity with biomedical language, constructing arguments) via advanced education are valuable assets for accessing care within stretched healthcare systems. Maternal Mental Health Alliance, an important advocacy organisation in relation to perinatal mental health, has highlighted gaps in knowledge related to equity are important to address if NHS England's policy ambitions for perinatal mental health are to be met (Maternal Mental Health Alliance, 2023b). For this reason, further research in this area could have valuable impacts on policy and practice.

A significant contribution this research has made is illustrating the different ways that women's reproductive decision making is influenced by their mental health histories. Preconception care is an important part of the perinatal mental healthcare pathway, and data from both participant groups indicates a shared perception of preconception care as relatively limited in its current, highly medicalised form. Research to understand the acceptability and feasibility of implementing a more holistic approach to preconception care for women with a history of SMI would be a fruitful avenue for future research; one that may meaningfully impact practice.

This study demonstrates that work and employment is a significant feature in women's narratives of perinatal mental illness. As contended above, this social determinant of mental health has, to the best of my knowledge, been largely neglected in the perinatal research literature, and others have argued perinatal mental health has historically been overlooked in

social science work and employment scholarship (Wilkinson, Lennie and Duddin, 2018). The Women's Health Strategy highlights women's health in the workplace as an area of action indicating this is an area of future research which could be highly impactful.

Both participant groups discussed interventions delivered by actors outside of healthcare, for example, services delivered by the community and voluntary sector or private psychotherapy, thereby indicating that future research in relation to perinatal mental health may benefit from taking a 'multi-sectoral approach', enabling a deeper understanding of the wider knowledge, expertise, reach and resources available to support women (Salunke and Lal, 2017).

Final comments & personal reflection

Questions of inequality as they related to gender are core concerns of feminist inquiry and, as a feminist researcher, it was my intention to conduct a project where the experiences of women sat at the very heart of the research. I believe choices I have made throughout the past three and a half years have facilitated this. Through seeking the advice of women with lived experience whilst scoping this project, their concerns about stigma became a core focus of the research. Choosing to interview women first, ahead of professionals determined that their words significantly shaped the second phase of data generation. As analysis was conducted in parallel with data generation, women's experiences were the foundation of the coding framework. Within this thesis, the series of findings chapters purposely opened with a detailed account of women participants' experiences. What they said came first.

It is also my intention that the research has a life beyond this thesis. To enable this, once I have completed the final stages of the PhD process, I aim to apply for further funding to develop creative, accessible outputs (for example, illustrations or animations) to use for dissemination purposes. I wish for these to be developed in collaboration with women, health professionals and those working in the voluntary sector so that their voices remain central to the work. I intend for these activities to be undertaken in parallel with more traditional academic dissemination, publishing relevant findings in academic journals and presenting at conferences, which will be valuable mechanisms to share the findings with different professional audiences.

Fundamentally, this research is about life itself. Whilst at times this research has been challenging and deeply affecting, in all other ways it has been a great privilege to have worked towards a doctorate by researching this area of women's health. As such, I would like the closing words of this thesis to be those of gratitude to each of the 34 participants who shared their time and experiences with me so generously. Thank you.

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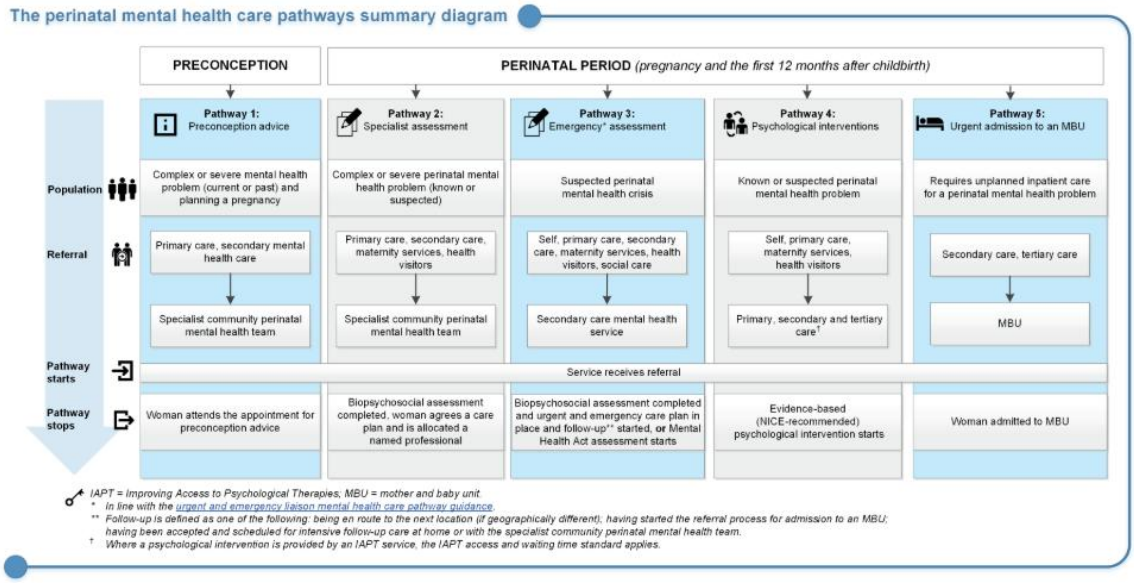
Appendices

Appendix 1 – Perinatal Mental Healthcare Pathways Summary Diagram



Perinatal Mental Healthcare Pathways Summary Diagram.

