

**PREGNANCY, WOMEN'S MENTAL
HEALTH AND SOCIO-ECONOMIC
DEPRIVATION: A PARTICIPATORY
QUALITATIVE STUDY**

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ABSTRACT

Background/objectives

Women's mental health during pregnancy is important for individual and family well-being. British public health and academic policy and guidance promotes service user involvement in health care and research, however collaborative research remains underrepresented in literature relating to pregnant women's mental health. The aim of this participatory research was to explore women's and professionals' perspectives on mental health and on services for pregnant women.

Method

This qualitative research was undertaken with the involvement of three community members who had firsthand experience of mental health problems during pregnancy. All members of the team were involved in study design, recruitment, data generation and different stages of thematic analysis. Data were transcribed individual and group discussions with 17 women who self-identified as experiencing mental health problems during pregnancy and 16 professionals who work with this group. Means of establishing trustworthiness included triangulation, researcher reflexivity, peer debriefing and comprehensive data analysis.

Findings

Commonalities and differences between women's and professionals' perspectives were examined with particular reference to contexts of relational, systemic and ecological conditions in women's and professionals' lives. There were significant areas of commonality including:

- Factors that undermine women's mental health during pregnancy
- Levels of formal and informal support available to women
- Professionals' knowledge and organisational pressures
- Accessibility of specialist services
- What is needed to support women's mental health

Conclusions and Recommendations

Women's mental health is predominantly undermined or supported by relational, experiential and material factors. The local context of socio-economic deprivation is a significant influence on women's mental health and service demand, capacity and resources. Recommendations are made in relation to community and service developments, staff support and training, and future research.

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CHAPTER ONE

INTRODUCTION

1.1. General Overview

This thesis presents a participatory, qualitative study of women's mental health during pregnancy in a British locality with high levels of socioeconomic deprivation. A team of co-researchers carried out the study, which involved generating qualitative data with women who had experience of mental health problems during pregnancy, and professionals who worked in the services that these women used. The study was undertaken between 2008 and 2012.

1.2. Rationale for Undertaking this Project

The original impetus for this research came from my experience of working in the researched locality as a clinical psychologist in National Health Service (NHS) Adult Mental Health services between 2002 and 2007. I frequently worked with women who were at one stage or another in a life-cycle of violence, abuse, neglect and emotional harm. Sometimes they were young adults still surviving in, or just leaving abuse in their families of origin. Sometimes they were women with young children, escaping violent relationships. Sometimes they were older women looking back at their own traumatic lives and expressing regret about their lives and their inability to prevent their own children from experiencing neglect or abuse. Sometimes those women's adult children were also receiving our services, and sometimes their young children were looked after by local authorities or receiving services from the Child and Adolescent Mental Health Service.

The social context of many service users' lives was one of poverty, poor housing, difficult educational experiences, limited opportunities, experience of powerlessness and low aspirations. I was aware that the individual work that I could do with these women, in my role as an NHS clinical psychologist, often involved trying to help them make sense of the past and rebuild parts of their lives in some small ways. This work may have, at best, occasionally led to a transformation in a person's life. Most often it was focused on amelioration of harm that had existed in their lives for many years. It was work that positioned me as expert helper, and the service user as recipient of treatment. In spite of the expertise invested in my role, my overwhelming feeling was one of powerlessness against a tide of distress, in which no amount of supply could meet the ever-increasing demand, and increasing waiting times for therapy. Therapy may have made some inroads to helping individuals feel more empowered but it was often hampered by systemic barriers and damaging ecological conditions within their lives.

Alongside my psychological work in the NHS mental health service, were a few opportunities for research, research methods teaching, and to supervise small projects aimed at promoting mental health in the locality. These opportunities, following my earlier interests during clinical psychology training, gave me access to a network of colleagues across the UK who were active in critical and community psychology research and action. These colleagues were generous in offering support and critique in equal measure, and gave me opportunities to think about current and alternative ways of working. I had opportunities to hear about how colleagues had moved away from ameliorative work in the expert provider role, and worked towards something that was collaborative and transformative (for example: Bostock, Plumpton & Pratt, 2009; Carrick, Mitchell & Lloyd, 2001; Fryer & Fagan, 2003;

Kagan, 2007). I began to think about working on a project that had a broader scope and a larger scale than individual clinical work could have. I realised that within the NHS, this work would always be squeezed into the ever-shrinking spaces between the demands of a clinical and increasingly managerial workload.

From my clinical experience, professional reading and previous research (Franks, Gawn & Bowden, 2006; Franks, Henwood & Bowden, 2007; Franks, Gawn & Bowden, 2007), I was aware that a range of social, material and relational conditions were involved in the generation of emotional distress. From a health promotion perspective it had also seemed useful to consider where would be a useful place to intervene in a cycle of intergenerational patterns of despair (Bournell, 2011).

Through awareness of the local provision of mental health support for women with new babies, it was apparent that the service focus on mothers' and babies' wellbeing did not extend to the period prior to birth, although my clinical experience suggested that maternal mental health problems existed through the lifespan. Examining the literature has given this impression substance, and extended my understanding and knowledge of the field of antenatal mental health and the theory and practice of participatory research.

A significant issue in this research relates to the production and ownership of knowledge. In the case of this project, the knowledge in question relates to women's mental health during pregnancy. There is a large quantity of academic and professional literature in this area, and yet, very little is heard of the voices of women who have experienced mental health problems firsthand. The qualitative research addressing this subject is mostly undertaken by professional or academic researchers, and is not explicitly participatory research. The research team undertaking this research have agreed that it is important to explore mental health in

pregnancy from the perspectives of the women affected, and for women to be included in the research process. The development of a research team made up of people with different perspectives, knowledge and skills is intended to address the bias in current literature, which approaches the subject of mental health from professional and academic perspectives.

1.2.1. Members of the research team

The research team was made up of one PhD student, three women from the locality who have experience of mental health problems during pregnancy with three academic supervisors from the University of East Anglia. Not all community co-researchers have given their consent to be identified within this thesis. Details of how co-researchers became involved in this research are given in Chapter Five, section 5.3. Two co-researchers have used community and NHS Mental Health Services in the past, and one had experienced domestic abuse during pregnancy, but did not use services in relation to distress caused by this experience. All community co-researchers have more than three children, two were pregnant at the time of starting this research, and one had had a baby in the previous year.

1.3. Local Context

This research was undertaken in a small coastal town in East Anglia that is identified as having high levels of social and economic deprivation. The population of just under 100,000 is predominantly White/British (92.8%), White/Other (3.6%) and under 1% of any other single ethnic group. In years prior to 2000, the proportion of White/British people in the population was greater, and the very small increase in White/Other groups in the population is the result of economic migration from across Europe, including the 2004 European accession states of Cyprus, Czech

Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovakia and Slovenia (Franks, Gawn & Bowden, 2006). Employment within the town varies throughout the year, with seasonal unemployment rates from 2009 to 2012 fluctuating between approximately 5% during the summer and between 6% and 7% in the winter. The largest numbers of employee jobs are in the Public Administration, Education and Health Sectors (30%), with more than half this proportion in Retail and Wholesale (18%). Other significant sectors are in tourism-related businesses (17.5%), finance, IT and other business activities (15%) and manufacturing and construction (13%) (Office of National Statistics, 2013).

Of the 11 political Wards in the town, 10 are within the most deprived 10% of wards in the East of England. Many measured levels of inequality and health outcomes are significantly poorer than the averages across the region and the rest of England, including deprivation; numbers of children in poverty; low educational achievement; smoking during pregnancy; breast-feeding initiation; physical activity in childhood; teenage pregnancy; adult smoking; incapacity benefits for mental illness; hospital stays for alcohol related harm; people diagnosed with diabetes and excess winter deaths (Association of Public Health Observatories & Department of Health, 2010). Further statistics show that life expectancy at birth is approximately two years shorter than that of the regional average; that there is a higher rate of severe mental illnesses as registered by General Practices; the Comparative Illness and Disability Ratio is higher than the regional average and the proportion of people permanently unable to work due to ill-health and disability is greater than the regional and national averages (Hill, Blundell & Mills, 2009). Many of these outcomes relate to underlying deprivation and social inequalities, or the 'causes of the causes' (Marmot, 2005).

This locality presents a valuable setting for research into pregnant women's mental health in an area with atypically high levels of social and economic deprivation in the Eastern Region. The purpose of this research is both the production of transferable knowledge relating to the impact of deprivation on pregnant women's mental health, and useful contextualised knowledge to inform local developments for the promotion of women's mental health during pregnancy.

1.4. Overview of Chapters

This thesis is made up of 9 chapters.