NHS England, 2018. Available at: https://www.england.nhs.uk/publication/the-perinatal-mental-health-care-pathways/ (Accessed: 8th May 2024)

Appendix 2 – Interviewers Guide (Women)

INTERVIEWERS GUIDE (Women's Interviews)

Formalities/Consent

- Thank participant for their time, check if any interruptions planned, check if there's time restrictions (e.g: need to collect kids from school).
- Explain structure of interview
- Explain what to do if phone/internet cuts out
- Take consent (Verbal/Form)

Introduction to me/interest in the subject

Before we start, I think it's only fair as we'll be talking about some quite personal things today to tell you a bit about me and why I'm interested in this area of research.

> *"My name is Charli. [explain background] I don't have any kids – but I'm an auntie and a god mum (oldest [age], youngest is [age]). I've never been diagnosed with SMI, but [explain history]. I imagine that probably sparked my interest in mental health when I was growing up and has been a consistent interest of mine in the research I do. Growing up where I did, and living where I've lived – I think has driven my interest in inequality and in discrimination – and wanting to do work that strives to make care better for everyone – especially people for whom healthcare is sometimes difficult to access for whatever reason… In my mid-late 20's I did a lot of volunteering [describe volunteering role]. I'd say all these things have inspired this project to lesser or greater degrees. So yeah – that's a bit about me…. Happy to answer any questions"*

Pre-amble

- Introduce expectations: will be taking notes (but am listening), no right or wrong answers, can repeat or come back to questions.
- Ethical considerations: Discuss potential for difficult emotions, taking breaks, right to not answer questions etc.

[RECORDER TURN ON]

DEMOGRAPHIC QUESTIONS

- administer demographic questionnaire verbally.

- Ask to describe self in own words

***Signal about to start main part of interview* and Provide Background to study**

> ***"***As a researcher I'm interested in learning about women's health-related experiences. Particularly in this project I want to know more about women who've had mental health concerns and who're thinking of having a baby or not, are having or have had one. I want to know more about what healthcare is like for them, whether it's helpful or maybe been harmful, how they feel about it… Now, healthcare doesn't just happen in a bubble… Women's life experiences, their families, friends, communities and society more broadly are really important to think about too. Which is why I want to speak to you, and start by asking you some quite open questions.*

Now, whilst I've thought about having children, I've not had any myself yet. I've also not experienced a mental health condition like yours. I'm really keen to understand as much about these two experiences as possible and how they influence each other. I'm interested in what this has been like for you.

I want you to tell me as much as possible about motherhood, or contemplating motherhood and mental health -and mental health – what those things mean to you.... I've been speaking quite a lot so far and it's time for me to hand over to you really... "

"Grand Tour" Questions

- Do you want to tell me about your journey with your [1/2/3] pregnancy and your mental health, when you had your [son/daughter]?

- Do you want to start by telling me about the/any time(s) in your life where you were thinking about having a baby?

Start wherever you'd like....

[STRUCTURAL/PROMPT QUESTIONS BELOW... Use as appropriate]

'Wind Down' Questions: to close interview

- Do you have any advice for anyone who has been through similar experiences to you?
- In this interview I was interested in women's experiences of mental illness and how that affects their [relev. RR Experience] Is there anything you didn't tell me that you wish you had? OR Is there anything that I should've asked you that I didn't?

[RECORDER TURN OFF]

Thank participant, explain follow-up, voucher etc. Close call/video.

Potential Prompts by key concept

STIGMA

- Some other women I have spoken to have talked about being judged or being scared of being judged by various different people – could you talk about whether you've felt the same or not?
- *[***if participant uses the word 'stigma'***]* Stigma comes up a lot when we talk about maternal mental health – can you talk a bit about what that word means to you?

ACCESS

- Tell me about any care and support you got from the NHS or other organization's for your mental health whilst [relevant RR Experience]? Were there things which made getting support easy/difficult for you?
- Could you reflect on what influence you think your identity (things we talked about earlier) might've had on the care you received – this could be in either a positive or a negative way or somewhere in between?

RISK

- Were there any things in particular you were worried about having a baby?
- Have you ever been told – by a professional - about how your past experience/family history of mental illness might affect you during pregnancy/after birth/whilst a mum?

MISC

- Can you tell me a bit about your appointments for your mental health during pregnancy/after birth?
- Can you tell me a bit about any community/hospital treatment for your mental health you had during pregnancy/after birth?
- Can you tell me a bit about your booking appointment?
- When were your mental health problems first mentioned during your perinatal care – did you bring it up? Did staff already know? Was there a moment it became obvious they knew?
- How you think staff knowing about your mental health shaped the care you received? How did you feel about it? Why do you think they did particular things?
- Have you felt able to be yourself around professionals?

Contrast Questions

- “What’s the difference between the care you received at X and the experience you had at Y?”
- “what were the differences you feel between how X health professional treated you vs Y health professional?”
- “what’s the difference between your experiences with your mental health after your first baby and second baby?”

Appendix 3 – Memo Templates

Memo Template (for professional participants)

Focus Group ID/number of participants:

Interviewer: Charli Colegate

Date/Time of FG and memo completion:_

Location:_ _____

Complete this form as soon as you possibly can after the interview so that details are fresh in your mind. Type into the boxes as much information as you have.

POST INTERVIEW REFLECTIONS
Setting (Location, quality of connection, many interruptions? any other people (not FG attendees present?)
General observations on the process of the FG (detail, flow, openness, detail etc.)
Your identity and relationship with each participant. Thoughts on possible impact on data.
Participant's identities and relationships with each other – any implicit rules/norms/beliefs shared or not?
Key themes or issues from the Group (what were the respondent's main messages?)
Gaps? Silences? Things you expected to hear about? Areas of sensitivity or tension? Sense of 'rehearsed' story or an just explanation of guidelines?
Surprises? Inconsistencies within the group?
Things you could not cover that perhaps should have been. Need for follow-up?
Themes in common/different to earlier Focus Groups:
Links to findings from women
New topics/issues/changes that we need to incorporate into the guide for future groups:

REFLECTIONS FROM TRANSCRIBING

Key themes or issues from the group – are these different from your original reflections?
What were the 'missed opportunities'?
Stigma
Risk
Access
Additional areas of note
Connection to research questions: **RQ1** **RQ2** **RQ3** **RQ4**
Thoughts/feelings/emotions which arose during transcription?