1. This introductory chapter includes information about the background to the research, including the context of the place in which the research was conducted and provides an overview of the whole thesis.
2. Chapter Two explores the theoretical foundations that informed the research with a rationale of the importance of this in relation to the role of researcher reflexivity in qualitative research. The influences examined in this chapter include feminist approaches to knowledge, personal experience, clinical psychology as a profession, critical and community psychology as an approach to psychology and influential ideas from systemic thinking.
3. Chapter Three explores the broad base of knowledge within the academic literature relating to women's mental health during pregnancy. This is largely informed by quantitative research.
4. Chapter Four delivers a more focused review of qualitative literature that examines women's experiences of mental health during pregnancy. This literature includes studies that explore women's experiences of particular mental health problems, and life experiences that have had a negative impact on their mental health.

5. Chapter Five presents a rationale for using participatory research methodology and connects this approach to the underpinning feminist and critical psychological frameworks outlined in Chapter Two. The remainder of this chapter outlines the method used to carry out the study, explores issues of methodological rigour and reports ethical considerations.
6. Chapter Six presents findings from the data generated with women who have had experience of mental health problems during pregnancy.
7. Chapter Seven presents findings from the data generated with professionals who work with pregnant women who experience mental health problems.
8. Chapter Eight comprises two main parts. Part one examines the importance of findings from Chapters Six and Seven and the relationships between the two sets of data. This chapter includes discussion of the light that is shed on the research questions by the analysis of data presented in findings chapters. In the second part of this chapter, matters of methodological rigour are discussed, including the strengths and limitations of the study, with particular reference to the quality criteria that are presented in Chapters Two and Five.
9. Chapter Nine provides an overview of the main conclusions of this research and presents recommendations for professional practice training and support, community development and future research.

CHAPTER TWO

THEORETICAL FRAMEWORKS

2.1. Overview

Philosophical and theoretical frameworks for the research were articulated at the outset with an expectation that there would be ongoing development throughout the research process.

Articulating these frameworks and the contexts for the research at the outset has served a number of functions:

- Making explicit at an early stage some of the initial guiding principles as a point of reference when encountering difficult decisions. This was an evolving set of principles as the project progressed
- An account for reflexive purposes to illuminate the process of change for me as a researcher
- To provide a reference point to both orient the reader to the initial guiding values and principles of this research, and also to allow the reader to follow the progression of the research from its outset through the processes of change

2.2. Reflexivity in Qualitative Research

It was important for me to reflect on my position at the outset of this project in order to undertake a situated and reflexive piece of research. Mauthner and Doucet (2003) argued that reflexivity relates not only to the researcher's social location and emotional responses to the researched, but also her theoretical location and the

influence that this brings to bear on her interpretations of the data and the conclusions that she reaches.

The approach that I took to this research assumed that the role of the researcher is important in the construction of the whole process of the research, from the development of the broad area of research and the initial questions, through the design, undertaking, analysis and dissemination (Mason, 2002). As a participatory research project, this becomes more complex, as these questions needed to be addressed with a number of co-researchers, rather than independently determined.

As the person who initiated this research project, however, from the outset many of the decisions that shaped the research were informed by my values, experiences, and philosophical standpoint. There were aspects of the research, decided by me and the academic supervisory team, which would be problematic to be open to negotiation.

Examples include the location of the research, the broad subject of antenatal mental health, and the participatory nature of the approach. As a consequence of these decisions, the research was constrained to a particular set of directions within a participatory model.

In addition to the initial practical decisions, the conceptual work in considering frameworks for the production of knowledge has shaped the development of the independent academic task of producing a PhD thesis. The thesis is necessarily an intellectual work that is the sole responsibility of the post-graduate researcher who submits it for evaluation. This requirement presents a set of dilemmas for a research project that is undertaken as a participatory endeavour. This research was conceptualised as a community project, originally initiated by the author, but which had aspirations for joint ownership, cycles of the action research process, and sustainability beyond the end of the PhD process. The PhD, in contrast, was a time-

limited academic project that located under the umbrella of the broader community project. This rationale placed this PhD in a relationship to the community project that is similar to other PhDs undertaken as one part of a larger programme of research within an academic setting.

The PhD and community project elements of this research have had different requirements in relation to demonstration of quality and value. The standards expected for the community project have been subject to negotiation with the participants. In contrast, the standards expected for a PhD thesis are pre-defined within an academic institution. There is a clear differential in power between the PhD student and the university that awards the PhD. Conceptualisations and potential implications of power as they relate to this research are discussed in greater detail below, however, it is important to note at this point that there were different constraints placed upon a postgraduate researcher than there should necessarily be upon participants in a community research project. This difference has produced one of the many tensions anticipated in undertaking PhD within a participatory community research project. Amongst the requirements that may be more pertinent within an academic context are those related to academic standards of quality in research. As an academic researcher, the approach I have brought to this qualitative research emphasised participation, conceptual rigour and philosophical coherence as means of establishing quality and relevance (Mason, 2002; Yardley, 2000). Further details on frameworks for establishing quality in qualitative research are provided in Chapter Five. In contrast with the PhD thesis, the community research project needed to develop a more collaborative and negotiated set of standards against which it is judged. These are based on usefulness and local relevance of the research, although there have also been issues to consider regarding what constitutes quality

from the perspective of community members. There are likely to be areas of overlap and complementarity as well as tensions within these different frameworks for quality.

2.3. Epistemological and Ontological Perspectives in Qualitative Research

Some researchers approach the question of epistemology and ontology with a degree of scepticism, arguing that as psychologist or nurse researchers, or as community researchers, for example, we are not philosophers and need not concern ourselves with solving problems of philosophy in our research (Seale, 1999). Others have expressed a wish to move beyond questions of epistemology and ontology to locate themselves within a more pragmatic position, arguing that the philosophical questions are simply not of interest or relevance to their work (Yardley & Bishop, 2007). They argue that the best evaluation of quality within qualitative research is a pragmatic one, that is, whether the research works in shedding light on the research questions. This argument can be seen as rather circular, however, and therefore unconvincing. How are we to know ‘what works’ from a pragmatic sense, without an underlying framework by which to judge the quality of the research itself, and by extension, the answers that it produces?

In contrast, Mason (2002) emphasises the importance of establishing the researcher’s ontological and epistemological position early on in the research process. She argues that clarity about these issues, and coherence within the overall research, are essential to developing a good research design and therefore producing a useful and meaningful piece of research. The importance of clarity and coherence in relation to ontology and epistemology within qualitative research becomes clearer when we consider the problems that can arise when there is a lack of clarity.

Without being clear about the frameworks of knowledge, it is difficult to justify and defend the knowledge that is being produced. Weakness on this can undermine the claims that are made from the findings of research, and render it vulnerable to criticism that diminishes the value of the findings. This, like other forms of poorly designed or executed research could be seen as unethical in relation to its potential to waste resources including time and good-will of participants.

2.4. Qualitative Research Methods and Epistemology - An Overview

Within many of the qualitative research traditions, the notion of a simple and direct relationship between the knowable world and its observers has been contested (Mason, 2002; Parker, 2005; Strega, 2005). The traditional, positivist version of science has promoted the assumption that it is possible to directly observe and measure the objects of scientific study. Thus it has been considered possible to directly know the reality of the world as an objective observer (Moses & Knutsen, 2007). For many researchers, this is a taken-for-granted assumption, and without consideration of the alternatives, it is often the position that is taken up by default. However, many alternative epistemologies contest such a direct and simple relationship between the knower and the known. They situate the knower in a context of social, political and personal histories, and argue that objective knowledge is theoretically and ethically problematic as a consequence (for example: Strega, 2005). These challenges come from a range of philosophical directions. Because they are the very frameworks within which an argument about knowledge is situated, the foundation upon which the claims of the research are made, it is important to be clear about what they are.

A further problem that can arise when epistemology is not fully considered throughout the project is that criteria used to judge the quality of the research are

inappropriate to the methodology and declared epistemology (Willig, 2001). These issues will be discussed further in a subsequent section of the Methodology chapter focused on epistemology and quality in qualitative research (5.5.1).

In a complex world, which often defies attempts at generating the theoretical and epistemological coherence described above, dilemmas arise from the intersection between different foci of attention within a research project. Amongst the dilemmas and tensions within this research project are many intersecting priorities around how the production of knowledge is conceptualised. From the perspective of an academic researcher, navigating these multiple dimensions and their relationship to each other is a complex process. Amongst the dimensions to be explored are questions about: what knowledge is of practical use in different settings; what knowledge is valued and by whom; how do power, gender and social position relate to the production of knowledge; how are materiality and discourse related within the production of knowledge (particularly in relation to the production of knowledge related to women's embodied experience of pregnancy); what types of knowledge are of interest (for example, representational reflexive and relational knowledges (Park 2001)) and so on. These questions seem to defy a simple decision regarding whether to work within a particular philosophical framework. They demand further detailed thought and exploration in order to be of use in matters of design, analysis, and establishment of criteria by which to judge the quality of the research.