Memo Template (for women participants)

Participant ID: PAR

Interviewer: Charli Colegate

Date/Time of interview and memo completion:_

Location:_ _____

Complete this form as soon as you possibly can after the interview so that details are fresh in your mind. Type into the boxes as much information as you have.

POST INTERVIEW REFLECTIONS
Interview setting (Location, quality of connection, many interruptions? any other people present?)
General observations on the process of the interview (detail, flow, openness, detail etc.)
Your identity and relationship with interviewee. Thoughts on possible impact on data. .
Key themes or issues from the interview (what were the respondent's main messages?)

-
Gaps? Silences? Things you expected to hear about? Areas of sensitivity or tension? Sense of 'rehearsed' story?
Surprises? Inconsistencies within the interview?
Things you could not cover that perhaps should have been. Need for follow-up?
Themes in common with earlier interviews:
New issues that we need to incorporate into the guide for future interviews and people to follow up:
REFLECTIONS FROM TRANSCRIBING
Key themes or issues from the interview – are these different from your original reflections?
What were the 'missed opportunities'?
Stigma
Risk
Access
Additional areas of note
Connection to research questions: **RQ1** **RQ2** **RQ3** **RQ4**
Thoughts/feelings/emotions which arose during transcription?

Appendix 4 – Stakeholder Engagement document to support informal conversations with women with lived experience

NIHR | School for Public Health Research

NIHR | Applied Research Collaboration Yorkshire and Humber

Summary of PhD project

The mental health of women during pregnancy, birth and beyond is important for individuals, their babies and families.

Lots of research on perinatal mental health is about postnatal depression. Much less research has been done on severe mental illnesses (SMI) such as bipolar disorder, schizophrenia, postpartum psychosis or complex conditions such as borderline personality disorder/complex PTSD.

Because of the potential consequences of women becoming unwell after their babies are born, the NHS is keen to support women to stay well and to work with them to try to reduce any potential risks. They do this by supporting women to make decisions before they become pregnant (via preconception care) or by supporting them during their pregnancy (as well as afterwards too).

To shed more light on this area, I am thinking of trying to answer the following questions during my PhD:

1. How does women's awareness of their risk of developing SMI postnatally influence their experiences of pregnancy and motherhood, or their decision to have a baby or not?
2. Are there inequalities in preconception and antenatal mental healthcare for women with/at risk of SMI? (i.e: are these services used more by some people than others?)
3. If these services are used by some people more than others – why is that the case and what can we do to make services better for everyone?
4. What are the consequences for women of being identified as being at high risk of SMI postnatally?

I'm hoping to answer these questions by speaking to women from all walks of life and healthcare professionals.

I want your views on whether you think there's value in doing this research. There are some questions below I'd like to ask you, to help shape the final research project.

Questions for you

- What do you think are the biggest problems faced by women who know they are at risk of becoming mentally unwell after their baby is born?
- Do you think what I've outlined in the summary is a valuable area for research?

- What do you think is good about it?
- What do you think is bad about it?
- Is there anything else you would encourage me to look at? Or anything else you'd like to say?
- Are there other important issues that you think need to be looked at by researchers? Anything you think we don't know enough about how to support women?

Finally,

- Would you like to be kept updated on my progress – once I start the project next year? **Yes/No**
- Would you like to be more involved in my work moving forward? **Potentially/No**

If you're potentially interested in being more involved, I'll be in touch with more info. Note that if you are keen to be more involved, I would be able to pay you for your time.

Project contact details for further information.

Charli Colegate, Lead Researcher (ccolegate1@sheffield.ac.uk)
Professor Sarah Salway, Primary Supervisor and Designated Safeguarding Contact (DSC) (s.salway@sheffield.ac.uk)

Appendix 5 –Participant Information Sheet (Women)

Motherhood and mental health: A qualitative study of women's experiences and the professionals who support them

Information Sheet for Women

Hello, my name is Charli Colegate and I am inviting you to take part in a piece of research that I am conducting for my PhD at the University of Sheffield. Before you decide whether or not take part, it is important for you to 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. You may wish to discuss this with friends, family or perhaps a trusted professional involved in your care.

Please ask me, Charli (the lead researcher) if there is anything that is not clear or if you would like more information. Take all the time you need to decide whether or not you wish to take part. Thank you for reading this.

What is the project's purpose?

The aim of this project is to understand more about motherhood and serious mental illness (SMI). Specifically, I want to understand more about how women make decisions about motherhood if they have a personal or family history of SMI. I also want to find out how professionals, women and their families can better understand each other to make sure that women from all walks of life get the help they need to thrive.

To do this I will be speaking with women with a personal or family history of SMI to understand their experiences. I will also be speaking with professionals who provide support, treatment and advice to women with a personal or family history of SMI. I will be collecting data throughout 2022 and early 2023.

Why have I been chosen?

You have been chosen because your personal background and experiences are relevant to the study's objectives

Do I have to take part?

It is up to you to decide if you want to take part or not. If you want to take part, you will be asked to signed a consent form to keep with a copy of this information sheet.

If you decide to take part now and change your mind later, that's OK. You can withdraw at any time up until 1st December 2022. You don't have to give a reason and there will be no negative consequences. If you wish to withdraw after the interview has been completed, please contact me, Charli Colegate (ccolegate1@sheffield.ac.uk). The reason why you are not able to withdraw after the 1st December 2022 is that your data may've already been analysed and be part of a larger group of data.

You should also be aware that if you choose to participate in this research, this is not a legally binding agreement nor is it creating an employment relationship between you and the University of Sheffield or the partners which have funded this research.

What will happen to me if I take part? What do I have to do?

If you decide to take part, I anticipate we might talk for around one and a half hours. This may be shorter or longer depending on how much we have to talk about and how much time you have available.

I will conduct an interview with you, asking you about your life experiences, your views, perceptions and opinions on various things you have experienced in your life. This might include:

- Your life
- Your family
- Your experiences of mental health and illness
- Your experiences of healthcare/other services
- What you think might make care better for women like you

Some of these topics might not be relevant to you or your life, or you might not want to talk about them, and that's OK. You do not have to answer any questions you do not want to.

Before the interview begins I will ask you a number of questions about you and your life (e.g: your age, where you live, your ethnicity). I will also ask if you would like to pick a pseudonym (i.e: a name to be used in place of your real name) for yourself. This pseudonym will be used when I draw upon quotes from our conversation in my PhD thesis or in other outputs from the project.

Will I be recorded, and how will the recording be used?

You will be asked for your permission to record the interview. Before beginning the recording, I will say 'I'm going to start the recording now'. The recording will only ever be listened to by me and a University Approved transcriber, who will turn the recording in to a written document. Having a written document of the interview makes it easier for me to analyse. No one outside the research team (except the transcriber) will have access to the original recording and it will not be used for any other purpose.

What are the possible benefits of taking part?

There are no immediate benefits to people participating in the project, however, it is hoped that women may find the experience of telling their story helpful in some way.

As a token of thanks, and to help cover your expenses of participating, you can opt to accept a £25 Love2Shop voucher.

What are the possible disadvantages and risks of taking part?

Due to the nature of the topics to be discussed in the interview, it is possible that you may find parts of the interview upsetting. You are able to stop the interview at any time, take breaks, or cut the interview short.

You may find that you may not become upset right away, but talking about particular topics might affect you in the days after the interview. I may follow up with you in this period to check to see how you are doing.

For participants who wish to accept the token of thanks and who are in receipt of benefits (e.g: Universal Credit), there may be a potential risk to your payments. If this applies to you, there is a free and confidential Benefits Advice Service you can use to find out more information. Please contact me should you have any questions at all about this and we can have a chat.

Will my taking part in this project be kept confidential?

All the information collected about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team. Their contact details are given at the end of this sheet.

I will take great care to ensure that you will not be able to be identified in any reports or publications. The researcher will use pseudonyms for names and change identifying details (e.g: place names). However, it should be made clear that those who are familiar with your history may be able to identify you from details that you have given. I am unable to guarantee complete anonymity in that regard.

There may be certain circumstances where I have a duty of care to break confidentiality (e.g: if you disclose ongoing abuse, or you are at immediate risk of hurting yourself). I will inform you of the course of action I will take.

What is the legal basis for processing my personal data?

According to data protection laws, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

'As we will be collecting some data that is defined in the legislation as more sensitive (information about racial or ethnic origin; sexuality; health), we also need to let you know that we are applying the following condition in law: that the use of your data is necessary 'for archiving purposes in the public interest, scientific research purposes or statistical purposes' (9(2)(j)).

What will happen to the data collected, and the results of the research project?

Recordings from the interview will only be accessed by the research team and a University approved transcriber. Recordings will be destroyed as soon as possible (when transcriptions are returned and pseudonymised). Transcripts of interviews will only be accessed by the research team and will be kept secure by being stored in encrypted files on university systems. "Data keys" (how data can be linked back to an individual) will be destroyed as soon as it will not affect the purposes of the research. Pseudonymised data (in the form of transcripts) will be kept until the PhD is completed and the research team have submitted the findings for publication. I anticipate this may be by the end of 2025.

The results of the research are not likely to be published until after the completion of the PhD in February 2023. However, I will circulate a brief summary of key findings to participants in early 2023.

Once her thesis has been archived, I will share a link with you where you can download a copy of the thesis. You will not be identified by your real name in any report or publication.

Who is the Data Controller?

The University of Sheffield will act as the Data Controller for this study. This means the University is responsible for looking after your information and using it properly.

Who is organising and funding the research?

This research is jointly funded by the NIHR School for Public Health Research (SPHR) and the NIHR Applied Research Collaboration (ARC) for Yorkshire & Humber.

Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by the Department of Sociological Studies [REF: 043513].

What if something goes wrong and I wish to complain about the research, report a concern or flag a safeguarding incident?

It you are concerned or unhappy with any aspect of the research and wish to make a complaint, please contact **Professor Sarah Salway** (s.salway@sheffield.ac.uk) in the first instance. If you feel your complaint has not been handled in a satisfactory way you can contact the Head of the Department of Sociological Studies [Professor Nathan Hughes n.hughes@sheffield.ac.uk]. If the complaint relates to how your personal data has been handled, you can find information about how to raise a complaint in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/data-protection/privacy/general .

If you wish to make a report of a concern or incident relating to potential exploitation, abuse or harm resulting from your involvement in this project, please contact the project's Designated Safeguarding Contact Professor Scott Weich (s.weich@sheffield.ac.uk). If the concern or incident relates to the Designated Safeguarding Contact, or if you feel a report you have made to this Contact has not been handled in a satisfactory way, please contact the Department of Sociological Studies [Professor Nathan Hughes; Nathan.Hughes@sheffield.ac.uk].and/or the University's Research Ethics & Integrity Manager (Lindsay Unwin; l.v.unwin@sheffield.ac.uk)

Contacts for further information.