Philosophical issues produce additional tensions and dilemmas within a participatory project, where there may not be a shared set of assumptions about the production of knowledge and the nature of the social world that is explored within the research (Gaventa and Cornwall, 2001). The questions of imbalances of power and differing agendas must be considered in attempting to balance the different priorities brought

by different members of the research team. As I will argue below, there is no simple solution to many of the tensions that arise within research such as this; however, ‘boundary critique’ and ‘process philosophy’ (Midgley, 2000) are theoretical frameworks that offer the resources examining these tensions and developing practical arrangements for action. These are outlined below in section 2.6.6.

For a researcher embedded within a social context, there will be inevitable difficulties in identifying the different ways in which the rules and assumptions of that social context impinge on the activity of doing research. However, my intention was to remain alert to the impact of context on my own behaviour and the behaviour of others in shaping the process of the research. In doing this, I have relied on a number of resources, including the critical lenses through which I reflect upon my activities and language, and the opportunities afforded by supervision and peer discussions in relation to the ongoing work.

2.5. Feminisms

As one of the above-mentioned lenses for reflection, critical feminist theory has been a guiding principle within this research, and consideration needed to be given to how feminisms relate to understandings about the production of knowledge. The term ‘feminisms’ points to the diversity of perspectives within feminist thought, including indigenous scholars’ and critical race theorists’ challenge to White Western versions of feminism that are Euro-centric and fail to acknowledge and theorise the different forms of oppression of women existing within the majority world (Strega 2005).

Whilst this research was undertaken in an area in England where the population is predominantly White, there have been recent demographic changes in the area, with the arrival of migrants from continental Europe and Africa. Thus a previously very heterogeneous population has recently become more diverse, and sensitivity to these

changes needed to be incorporated into the research. In addition to these recent changes, there are significant differences within the area in relation to educational and class privilege. Critiques of the dominant perspectives of White, Western feminism also relate to class differences within ethnically homogeneous groups, where the assumptions of women with positions of relative privilege, education and access to material resources need to be subject to reflection and critique.

Henwood, Griffin & Phoenix (1998) explored the 'simultaneously overlapping and contradictory domains of theorising' (p. 6) across feminist and poststructuralist approaches to knowledge and research. At the core of this tension is the difference between feminist standpoint approaches that prioritise a framework informed by women's material and social experience and poststructuralist emphasis upon attention to the fragments, inconsistencies and contradictions. Strega (2005) highlights the similarities rather than the differences between feminist and poststructuralist positions. Her focus is upon the common rejection of Enlightenment dualisms (masculine/feminine, rational/irrational, mind/body and so on). However, she takes issue with exclusion and misrepresentation of women within poststructuralist theorising and the absence of recognition given by prominent poststructuralist thinkers to early feminist and critical race theorists. She argues that these ways in which critiques of Enlightenment thought have been represented by White male, Western theorists is at risk of reinforcing dominant assumptions about who can produce legitimate knowledge. Knowledge is argued to be central to understanding gendered relationships within hierarchies of power, where it is used as a means of social control, and as a means of reproducing dominant cultural relationships (Oakley 1992).

Rose (2009) presents further feminist critique of Enlightenment thinking in relation to research carried out by mental health users/survivors. She argues that an Enlightenment epistemology that focuses on the duality between intellect/emotion and rationality/irrationality can downgrade the status afforded to knowledge produced by people who are labelled as mad or otherwise irrational. Rose suggests that within this rational/irrational duality, the psychiatric professionals and researchers have been considered as being in possession of the only valid and universal truth. She challenges the universality of this truth, and argues that the alternative knowledge produced by people working outside of mainstream positivist research should not be disregarded.

Maguire (2001) describes the lack of recognition of feminist scholarship within action research as 'unsettling' (p. 60), given the extent to which feminist approaches to the production of knowledge have informed the development of this and many other critical traditions. Maguire argues that since the second wave of feminism in the 1970's, core to feminist approaches to academic work is the emphasis on transformation, not purely observation and description. Feminist enquiry centres gender in the analysis of power relations. Maguire draws upon action research literature to illustrate how, compared with female gender, male gender is often invisible and unproblematised in relation to the research endeavour and theoretical underpinnings. This, she argues, illustrates the pervasive and often implicit way in which female gender is constructed as 'other' in relation to a male norm. These criticisms also apply within mainstream ways of constructing a gendered female identity, which can implicitly locate diverse identities including race, class, ability and sexuality in an ignored, inferior or 'othered' position in relation to a White, Western, heterosexual, able-bodied and middle-classed version of womanhood.

I have argued above that this research is situated in a context of my own experience and values, and also within broader theoretical and philosophical frameworks. I outline below some of the significant influences on the development of this project, and my position within it.

2.6. Personal Experience

I begin with a brief summary of aspects of my early life experience that I consider to be relevant to the perspective I bring to this work.

I was the younger of two sisters, second generation migrants raised by a single mother in a large, multi-cultural Canadian city. My mother was British and living far from her family of origin. She was relatively unsupported, having separated from my father when my sister and I were aged 7 and 5. Without a comprehensive system of welfare, our mother worked to support her small family, and as a result we lived in relative material poverty. She usually travelled a long way to work, taking her away from the household for long hours. We moved house several times during my childhood, as a result of an attempt to live somewhere better, only to find that the better place was unaffordable. My sister and I went to ordinary state-schools in neighbourhoods that were often mixed with people of varying levels of poverty and modest wealth. This experience often meant that we were amongst the poorest children in our various schools, but mixed with friends who had middle-class aspirations. The schools we went to were often good examples of how well people from different ethnicities and cultures can live alongside one another, and there was a high level of integration with no apparent ethnic or racial conflict. These schools and our teachers generally were supportive, encouraging and rewarding of our earnest attempts at learning. Between the ages of 5 and 10, I had regular contact with my father at weekends. There were distinct differences between my parents in what I

would describe now as values and ontological assumptions. My father saw the world with clear and constant delineations between black and white, right and wrong. For my mother, the world was made up of a continually shifting pattern of truths. My sister and I grew up in the dialectical space between these two, frequently contradictory, positions. We learned about diversity of perspectives and the importance of tolerance. We inhabited a world without a singular truth, and a world in which the existence of a singular truth was both vehemently asserted and simultaneously disregarded. Gendered and cultural polarities were highly salient within this context.

These particular memories are very personal, but they are also important to contextualise the perspective that I bring to this research. In reflecting about what assumptions I held at the outset of this project, this was the narrative that took precedence over others. This is not to call it true, or more true than other memories. To reflect upon the impact of my values and assumptions in this work, it has been relevant to consider the influences that were important in their formation. I could only do this from the perspective of my current values and assumptions. The above reflects an attempt to make sense of personal history in a way that is brief but explanatory in relation to my perspective. This is an ongoing and developmental process that evolves over the course of this research and beyond.

The opportunity to reflect on the impact of the past, and the way in which I have done so, has been shaped by my subsequent experiences as a psychologist. It is through the lens of training and experience in psychology that I have been able to undertake this reflection.

2.6.1. Clinical psychology training and experience

Many of the underlying assumptions that have had a bearing on my approach to this project originate in my training and experience as a clinical psychologist. Prior to beginning this research I initially completed a Bachelor of Science degree in human psychology, after which I worked for several years in caring and supporting roles with people within a wide range of contexts. I spent a further two years working in the NHS as an assistant psychologist and three years undertaking clinical psychology training within a university and various NHS departments. Most recently I worked for five years as a clinical psychologist in NHS mental health services and teaching trainee clinical psychologists. Within most of this work, I have found myself aligned with people located at the margins of our society, including working with people with serious and enduring mental health problems, profound learning disabilities, workers in the sex-trade, gay men dying from AIDS, migrant workers and asylum seekers, women experiencing domestic violence, and survivors of many kinds of abuse. This work has raised my awareness of the damaging effect of structures of power and privilege on those who are marginalised within existing social orders. Whilst seeking to bring a critical perspective to my work, and often locating myself at the margins of mainstream clinical psychology, it is inevitable that my assumptions are profoundly informed by the context of psychological theory and practice. In reflecting on my experience of working in the NHS and my training in psychology, I am aware that there is a great deal of knowledge and assumptions that I take for granted, and which informs my thinking in ways that seem automatic rather than considered. This process was illustrated to me very clearly at an early stage in the project, when I met with potential collaborators. In describing themselves and their situations, I found myself formulating many aspects of the

conversation from within a psychologist/mental health professional standpoint. My experience of training and working within a mental health system appears to have structured my thinking, and I found myself making automatic connections between the description that was given to me of an experience, with medical diagnosis and mental disorder as it would be described within a diagnostic manual or mental health team meeting. My ability to recognise this and other habitual ways of thinking has been made possible through the opportunities to reflect critically on my own thoughts and assumptions in the light of exposure to ideas within critical and community psychology, however, there are inevitable blind spots that I hoped would be further illuminated through the process of this research.

2.6.2. Critical and community psychology

Early in my clinical psychology training, I was introduced to community psychology as an alternative framework for understanding psychological processes by a supervisor who subsequently became my manager and the supporter of the work I undertook in my role as a clinical psychologist (for example: Orford, 1992; Bostock, 1998). The approaches developed by critical and community psychologists provide a critical framework for evaluating mainstream psychological theory and practice. Since that time, colleagues in critical and community psychology have been a source of inspiration, support and incisive critique. Opportunities to present ideas about an earlier research project (reported in Franks, Gawn & Bowden, 2007) for critical comment have directly led to the developments that brought me to a participatory approach for the current research. Colleagues in critical and community psychology at our presentation were critical of the extractive, and expert driven approach that we had brought to our research, and gave us an insight into participatory approaches as an alternative way of doing research.

Community psychology is a developing field, in which various protagonists present alternative versions of the approach. I have selected the following definition of community psychology as an illustration of the approach that I have taken in this project:

‘Community psychology offers a framework for working with those marginalized by the social system that leads to self-aware social change with an emphasis on value-based participatory work and the forging of alliances. It is a way of working that is pragmatic and reflexive, whilst not wedded to any particular orthodoxy of method. As such community psychology is one alternative to the dominant individualistic psychology typically taught and practiced in the higher income countries. It is *community* psychology because it emphasises a level of analysis and intervention other than the individual and their immediate interpersonal context. It is *community psychology* because it is nevertheless concerned with how people feel, think, experience and act as they work together, resisting oppression and struggling to create a better world.’ (Burton, Boyle, Harris & Kagan 2007, p. 219)

In this definition, the emphasis in the language of working together, allegiances and participatory methods illustrates the importance placed by critical and community psychology approaches on reducing the powerful dynamic that often arises between professionals/academics (us) who are often seen as doing something to/on service users/research subjects (them). This dynamic also exists in reverse, in that people in professional/academic roles can be perceived as other and excluded from insider perspectives by members of communities when the people in these formal roles are perceived as ‘them’. Participatory methods as used in this project aimed to reduce

the 'us and them' dichotomy by developing a collaborative relationship where the commonalities, shared interests and activities of all members of the research team take precedence over the differences between our backgrounds or positions. This does not imply that our differences are not regarded as important and valuable in the process of the research, but rather that the differences of perspective and experience can be used as complementary strengths to improve the research in which we share an interest.

Critical and community psychologists often explicitly reject the pathologising of individuals within mental health, education and other organised systems. The community level of analysis incorporates a social and political analysis that identifies context and ecological conditions of living as primary in the causation of distress (for example: Orford, 2008). Taken in contrast to assumption-laden thoughts in relation to meeting potential collaborators on this project, this approach enabled me to bring a reflective perspective on the ways in which people with mental health problems are routinely conceptualised within mental health services. This is a challenging endeavour, which requires awareness and thought and which illustrates the ways in which we can at times appear to simultaneously hold multiple and contradictory perspectives (Wagner, Duveen, Verma, & Themel, 2000).

There are helpful parallels between critical, community psychology and systemic approaches to mental health. As a clinical psychologist, I have undertaken further training in systemic approaches to therapy, and this also informed my approach to the current research. The practice of systemic family therapy developed in part from a critique of psychological therapies that focus on the decontextualised individual, and locate psychological problems within an individual rather than in the relational context.

2.6.3. Influential ideas from systemic family therapy

Within mainstream clinical psychology, there are multiple, often competing theoretical approaches. Some, such as cognitive behavioural therapy (CBT) have become dominant in clinical psychology practice in NHS Adult Mental Health services. Others, such as systemic family therapy have had greater influence in Child and Adolescent Mental Health Services, alongside other models such as CBT. Systemic thinking has been particularly influential for me, largely due to its capacity to conceptualise therapeutic approaches within a social and political context. The debates in the systemic literature, particularly regarding concepts of neutrality, instrumentality and irreverence have been significant in my developing thinking about research and practice.

2.6.3.1. First order and second order perspectives

This distinction was initially drawn within systems thinking and family therapy (for example: Dallos & Draper, 2000). It is important because of the shift in perspective regarding the relationship of the therapist to the family. In early family therapy a modernist perspective was held about the objectivity of the therapist, with the family as the object of intervention and the therapist positioned outside of the family system. From this position, the gaze of the therapist tended to be directed into the family system as a pathological unit, and not requiring reflection regarding the therapist's own agenda, and idiosyncratic ways of understanding the family. The therapist was conceptualised as an objective expert. Subsequent developments, informed by postmodern and constructivist views of the world challenged the outsider/objective position of the therapist, and began to conceptualise the therapist as entering the family system, and as having her or his own distinct understandings that are different to that of another therapist. Therefore, the position of looking into

the family from the outside (a first-order perspective) has for many people, been replaced by a position of looking out from and back at the family system, including the therapists role in relation to the family (a second order perspective).

Similar changes have happened in the world of qualitative research, where the researcher is no longer seen as an objective observer, but as bringing her or his own perspective, informed by various influences, to the process of doing research. The researcher is therefore not separate from the research, but has an important role in shaping the course of the research.

2.6.3.2. Irreverence

I have frequently found myself in a dilemma between the wish to work toward positive change, and concerns regarding my ability to examine the ethics of the influence I have on people with less power than me. Within the struggle between instrumentality and non-instrumentality lies the potential to do nothing so as to avoid abusing power (Cecchin, Lane & Ray, 1993).

The understandings and knowledges held by different groups, such as community members and professionals can be at times compatible, and at times in conflict.

According to Mendez, Coddou and Maturana (1988) ‘a claim to objective knowledge is an absolute demand for obedience’ (p. 170), yet this is often the position taken up by experts and professionals with the intention of offering support or help. As an NHS trained and employed psychologist, I cannot be ‘outside’ of these systems, and there remain questions for me about the degree to which I am able to take a meta-perspective in relation to this. Conflicts can arise when two or more individuals come together to address the same concern, but from different views of the world. Our experience and knowledge are considered to be necessarily subjective, and are shaped by our interactions with others. By accepting that there are multiple, equally

legitimate understandings of reality, no one version is privileged over another. Differences are not seen as arising from bias or error, but as a consequence of diverse subjective standpoints and positions.

The concept of irreverence is helpful here. According to Cecchin, Lane and Ray (1993), the irreverent therapist does not expect to be followed, or to define the action, but only to suggest that some action may be helpful. The rejection of the concept of a single, unitary truth in relation to experience is compatible with poststructuralist approaches to knowledge and enables a different approach to working with varied cultural constructs of mental health. It involves the ability to remain irreverent about our own theories and hypotheses, and leads to the development of a more nuanced appreciation of the role of culture and context in psychological distress.

The concept of irreverence (as applied to family structure, beliefs and potential for change) can equally be applied to organisational structures within the services that may lead to punitive, inappropriate or inequitable service delivery. Like family systems, different levels of organisational system can be 'perturbed' by different interventions, for example, bringing together professionals to consider how we respond to needs of communities and asking questions about how our systems work to exclude or disadvantage people.

2.6.3.3. Neutrality

There has been considerable debate in the systemic literature regarding the possibility and desirability of taking a position of neutrality (for example, Cecchin, 1987), and even what neutrality means. A helpful distinction for me has been between neutrality as a technology within interactions and the recognition that the

overall stance of the psychologist/therapist/researcher is not morally or ethically neutral (Lang, Little & Cronen, 1990).

Jones (1993) described a position of neutrality as necessarily attending to inequalities. She argued that neglecting to do this is communicating/condoning (through silence) the normality of power imbalances. She emphasised the importance of reflexivity in order to identify our own assumptions, and this has been significant in helping me to think about my research. Attending to social and cultural influences is seen by Jones as 'an intrinsic part of what assures a therapist's responsible attention to all relevant issues which organise and influence the lives and well-being of clients' (p. 150). She also described how initiating an interaction triggers and influences a response, but does not specify it, thus reinforcing the active and empowered position of community members.

The idea that the therapist or researcher can be seen as enacting social expectation/rules (Mendez, Coddou & Maturana, 1988) enabled me to think about my role as potentially challenging and shaping local ways of working. The possibility of stepping outside the normal way of working related to my hopes of inviting people to work together in ways that do not fit with current positioning (as passive recipients of healthcare, for example). Rather than providing the answers, the aim is to help the community to generate their own changes, and develop new ways of relating to professionals and each other. By asking circular questions within research interviews, we are starting up a new 'conversation' between service providers, potential service users and other community members.

2.6.3.4. Circularity and feedback

Circularity in family therapy refers to the iterative process of seeking feedback from the family to inform the direction of each subsequent step in the therapy (Selvini,

Boscolo, Cecchin & Prata, 1980). Within family therapy, the process of asking circular questions is intended to create curiosity within the family and therapy systems (Cecchin, 1987). The research project itself is based on a process of gathering information and feedback from community members and workers about their understandings about their experiences, and relationship to services. The ideas of feedback and circularity were influential in developing a reflective space for consideration of the ethics of the project work. In common with earlier experiences of researching with marginalised groups, it has been important to use opportunities for feedback from colleagues and community members to develop a reflective space for consideration of the research process and dilemmas.