Lead Researcher: Charli Colegate (ccolegate1@sheffield.ac.uk) Telephone: 07903866777
Primary Supervisor: Professor Sarah Salway (s.salway@sheffield.ac.uk)
Secondary Supervisor & Designated Safeguarding Contact (DSC): Professor Scott Weich (s.weich@sheffield.ac.uk)

University Address:
Department of Sociological Studies
University of Sheffield
Elmfield Building
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Sheffield
S10 2TU

Telephone: +44 114 222 6400

Appendix 6 –Participant Information Sheet (Professional)

Motherhood and Severe Mental Illness: a qualitative study of stigma, 'risk' and access to perinatal mental healthcare

Information Sheet for health and care practitioners

Hello, my name is Charli Colegate and I am inviting you to take part in a piece of research that I am conducting for my PhD at the University of Sheffield. Before you decide whether or not take part, it is important for you to 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.

Please ask me, Charli (the lead researcher) if there is anything that is not clear or if you would like more information. Take all the time you need to decide whether or not you wish to take part. Thank you for reading this.

What is the project's purpose?

The aim of this project is to understand more about motherhood and severe mental illness. Specifically, I want to understand more about how women make decisions about motherhood if they have a personal or family history of severe mental illness. In addition I am interested in how professionals, women and their families can better understand each other to make sure that women from all walks of life get the help they need to thrive.

I will be speaking with professionals who provide support, treatment and advice to women of reproductive age with a personal or family history of severe mental illness. The project will also entail speaking with women with a personal or family history of severe mental illness to understand their experiences. I will be collecting data throughout 2022 and early-mid 2023.

Why have I been chosen?

You have been chosen because your particular professional background and experiences are relevant to the study's objectives.

Do I have to take part?

It is up to you to decide if you want to take part or not. If you want to take part, you will be asked to sign a consent form to keep with a copy of this information sheet.

If you decide to take part now and change your mind later, that's OK. You can withdraw at any time up until 1st August, 2023. You don't have to give a reason and there will be no negative consequences. If you wish to withdraw after the focus group has been completed, please contact me, Charli Colegate (ccolegate1@sheffield.ac.uk). The reason why you are not able to withdraw after the 1st August 2023 is that your data may have already been analysed and be part of a larger group of data.

You should also be aware that if you choose to participate in this research, this is not a legally binding agreement nor is it creating an employment relationship between you and the University of Sheffield or the partners that have funded this research.

What will happen to me if I take part? What do I have to do?

If you decide to take part, you will participate in a focus group discussion with up to 4 other professionals, likely working in different roles to you, for up to one and a half hours. This may be shorter depending on how much you and others have to talk about and how much time you have available.

The researcher will ask questions about your professional experiences, your views, perceptions and opinions on various topics. These topics include:

- Your experiences of caring for women with a personal or family history of severe mental illness
- What 'risk' means to you at work
- Your experiences of working with other professionals
- What you think might make care better for women from different backgrounds
- What you think stops women from getting the best care and support they can

Some of these topics might not be relevant to you or your work, or you might not want to talk about them, and that's OK. You do not have to answer any question you do not want to.

Will I be recorded, and how will the recording be used?

You will be asked for your permission to record the focus group discussion. Before beginning the recording, the I will say 'I'm going to start the recording now'. The recording will only ever be listened to by me and a University Approved transcriber, who will turn the recording in to a written document. Having a written document of the focus group discussion makes it easier for me to analyse. No one outside the research team (except the transcriber) will have access to the original recording and it will not be used for any other purpose. It will be deleted as soon as the transcription has been completed.

What are the possible benefits of taking part?

There are no immediate benefits to people participating in the project, however, it is hoped that professionals might find the experience of hearing about others' practice and sharing insights from their own would be helpful.

As a token of thanks, and to help cover your expenses of participating, you can opt to accept a £25 Love2Shop voucher.

What are the possible disadvantages and risks of taking part?

Although you may work in healthcare or social work day-to-day, you may find the nature of the topics to be discussed in the focus group upsetting. You are able to withdraw from the discussion at any time

You may find that you may not become upset right away, but talking about particular things might affect you in the days after the focus group. The researcher may follow up with you in this period to check to see how you are doing.

For participants who wish to accept the token of thanks and who are in receipt of benefits (e.g: Universal Credit), there may be a potential risk to your payments. If this applies to you, there is a free and confidential Benefits Advice Service you can use to find out more information. Please contact the lead researcher should you have any questions about this.

Will my taking part in this project be kept confidential?

The 'ground rules' of participating in the group state that all discussions must be kept confidential. When participating online, you can choose to keep your camera on or off, to use your name, identify your place of work etc. Others participating in the focus group will be aware of your identity, to whatever extent you have chosen to disclose it.

All the information that we collect about you during the course of the research will only be accessible to members of the research team. Their contact details are given at the end of this sheet.

I will take great care to ensure that you will not be able to be identified in any reports or publications by removing identifying information (e.g: names of places of work, towns/cities). I will use your profession and region of work when attributing direct quotes in reports/publications (e.g: Specialist Midwife, North of England; Health Visitor, South East England). However, it should be made clear that it is possible that others who are familiar with your work may be able to identify you from details that you have given. The researcher is unable to guarantee complete anonymity in that regard.

How will the research team manage any criminal or other disclosures made during the focus groups?

As discussions will centre on professional practice, it is anticipated that disclosures of a criminal nature are not at all likely. In the highly unlikely event participants make a disclosure of criminal activity or gross misconduct in the course of the focus group. This will immediately be reported to the project's supervisors and safeguarding lead (who is a senior clinician). They will advise on further action which will be dependent on the nature of the disclosure. E.g: disclosure of gross misconduct may be reported to the relevant parties at the participant's employing trust, or another relevant body such as GMC.