2.7. Power

Feminisms, critical community psychology and systemic thinking centre an analysis of power in reflecting on the relationship of the therapist/psychologist/researcher in relation to both the communities they serve, and the organisations or institutions in which they work.

A common critique presented regarding mainstream approaches to research relates to the way in which claims of objectivity or neutrality can disguise and fail to challenge how inequalities in power are enacted in the field. According to Parker (2005) ‘all research is action that works for or against power’ (p. 123). He argues that research can either reproduce existing power relations, or can provide tacit support for those in power through claims of neutrality. In common with Parker’s approach, Jones (1993) develops a comprehensive account of how systemic thinking can inform critical reflection on how the therapist engages with power in a clinical setting. Given the overlapping activities and kinds of relationships that are experienced in

therapeutic and some research settings, Jones' contribution is of relevance within the current research arena.

Within many forms of systemic family therapy, the therapist is considered to enter the family system, rather than remaining on the outside. Jones (1993) suggests that from this insider position, the therapist and family work together to observe and describe the system, to consider how it may be different, and explore ways that change could be brought about. The therapist does not take the position of an objective outsider in this activity. This approach can be seen to parallel the process of participatory action research. Both Parker and Jones, from different traditions, have been influenced by the work of Michel Foucault. The relevant work relates to Foucault's argument that historically, some ways of understanding, describing and acting in the world become dominant, while others are subjugated and marginalised (Gutting, 2005). This is an important idea within this research, due to the emphasis that it places on the search for understanding of how these unspoken and often unrecognised assumptions are enacted in the research field. The argument put forward by authors such as Parker and Jones, strongly influenced by Foucault, is that as a therapist or researcher, the way that we act, and seek to understand, is influenced by the dominant ways of thinking and acting present in our cultural context. These are argued to support and maintain the existing structures of power within the setting in which we work. For this reason, we are likely to maintain the existing power dynamics by claiming to be neutral or objective, and failing to reflect on how our implicit assumptions affect the work that we do. If we consider that the existing order may be in some way implicated in the development of the problems in the research setting (for example through the experience of poverty, lack of power, or stigma associated with mental health or young/single-parenthood), then it is essential

that we bring a critical perspective to bear on how our actions are informed by the dominant cultural assumptions. Gaventa & Cornwall (2001) emphasise the importance of how existing imbalances of power are reinforced by the culturally dominant means of producing knowledge; this forms part of their rationale for undertaking participatory research.

As researcher and professional with doctoral level education within a research team made up of women who do not have the same level of education or professional status, it was important to recognise the ways in which my power in the situation (reflecting the social order of status, expertise and authority) is maintained by certain ways of talking, engaging and acting within that setting. These ways of talking, engaging and acting may be supported by complementary ways of talking, engaging and acting by others in the setting, such as by other members of the research team, who may defer to my perspective, and by other professionals and academics who value my perspective above those of the other members of the team.

The idea of complementarity in relation to power has been debated within the literature on systemic family therapy. Jones (1993) described complementary interaction as the 'reciprocity between protagonists whose actions are responses to, and elicited by, the actions of the other' (p. 141). In complementary interactions, it is suggested that the enactment of power by one party in a relationship depends on the other party acting in a way that enables the power of the other to be enacted. Within the tradition of family therapy, this understanding is connected to the stance of curiosity and non-judgement – the attempt to observe and understand the dynamic relationships within a family functioning as a system without placing blame and responsibility on any one individual. Curiosity is part of the systemic therapist's attempt to maintain an open mind and avoid reaching simple conclusions rather than

continue to explore different possibilities (Cecchin, 1987). Jones suggests that there are obvious limits to an understanding of behaviour based on complementarity when taken to the extreme, as in the abuse of children within families and the relationship between torturer and prisoner. In such cases, she suggests, it would be absurd to suggest that the victim's behaviour in some way enables the abuse. Jones goes on to argue that factors such as social attitudes and personal experiences are important in shaping how people respond to one another in relationships. A pertinent example of these influences comes from a feminist analysis of how intimate partner violence reflects the sexist and patriarchal culture within which these intimate relationships exist (Goldner, Penn, P, Scheinberg, & Walker, 1990; Yllo, 1998).

Thus, in relation to potential effects of complementarity within the research relationship, it is important to recognise the extent to which social forces are active and shape the way members of the research team relate to one another. There is not considered to be a straightforward relationship in which the higher-status researcher is always more powerful than the other members of the research team. However, it would be an oversight not to incorporate an understanding of this in the process of undertaking the research as a collaborative endeavour.

2.8. Working with Difference in Collaborative Knowledge Production

This chapter has given an overview of the different personal/professional influences and theoretical perspectives that I have brought to this research project. I have argued that it is important to consider these influences at the outset of a qualitative research project and to situate the research in this context. As I have suggested, there is a complex set of intersecting influences and priorities within this research.

Through these multiple influences, it has been important to find practical ways of working collaboratively with co-researchers.

2.8.1. Boundary critique & process philosophy

In the face of many and potentially contradictory perspectives, there was the potential to seek a simple, rule-based system for developing the direction of the project and my perspective. In supporting trainee researchers in clinical psychology, I have often suggested that it might be helpful for them to establish a theoretical and epistemological perspective, and remain consistent in how this is applied in their research. This will give them the underpinning system on which to build their subsequent decisions, such as what approach to take to the generation of data, how to demonstrate trustworthiness, how to analyse data, and so on. In this research, there were limitations to undertaking a participatory project from a fixed perspective, when there were multiple and contradictory views that needed to be taken into consideration.

An alternative approach is presented by Midgley (2000) in his explication of process philosophy and theoretical pluralism. Boundary critique has been employed in context of critical systems thinking and has its origins in critique of subject/object dualism. Midgley refers to the generation of 'process philosophy', rather than 'content philosophy' (p. 78), and emphasises the process of drawing a particular boundary around the subject of interest – determining what is included and what is excluded. The boundary drawn by a 'knowledge generating system' (p. 76), such as a research team, is the focus of his process philosophy. The process of making boundary judgements is the prime level of analysis (rather than the maker of boundary judgements or the judgements made). Midgely argues that this dispatches with the dualism inherent in consideration of subjects and objects.

The drawing of the boundary is the process to which he attends, rather than just the content within the boundary itself. Thus Midgley considers different epistemologies

can be understood in relation to process. He provides the example of Marxism, in which a boundary is generally drawn around economic and social systems. He compares this with other perspectives where the boundary may be drawn around different subjects of interest. Feminist approaches can be seen as drawing a particular boundary around the body, language, power and other gendered social constructs, in comparison with other perspectives that prioritise other issues in research. Different boundaries can be drawn in relation to different feminisms. Western feminism, for example has been critiqued as failing to include within its boundary the construct of race and Western privilege.

Using this approach, the boundary defines the main focus of attention, but it is not an absolute or fixed focus, and the process of drawing the boundary is also given attention and reflection. Boundaries to be considered include relevant knowledge and people who are involved in its production, for example: what is the 'knowledge generating system'? This requires second order reflections and knowledge production (looking out from and back at the knowledge generating system).

Boundaries of any system are not considered to be determined by nature, but are defined in social contexts, and are consequently not static. Midgley emphasises the importance of embedding values into the philosophical stance taken in research and action. He argues against the acceptance of an objective, value-free version of scientific epistemology on the grounds that all research is carried out in a social and value-based context. Boundary judgements are closely connected with values and ethical considerations, and this reflects the need for critical reflection on boundary judgements. Again, this is a second order reflection, and signals the importance of broad participation in development of critique from multiple perspectives. Paying attention to these processes within this research project has enabled me to hold a

reflexive perspective in relation to my own boundary judgements and how they relate to the boundary judgements made by others who were involved in the research, and who were relevant to the research, such as other professionals, organisations, and so on.

Taking this approach from the outset of the project has been helpful at very early stages of discussion about the research. One example relates to a critique of the project as being initiated from outside of the researched community, and therefore not constituting ‘proper’ participatory research. In considering the judgements about what constitutes a particular boundary of community membership, it is possible to consider boundaries that include researcher as clinician alongside other workers, professionals and women in the area. In considering who ‘counts’ as an insider in this community, it is possible to draw a boundary around a community of people, including professionals and local mothers who have a personal interest in the well-being of women in this community. This has helped in overcoming some of the artificial divisions between ‘us’ and ‘them’, in a similar way as reconsidering a boundary judgement regarding who can be a legitimate researcher, and what constitutes legitimate expertise in relation to the subject of the research.

In relation to the process of making these philosophical decisions about my approach to the research from the outset, it was important to acknowledge that there is still a dominant philosophy on knowledge, with its foundations in Enlightenment thinking. Although among many qualitative researchers and family therapists it is common to find sympathies with poststructuralist and systemic ways of understanding the world, this project was undertaken within a set of broader cultural and organisational systems that do not share these perspectives, including other members of the research team. This context has had a wide ranging effect on the process of the

research in ways that were not predictable from the outset. It has been in relation to these challenges that I consider my background and skills, and theoretical frameworks of boundary critique, process philosophy and systemic thinking provided resources for my own reflexivity in navigating a way through the research process.

2.9. Summary

The frameworks of knowledge that I have employed in this process are of importance in relation to how they have shaped the research and the way that I have written about it. Without making these theoretical questions explicit, there was a risk that I would default to uncritical ways of thinking in the process – and that this would inevitably shape the way that I engaged with all elements of this research. I have aimed to remain aware of these values throughout the process of this research, and revisit these issues in section 8.4 in the Discussion chapter.

Further context and direction for this research is drawn from the academic literature. In the following two chapters this literature is reviewed in relation to broad academic and professional knowledge relating to women's mental health during pregnancy, and to women's firsthand experiences of mental health problems during pregnancy.

CHAPTER THREE

LITERATURE REVIEW 1

3.1. Introduction

It is important to note that this literature review was not undertaken collaboratively, but was part of the author's PhD process. The research team discussed the possibility of reviewing the literature together, and it was agreed that this was not an area of interest to any of the community co-researchers. In addition, some co-researchers expressed uncertainties about their ability to engage with written material at the level of published scientific literature. One co-researcher described herself as having dyslexia and recalled struggling with literacy-based tasks at school. All co-researchers described time limitations due to work and parenting roles and expressed greater interest in conducting the research activities of gathering and exploring data. This is one area where the different interests and requirements of members of the team diverged.

The focus of this research is on development of knowledge from a 'bottom up' perspective. Without the involvement or interest of non-academic co-researchers, it is reasonable to ask, 'why undertake a literature review in this research?'

Beyond the requirements of the PhD process, the purpose of literature review was to:

- Identify gaps in the existing literature;
- Inform the research team of issues that are considered to be relevant in the wider field. This will help to inform how we discuss issues with participants and what questions we ask during data generation;

- Sensitise us to the issues being discussed and debated in the scientific literature;
- Provide context and comparison for our findings
- Explore how scientific literature relates to community members' perspectives.

These elements of the research may be of greater interest to academic members of a research team, as compared with members of the research team who have an interest in developing knowledge about local understandings and experiences of mental health, with a view to informing local people and services. This is one of the ways in which this research collaboration needed to be flexible in order to take into account the different interests of different members of the team. As part of a collaborative participatory research team an academic researcher does not take a purely facilitative position to enable the co-researchers to conduct the research, but is also engaged in the research process with personal and professional interests.

The focus of this literature review is on antenatal mental health, rather than post-natal mental health. This does not imply that antenatal mental health is seen as separate to, or as more important than the mental health of women throughout the lifespan. However, there is a substantial literature on perinatal mental health and for the purposes of this review it was necessary to focus the search for relevant literature specifically relating to women's experiences during pregnancy.

The literature review uses a broad definition of what 'mental health' means. The rationale for keeping this broad relates to the importance, within the project as a whole, of bringing a responsive, rather than prescriptive, approach to understanding how mental health is understood beyond professional and academic communities. If it had been decided from the outset of the project that 'mental health' had a

particular meaning, this could limit the ways that participants were able to talk about their experiences, affect our ability to hear alternative accounts and prematurely narrow the range of literature that might be available to inform the research.

Although the literature review was not a collaborative undertaking, it remained important to retain a consistent approach to the intellectual work of this research.

3.1.1. Searching the literature

The literature review was undertaken using a range of search terms, with a view to developing a comprehensive overview of existing research to inform the project. Search terms focused on ‘mental health’ as a broad term, combined with the terms ‘pregnancy’, ‘antenatal’ and ‘perinatal’. This produced a very large number of returns, and these were scanned for relevance to women’s mental health during pregnancy. Existing published guidance on services for pregnant women in the UK was accessed and reviewed. Further resources were identified from references within the examined literature. Literature focusing on postnatal mental health was excluded, as was literature that primarily focused on biomedical influences of pregnancy on mental health. Rather, the topic of interest within this research is how mental health problems are experienced during pregnancy, what is the impact of psychosocial influences, and what do women need from their services and communities to support their mental health during pregnancy.

3.2. Literature Review Overview

The literature search identified an extensive range of published resources. These were categorised under a number of headings, which will provide the structure of this chapter, as follows:

1. Why is mental health in the antenatal period considered to be important?

2. What mental health problems have been explored in recent research, and how have they been described?
3. What guidance is provided to professionals in the United Kingdom regarding practice in relation to mental health during pregnancy?
4. What life experiences and other factors are considered to be associated with poor mental health in pregnant women?
5. A further chapter reports a more focused review of qualitative literature relating to women's experiences of mental health problems during pregnancy

3.2.1. Why is mental health during pregnancy considered to be important?

Maternal mental health during pregnancy has been widely researched and associated with negative outcomes for women's children. The effects of poor mental health include preterm labour, low birth weight and early neonatal complications (Alder *et al*, 2007; Ashdown-Lambert, 2005; Jablensky, Morgan, Zubrick, Bower, & Yellachich, 2005). Longer term correlations have been identified between poor maternal mental health and childhood neurodevelopmental problems and adolescent mental health and behavioural problems (Talge, Neal & Glover, 2007; Pawlby, Hay, Sharp, Waters & O'Keane, 2009).

Beyond the potential impact on her children, a woman's mental health during pregnancy is also closely connected to her risk of ongoing mental health problems after delivery. A review of the research literature establishes the association between antenatal and postnatal depression. Particular factors associated with postnatal depression were pre-existing depression, anxiety, life stresses and low levels of social support during the pregnancy (Robertson, Grace, Wallington, & Stewart, 2004). Enquiries into maternal deaths in the UK have illustrated the relatively rare but tragic consequences of poor maternal mental health for families with new babies.

These reports show statistics of 71 maternal deaths from ‘psychiatric causes’ recorded from 1994 to 2008 (CMACE 2011).

3.2.2. How have women’s mental health problems been explored in recent research and publications?

Most of the research reviewed has examined mental health from within the medical model. A search of literature examining women’s mental health during pregnancy demonstrates a dominance of diagnostic categories, with depression as a prominent feature.

Research has focused on particular mental health problems as defined within diagnostic frameworks, particularly the Diagnostic and Statistic Manual of Mental Disorders (DSM), published by the American Psychiatric Association (APA, 2000). In common with many authors, Hadwin’s (2007) summary of the range of mental health problems affecting women in the perinatal period, relies on a diagnostic framework. He categorises women’s mental health into:

- Anxiety disorders, including generalised anxiety, panic disorder, phobias including agoraphobia, obsessive compulsive disorder and post-traumatic stress disorder
- Dissociative disorders associated with trauma and somatisation disorder
- Antenatal and Postnatal depression
- Bereavement

Women’s mental ill-health is argued by Howard (2006) to be the most common ‘complication of childbearing’ (p. 277), clearly locating mental health within a medical framework. The medical terminology of ‘complications’ and uncritical promotion of a diagnostic approach to ‘managing’ women illustrates the unbalanced

power relationship that often exists between professionals and health service users. As an illustration, Howard's chapter in the text edited by O'Keane, Marsh & Seneviratne (2006) is titled 'Models of health care in the management of women with Psychiatric Disorders', linguistically presenting women as objects to be managed.

A further chapter in the same text, by Conroy and Moran (2006) addressing personality disorder describes women with this diagnosis using pejorative language such as 'inflexible', 'unpredictable', 'demanding' and describes professional responses to women with these diagnoses as 'difficult' or 'heart-sink' patients' (pp. 143-144). The reproductive potential of women described as mentally ill are sometimes a cause for significant concern by professionals and researchers (Boritz Wintz, 1999).

3.2.3. *Prevalence*

In the United Kingdom, research findings examining the prevalence of common mental health problems have differed across studies, with some suggesting that pregnant women do not have a greater risk of experiencing mental health problems than the general population of women who are not pregnant, (Gaynes *et al*, 2005; van Bussel, Spitz & Demyttenaere, 2006). The rates of depression during pregnancy are estimated at between 14-37% of the population, with anxiety symptoms being present in between 25-50% of women (Evans, Heron, Francomb, Oke, & Golding, 2001; Flynn, Blow & Marcus, 2006; Reid, Power & Cheshire, 2009). However the research has focused primarily on responses to researcher-defined measures such as the General Health Questionnaire v 12 (Goldberg, 1992), the Edinburgh Postnatal Depression Scale (Cox Holden & Sagovsky, 1987) or using diagnostic assessments for depression or mood disorders.