What is the legal basis for processing my personal data?

According to data protection laws, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

'As we will be collecting some data that is defined in the legislation as more sensitive (information about racial or ethnic origin; sexuality; health), we also need to let you know that we are applying the following condition in law: that the use of your data is necessary 'for archiving purposes in the public interest, scientific research purposes or statistical purposes' (9(2)(j)).

How will we use information about you?

We will need to use information from you for this research project. This information will include your name, contact details and any responses to questions you give in the focus groups. This information will be used to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number. We will keep all information about you safe and secure. You can find out more about how we use your information by asking a member of the project team, or by sending an email to the Data Protection Officer at the University of Sheffield (dataprotection@sheffield.ac.uk)

What will happen to the data collected, and the results of the research project?

Recordings from the focus group will only be accessed by the research team and a University approved transcriber. Recordings will be destroyed as soon as the transcripts are finalised. Transcripts will only be accessed by the research team and will be kept secure by being stored in encrypted files on university systems. "Data keys" (how data can be linked back to an individual) will be destroyed as soon as it will not affect the purposes of the research. 'Pseudonymised' (speakers identified by profession and region of work only) transcripts will be kept until the PhD is completed and the research team have submitted the findings for publication. I anticipate this may be by the end of 2025.

The results of the research are not likely to be published until after the completion of the PhD in February 2024. However, I will circulate a brief summary of key findings to participants in early 2024. Once my thesis has been archived, I will share a link with you where you can download a copy of the thesis. You will not be identified by your real name in any report or publication.

Who is the Data Controller?

The University of Sheffield will act as the Data Controller for this study. This means the University is responsible for looking after your information and using it properly.

Who is organising and funding the research?

This research is jointly funded by the NIHR School for Public Health Research (SPHR) and the NIHR Applied Research Collaboration (ARC) for Yorkshire & Humber.

Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by the Department of Sociological Studies [REF: 043513].

What if something goes wrong and I wish to complain about the research, report a concern or flag a safeguarding incident?

It you are concerned or unhappy with any aspect of the research and wish to make a complaint, please contact **Professor Sarah Salway** (s.salway@sheffield.ac.uk) in the first instance. If you feel your complaint has not been handled in a satisfactory way you can contact the Head of the Department of Sociological Studies [Professor Nathan Hughes n.hughes@sheffield.ac.uk]. If the complaint relates to how your personal data has been handled, you can find information about how to raise a complaint in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/data-protection/privacy/general .

If you wish to make a report of a concern or incident relating to potential exploitation, abuse or harm resulting from your involvement in this project, please contact the project's Designated Safeguarding Contact Professor Scott Weich (s.weich@sheffield.ac.uk). If the concern or incident relates to the Designated Safeguarding Contact, or if you feel a report you have made to this Contact has not been handled in a satisfactory way, please contact the Department of Sociological Studies [Kate Weiner - Head of Postgraduate Research; k.weiner@sheffield.ac.uk].and/or the University's Research Ethics & Integrity Manager (Lindsay Unwin; l.v.unwin@sheffield.ac.uk).

Contacts for further information.

Lead Researcher: Charli Colegate (ccolegate1@sheffield.ac.uk) Telephone: tbc
Primary Supervisor: Professor Sarah Salway (s.salway@sheffield.ac.uk)
Secondary Supervisor & Designated Safeguarding Contact (DSC): Professor Scott Weich (s.weich@sheffield.ac.uk) Telephone: tbc

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Appendix 7 – Consent form (Women)

NIHR | School for Public Health Research NIHR | Applied Research Collaboration Yorkshire and Humber

Consent Form : Women

Please tick the appropriate boxes	Yes	No
Taking Part in the Project		
I have read and understood the project information sheet (dated 01/02/2022) and the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)	☐	☐
I have been given the opportunity to ask questions about the project.	☐	☐
I agree to take part in the project. I understand that taking part in the project will include: • completing a brief questionnaire • being interviewed • the interview being recorded	☐	☐
I understand that by choosing to participate in this research, this does not create a legally binding agreement nor is it intended to create an employment relationship with the University of Sheffield.	☐	☐
I understand that my taking part is voluntary and that I can withdraw from the study at any time before 1st December 2022; I understand that I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.	☐	☐
How my information will be used during and after the project		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project – unless there is a concern about my safety or welfare.	☐	☐
I wish to claim the token of thanks (£25 Love2Shop Voucher) offered and I understand my name/email/address (ONLY) will be shared outside the research team so I can receive this.	☐	☐
I wish to receive further information about the progress of the research, its findings and project outputs	☐	☐
I understand and agree that my words may be quoted in publications, reports, workshops, web pages, and other research outputs. I understand that my real name will not be used in these outputs.	☐	☐
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, but only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
So that the information you provide can be used legally by the researchers		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	☐	☐

Name of participant [printed] Signature Date

Name of Researcher : Charli Colegate Signature Date

Appendix 8 – Consent form (Professionals)

NIHR | School for Public Health Research NIHR | Applied Research Collaboration Yorkshire and Humber

Consent Form: Health and care practitioners

Please tick the appropriate boxes	Yes	No
Taking Part in the Project		
I have read and understood the project information sheet (dated 01/02/2022) and the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)	☐	☐
I have been given the opportunity to ask questions about the project.	☐	☐
I agree to take part in the project. I understand that taking part in the project will include: • taking part in an interview • the discussion being recorded	☐	☐
I understand that by choosing to participate as a volunteer in this research, this does not create a legally binding agreement nor is it intended to create an employment relationship with the University of Sheffield.	☐	☐
I understand that my taking part is voluntary and that I can withdraw from the study at any time before 31st August 2023; I understand that I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.	☐	☐
How my information will be used during and after the project		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project – unless there is a concern about my safety or welfare.	☐	☐
I wish to claim the token of thanks (£25 Love2Shop Voucher) offered and I understand my name/email/address (ONLY) will be shared outside the research team so I can receive this.	☐	☐
I wish to receive further information about the progress of the research, its findings and project outputs	☐	☐
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that my real name and place of work will not be used in these outputs.	☐	☐
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, but only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
So that the information you provide can be used legally by the researchers		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	☐	☐