Although much research does focus on measures of diagnostic categories, there is some research that investigates more broadly defined experiences of mental and emotional problems in pregnancy. Research examining the prevalence of 'Common Mental Disorders' as identified using the Clinical Interview Schedule (Lewis, 1992) was undertaken in Brazil by Faisal-Cury and colleagues (2009). The interview schedule examines symptoms experienced during the previous week. The authors reported finding that more than 30% of a sample of 831 pregnant women experienced worry, anxiety, irritability, and somatic and sleep problems. Between 20% and 30 % of the sample experienced fatigue, obsessive symptoms and depression. Symptoms of hypochondria, compulsion and problems of concentration were reported by 10% to 15% of the study participants. A further 7% to 10% of pregnant women said that they experienced depressive thoughts, panic and phobias. Although this research may be culturally specific and may not be generalisable to the population of pregnant women in the United Kingdom, it does suggest that research should not necessarily limit exploration of women's mental health in pregnancy to categories defined by diagnostic frameworks. Although Faisal-Cury's research is not limited to examining particular diagnostic categories, it is focused on researcher-defined symptoms in a structured clinical interview, rather than providing women with opportunities to describe their experiences.

Jomeen (2004) argues that women's emotional wellbeing during pregnancy needs to be considered as a multi-dimensional construct, rather than screening for narrow, diagnostically-defined conditions. Jomeen's argument for a broader framework of assessing psychological status of antenatal and postnatal women includes self-esteem, quality of life and experience of control in addition to wider psycho-social

factors that have a negative impact on women's experiences. However, much current research and professional guidance continues to focus on diagnostic frameworks.

3.2.4. *NICE guidelines for professionals*

The UK National Institute for Health and Clinical Excellence (NICE) guideline on the provision of services for women with mental health problems in the antenatal period (NICE 2007) is also largely structured according to diagnosis. The broad areas regarding women's mental health discussed in this guideline are:

- Anxiety disorders including panic disorder, generalised anxiety disorder, obsessive compulsive disorder and post-traumatic stress disorder
- Eating disorders
- Depression, including antenatal and postnatal depression
- Bipolar disorder
- Psychosis, including puerperal psychosis (postnatal) and schizophrenia
- Personality disorder is mentioned briefly and infrequently in the guidance.

The guideline identifies a lack of evidence regarding the prevalence of the range of mental health problems during pregnancy or research evidence addressing the efficacy of treatment for mental health problems during the antenatal period. The guidance directs clinicians to published NICE guideline for specific diagnoses within the general population.

A further and significant limitation of the NICE guideline is the absence of clear guidance on mental health problems other than depression in the antenatal period. The guideline does provide information about safety of psychoactive medications during pregnancy.

Women with experiences of abuse in childhood, the effects of which may be diagnosed as personality disorders of various types (for example: Bierer *et al*, 2003)

are rarely mentioned in the guideline. Intimate partner abuse is mentioned briefly as a risk factor that may be associated with, or aggravate the development of mental disorders. The only mention of personality disorder (PD) is in a short section on treatment length, and is referred to in guidance that women with PD diagnoses should be referred to specialist services. There appears to be no direct guidance on treatment of women with these diagnoses. Abuse history is mentioned in one of the vignettes, and is described as a risk factor for poor mental health, but the guideline does not describe evidence of efficacy of psychological or pharmacological treatment of women who have experienced abuse.

NICE recognises the limitations in the guidance relating to the available research prompting it to describe the guideline itself as:

‘limited as a result of the paucity of research in this area. Most studies to date have focused principally on depression and psychotic illness, mainly in the postnatal period, and studies of depression have generally relied on the use of self-report measures applied at isolated time points. Therefore, caution must be applied to the interpretation of the data’ (p. 57)

There are further concerns about the structure and underpinning assumptions behind NICE guidelines. There exists a dominant, health sector-wide perspective that values randomised controlled trials (RCT) as the ‘gold standard’ in outcome research.

However, there are frequently considerable methodological weaknesses in even the highest level, best-controlled RCT studies of psychological therapy in mental health.

These studies are often strong on internal, but weak on external validity. RCT therapies are conducted by well qualified and supervised practitioners with monitored adherence to protocol and dedicated time for therapy delivery. This is

unlikely to reflect all clinical practice conditions in which evidence based interventions are delivered. The populations used in RCT studies are often single diagnosis, non-co-morbid, non-complex cases, which are selected out for intervention within the context of a research trial (Morrison, Bradley & Westen, 2003; Bolsover, 2007). The populations within which research trials are conducted are also unlikely to be representative of all of the populations in which therapy will be delivered. RCT research trials rarely report contextual factors such as the relational, social and material conditions of the researched populations (Mauthner, 1998; Moloney & Kelly, 2004). The NICE guideline, because of the emphasis on a hierarchy of research methods, potentially misses out important findings from research from a broader range of studies.

3.2.4.1. Service-user involvement in developing NICE guidelines

Service user involvement in producing the guideline reflects increasing recognition of the importance of public and patient participation in research and service development. The guide reports that two former service users were involved in the development of the guideline, although one of these representatives was also identified as a Senior Lecturer in Health and Social Care at a university.

Development of guideline tends to be standardized in that it follows a specified academic/clinical process with protocols for review, and maintains a standard hierarchy of evidence which does not generally include service user led research.

Questions can be raised about the impact of service user involvement on development of guidance, given that the opportunities for service user involvement and leadership are necessarily relatively limited.

3.2.5. *Other national guidelines*

Following the publication of guidance from NICE in 2007, the Scottish Intercollegiate Guidelines Network (SIGN) published a new guideline on the management of perinatal mood disorders in 2012. The guidance provides a definition of ‘antenatal’ as the period between conception and birth, but does not include in the definition any reference to the end of the pregnancy, either by termination, miscarriage or stillbirth. This illustrates the emphasis on the outcomes for the baby for much of the guideline and research about women’s mental health during pregnancy. SIGN guidance outlines the importance of the perinatal period in development of the relationship between mother and baby, and the impact on later educational and psychosocial development of the child.

Within the SIGN guideline, there is a primary focus on depression and puerperal psychosis, particularly in terms of prediction, prevention and treatment, and primarily in the postnatal period. The guideline cites the systematic review from Lancaster and colleagues (2010) regarding risk factors for antenatal depression. The guideline does not recommend using the Edinburgh Postnatal Depression Scale as a screening tool for Antenatal depression due to lack of evidence that screening has a positive impact on postnatal outcomes. Although the recommendations about screening in the antenatal period are focused on identification of risk of postnatal mental health problems, the guideline does not recommend psychosocial assessment during pregnancy to identify risk of postnatal depression, but emphasises clinical interview and professional judgement. This recommendation relies on knowledge and skills among maternity clinicians for identification of risk, although there are also questions about maternity professionals’ confidence in this area (Jomeen, Glover & Davies, 2009; McCauley, Elsom, Muir-Cochrane & Lyneham, 2011). The

Scottish guideline did not report any evidence on prevention of antenatal depression. SIGN (2012) reports a lack of evidence from a Health Technology Assessment to support the use of the Whooley questions recommended in the NICE guideline for identification of postnatal depression (“During the last month, have you often been bothered by feeling down, depressed or hopeless?”, “During the last month have you often been bothered by having little interest or pleasure in doing things?”, “Is this something with which you would like help?”).

SIGN (2012) emphasises the connection between antenatal and postnatal depression, recommending management for antenatal depression, but the guideline only reports evidence for one small couple massage training intervention in the antenatal period and a small number of psychological and psychosocial interventions in the postnatal period. The guideline addresses service design with a focus on specialist perinatal mental health networks and services. In common with the NICE guideline, the SIGN guideline cites evidence and gives clear recommendations on use of psychotropic medications during pregnancy. The overall picture from the SIGN guideline is congruent with the earlier NICE guideline: there is little evidence relating to antenatal mental health that meets the standards set within the review procedures. This process has excluded a range of research due to requirement for research quality standards, and does not adequately inform professionals about the needs of women experiencing antenatal mental health problems.

NICE (2010) guidance on services for pregnant women who experience complex social factors is driven by evidence of higher level of risk to women from the included groups and their babies. This risk is identified as relating to higher levels of mortality and morbidity, and later booking for antenatal care. The guideline focuses on women who experience one or more of four social conditions of drug/alcohol use,

migration (including refugees and asylum seekers), age under 20 years and intimate partner abuse. Although this does not focus specifically on women's mental health during pregnancy, it can be argued that some of these conditions may be related to women's mental health. Although risk was also identified as associated with ethnicity, poverty and unemployment, these issues are not addressed in the guideline. The main focus of this guideline is on organisation of services and practical ways of responding to pregnant women's needs.