Name of participant [printed] Signature Date

Name of Researcher : Charli Colegate Signature Date

Version 1 – 20/1/2023

Appendix 9 – Interview Follow up sheet (Women)

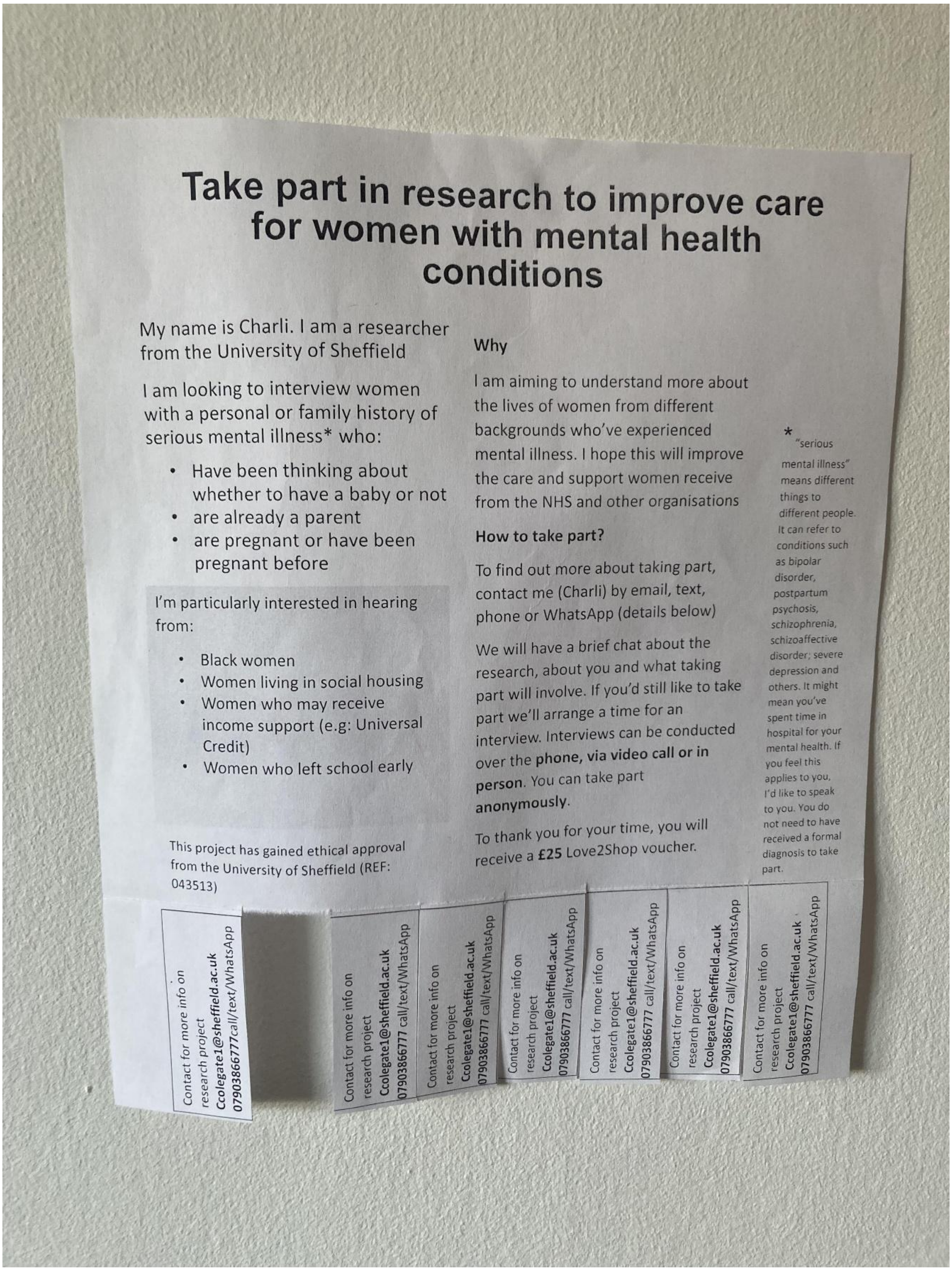
Thank you for participating in the interview this week, your contribution to the project is greatly appreciated. If you indicated that you'd like to hear about study findings, I'll be in touch toward the end of the year. If you wished to accept the token of thanks (Love2Shop voucher) for participating in the project, it will be sent to you shortly. Once received, please let me know it has arrived. If you have not received it within 2-3 weeks of our conversation, please don't hesitate to contact me (Charli), I will chase up.

Finally, if you found the interview distressing and are in need of support, I encourage you to speak to your GP or any other appropriate health professional who is responsible for your care. In addition, you and members of your family may find some of the following sources of support helpful:

- **Tommy's**: https://www.tommys.org/about-us/our-people/tommys-midwives Tommy's midwifery-led pregnancy line is available for anyone worried about mental health in pregnancy (0800 0147 800)
- **Action on Postpartum Psychosis**: http://www.app-network.org/ APP is dedicated to supporting women and families affected by postpartum psychosis (PP).
- **Bipolar UK:** http://www.bipolaruk.org.uk/ Bipolar UK is the national charity supporting people affected by bipolar.
- **Sheffield Maternity Cooperative** – SMC works to build care, support and community for pregnancy, birth, postpartum, abortion and loss. They run regular events online for anyone to attend – regardless of whether they live in Sheffield.
- **The Samaritans**: http://www.samaritans.org/ The Samaritans is a registered charity aimed at providing emotional support to anyone in emotional distress, struggling to cope, or at risk of suicide throughout the United Kingdom and Ireland, often through their free telephone helpline (116 123)
- **The Motherhood Group**: https://www.themotherhoodgroup.com/ is a social enterprise dedicated to sharing and supporting the Black maternal experience through events, workshops, peer support, projects and advocacy. They run a free counselling service to help new mums with their mental health problems. Contact info@themotherhoodgroup.com
- **Black Minds Matter UK:** https://www.blackmindsmatteruk.com/ this organisation connects Black individuals and families to free mental health services.
- **Maternal Mental Health Alliance Members List:** https://maternalmentalhealthalliance.org/about/members/list-of-member-organisations/ includes the contact details of many other charities and local organisations which may be relevant to you where you are.

Project contact details for further information, questions or concerns.
Charli Colegate, Lead Researcher (ccolegate1@sheffield.ac.uk) or
Professor Scott Weich, Secondary Supervisor and Designated Safeguarding Contact (DSC) (s.weich@sheffield.ac.uk)

Appendix 10 – Examples of Promotional Materials



Can you support research into better care for women with Severe Mental Illness*?

I am looking for practising:

- Health Visitors
- Midwives
- staff of any professional background working within specialist perinatal mental health teams

to **take part in a focus group.**

I would like to speak to you about your work if you have **provided care to women with a personal or family history of severe mental illness (SMI)** who:

- Have been thinking about whether to have a baby or not
- are pregnant
- are already a parent

Why

As part of my PhD, I am aiming to understand more about the perinatal care women with SMI receive. I hope this will help strengthen the care and support women receive.

- **How to take part?**

To find out more about taking part, contact me (Charli) on: ccolegate1@sheffield.ac.uk or call/text/WhatsApp on 07903866777

We will have a brief chat about the research, about you and what taking part will involve. If you'd still like to take part, you will be allocated to a group at a time that best suits you. Focus Groups will be conducted online.

To thank you for your time, you will receive a **£25** shopping voucher and a note of attendance for your CPD portfolio.

* "severe mental illness" is used in this study to refer to conditions such as bipolar disorder, schizophrenia, schizoaffective disorder; postpartum psychosis, severe depression, PTSD, eating disorders, personality disorders and others.

Charli Colegate, Doctoral Researcher

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Appendix 11 – Focus Group Guide

FOCUS GROUP GUIDE (Professionals)

Formalities/Consent

- Thank participant for their time, check time restrictions
- Explain structure of focus group
- Explain what to do if internet cuts out
- Background to study and summary of data collected so far (Women)
- Take consent (Verbal/Form)
- Cover Groundrules and Introduce expectations: you speak more than me, speak to each other, will be taking notes (but am listening), no right or wrong answers, can repeat or come back to questions. Be respectful, please don't answer emails etc.
- Ethical considerations: Discuss potential for difficult emotions, taking breaks, right to not answer questions etc.

[RECORDER TURN ON]

Introductions

– could you please say your name, role, where you work and a few words about what your working week has been like this week?

*[***If detail a bit scant***]* Can I ask you each to share a bit about your work with women who've got a history of/are experiencing SMI?

VIGNETTES (Pick 1, alternate)

Introduce vignette (share on screen, give a few mins to read) Then ask Q's below:

Mary is 22 years old. This is her first baby. She has been seen by secondary mental health services regularly over the past 7 years. She first came into contact with mental health services at 15 when she was diagnosed with OCD. She no longer has this diagnosis and has been diagnosed with different conditions now. She works part-time as a carer. Her partner was present for earlier appointments but hasn't been there for the past few. Mary doesn't really explain	**Tana** is 37 years old and has two children under the age of 10. This is her 3rd baby. She had no history of mental illness prior to having her first child in her late 20s, where she experienced postpartum psychosis. During her second pregnancy she was closely monitored but did not experience any significant mental illness before or after. She has struggled with anxiety off and on since first becoming a mum. She works 4 days a week in a professional role. Her partner has attended appointments when he is able.

- Tell me about the last time you saw a patient like this?
- What would your encounter with them look like on a really good day or a really bad day? (*** and that is a Good/Bad day for you… not for Mary/Tana)

MAIN TOPIC GUIDE

ACCESS

- What are the difficulties that are getting in the way of your team doing its work at the moment? (Prompt: has this changed over time at all?)
- Are there things you find particularly challenging about working with women with SMI at the moment? (Prompt: Are there particular kinds of patients, or mental health problems that are trickier for e.g?) (PROMPT: has this changed since you started practicing)
- Are there women or families that you think might be overlooked in your service/area currently and why?

RISK

- When women are identified as being at high risk of becoming (more) unwell perinatally, what would you and your team do? (PROMPT: Can you tell me more about the 'perinatal red flags')
- What are the things that influence your decisions about whether further interventions/referrals or escalations are made in regard to women's care?
- What do you think women with a history of SMI are most worried about in relation to motherhood**?**

STIGMA: Stigma came up a lot in my discussions with women

- Where do you think the stigma the women you work with comes from?

Closing questions

- In my study [reiterate focus] Is there anything that I've not asked you that you think I should've asked you… Or is there anything else you think is important to talk about that we haven't discussed?

- **If you had the power to change just one thing – to make sure <u>all</u> women were getting the help and support they needed?** [thinking big or small… are there things that might make care better for Black women for example, or women living in poverty]… I'll give you a minute to reflect on that and then we can come back to discuss…

Anything else?

[STOP RECORDING]

Thank participants, next steps. [End call]