The NICE (2010) guideline addresses a range of issues, and makes recommendations including:

- Overcoming barriers to accessing services.
- The need for training of professionals, including non-clinical staff such as receptionists, particularly with reference to women's communication needs. Guidance is provided on training in relation to specific areas where professionals need knowledge and skills for assessing and working with the relevant groups. Information and education for the woman about risks to her baby.
- Facilitation of access to services and contact with professionals.
- Flexibility within services for alternative and extended appointment times as needed.
- Development of referral pathways and links with professionals with specialist roles in statutory and voluntary sector organisations.
- Asking women about their satisfaction with services, and for responses to be used to guide local service development.
- The importance of respectful communication and openness about the need to share information with other services in relation to safeguarding concerns.

This guideline development used the NICE framework for grading evidence in relation to intervention outcome studies, but also included a wider range of research in seeking evidence to inform other clinical questions such as overcoming barriers to access. In common with other guidelines, the development group was heavily weighted with professional and academic members, but there were three members identified as ‘service users’. There was little transparency in the guideline document about the role and level of influence brought to the committee by the service user members.

3.2.6. Confidential Enquiries into Maternal and Child Deaths

The CMACE (2011) Report on Confidential Enquiries into Maternal Deaths in the UK focuses on a range of causes of maternal death, including psychiatric causes. The Enquiry identified characteristics of women who were less likely to attend for antenatal care including substance misuse, women known to social and safeguarding services, women experiencing domestic abuse, who were single and unemployed or whose partner was unemployed. The report emphasises risk to women’s mental health and access to care relating to their concerns that engaging with services might result in their child’s removal through safeguarding processes. These concerns may have an impact on the women’s willingness to disclose substance misuse. Review of maternal deaths exposed inadequate psychiatric care and risk assessment in the majority of cases where women were known to psychiatric services. In some cases, women were not referred to a specialist mother and baby unit, and many were managed by multiple psychiatric teams, with poor continuity of care. In a minority of cases, a physical health condition was misattributed to psychiatric causes, and therefore adequate medical care was not available to prevent death. In some cases the woman’s mental health presented a barrier to accepting medical care or adhering to

medical treatment (CMACE 2011). The report presents clear recommendations relating to referral pathways, communication between professionals and health services, and professional training relating to mental health.

The CMACE report highlights the importance and impact of services and professional relationships with women during pregnancy. Research has identified mixed levels of knowledge and confidence amongst midwives regarding antenatal depression, and identifies knowledge of postnatal depression as more widely addressed through training and service provision (Jomeen *et al*, 2009; McCauley *et al*, 2011). Further research by one of the CMACE report's authors has identified lack of confidence and knowledge amongst maternity professionals regarding women's mental health during pregnancy (Rothera & Oates, 2011). Although mental health in pregnancy had been identified as a significant concern in the 1990s and early 2000s, there had been/was little progress in developing the connected perinatal mental health services or midwives' confidence in primary care and mental health services in the following decade (Stanley, Borthwick & Macleod, 2006).

3.2.7. *Other relevant guidance*

The British Medical Journal Best Practice website (2012) recommends antenatal screening of women for depression, anxiety and psychosocial risk factors, within the guidance on standard antenatal care. The risk to mother and baby of negative outcomes from undiagnosed psychiatric disorders is given as the rationale for screening. The website cites guidance for repeated psychosocial screening throughout the pregnancy from the American College of Obstetricians and Gynaecologists (ACOG).

There is recognition within third-sector organisations of complex, interconnected elements of women's lives that have an impact on their mental health. Concerns are

frequently raised about parenting ability and the impact of women's mental health on future generations.

A report by Family Action addresses the current political context in UK in 2012, particularly in relation to the impact on family and community life of welfare benefit cuts and changes to tax credits. This report identifies the impact on maternal perinatal depression of social conditions such as low income, single parenthood and poor housing. Government development of a recent initiative, the Family Nurse Partnership, is critiqued for only addressing the needs of young and first time mothers, for whom additional specialist support will be provided in pregnancy and the first two years (Family Action, 2012).

Much of the identified literature, including NICE guidance, prioritises specialist, expert understandings of mental health and a medicalised and diagnostic approach to mental disorder. From a community psychological perspective (for example: Orford, 2008), it is important to work in collaboration with community members to develop an understanding of their diverse ways of making sense of their own mental health. The NICE guidance itself identifies the absence of a clear connection between understanding of aetiology and treatment in the available research, although the research included in NICE guidelines is restricted by the standards for inclusion as outlined above. This finding points to the potential usefulness of undertaking research that explores community perspectives on aetiology and develops links with potential ways of addressing the underlying causes of poor mental health.

From a critical/feminist perspective, which prioritises analysis of power within research and action, these reviews and guidelines give inadequate consideration to important issues of power in the structure of guidance, the research processes used and the content of the research reported (Mauthner, 1998).

3.3. Social/Contextual Models of Women's Mental Health

Alternative frameworks for understanding women's distress are presented from critical psychological, sociological and feminist perspectives that are congruent with the approach taken in this research. These perspectives challenge the individual and pathology-based understandings of women's mental health, and locate women's distress within a material, social and interpersonal context (Oakley, 1992; Hagan & Smail, 1997; Ussher, 2011). Medical and hormonal explanations for women's distress are critiqued as reflecting a model of women's lives where the normal condition is one of depression, and where women experience distress caused by intra-psychic conflicts rather than social conditions (Oakley 1992).

A critical psychological approach places an emphasis on materialist analysis of inequalities of power in relation to distress, and draws a connection between states of mind and material environmental conditions. Chronic life stress is associated with lower socio-economic conditions and negative health outcomes (Whitehead, 1992; Marmot, 2012).

Children, members of disadvantaged socio-economic groups, ethnic minorities and women are all, in varying proportions, likely to be subjected to oppressive social forces creating individual distress (Hagan & Smail 1997, p. 261).

Power is enacted in relation to gender and early life experiences of oppression, and distal influences that may lie beyond the individual's ability to identify (Hagan & Smail, 1997). For many women, it is not difficult to identify the impact on mental health of experiences of sexual abuse and violence in childhood and throughout the lifespan (Humphreys & Thiara, 2003; Ussher, 2011).

The impact of imbalanced power can also be seen in the relationship between pregnant women and health professionals, who hold positions of expertise and authority according to social norms and medical knowledge of healthy behaviour (Oakley, 1993; Stapleton, Kirkham, Thomas & Curtis, 2002).

Research processes that locate power and knowledge with professionals and academics can overlook the importance of women's experiences in relation to their own mental health. Methodological limitations within research can lead to oversights in recognising the complexity and importance of relationships in women's lives, when the emphasis is on testing existing theories. Such an approach can fail to capture women's subjective experience by using researcher-defined constructs and gender biased measures (Mauthner, 1998).

Babiker, (2009) proposes a material-psycho-social account of women's distress based on the relationship between the body, the self and societal pressures and expectations placed upon pregnant women. The existing research literature indicates associations between a range of social conditions and poor maternal mental health during pregnancy.

3.3.1. What experiences and other factors are considered to be associated with poor mental health for pregnant women

A review of the literature by Lancaster and colleagues (2010) focused specifically on factors associated with depression during pregnancy. The findings identified increased risk of antenatal depression among women with experiences of anxiety, life stress, a history of depression, lack of social support, unintended pregnancy, history of domestic violence, lower income, lower education, smoking, single status, and poor relationship quality. These associations support some findings of an earlier review of the literature focusing on risk factors for antenatal depression, which

identified a previous history of depression, single relationship status, lack of social support, poverty, a history of family violence, high levels of life stress, drug and alcohol abuse, termination of previous pregnancies, the pregnancy being unplanned, anxiety and ambivalence about the pregnancy and relationship difficulties (Bowen & Muhajarine, 2006). Single motherhood was associated with lower scores on a measure of depression than being in a relationship with perceived low levels of partner support (Bilszta *et al*, 2008), indicating that women in relationships that felt unsupportive were more likely to experience depression during pregnancy than single women.

In other published research and reviews, social disadvantage (Jasinski, 2004; Zelkowitz *et al*, 2008), loss of previous babies by miscarriage, stillbirth or early neonatal death (Côté-Arsenault & Freije, 2004), lack of social support and distressing life events (Reid *et al*, 2009) and immigrant status (Zelkowitz *et al*, 2008) have been connected with a negative impact on women's mental health during pregnancy.

Further research addressing effects of abuse in childhood and adulthood shows the negative impact on women's mental health during pregnancy. The review of literature by Jasinski (2004) identified effects of intimate partner abuse on perinatal outcomes such as lack of or late access to antenatal care, early labour, low birth weight, foetal trauma and a wide range of physical and emotional health conditions for mothers. These conditions included an increased likelihood of smoking, drug and alcohol use, poor diet, lower self esteem and severe depression. Intimate partner rape was associated with increased suicidality, substance misuse and post-traumatic stress disorder, compared with other forms of intimate partner abuse (McFarlane, 2007).

A history of childhood sexual abuse has a significant negative effect on women's mental health during pregnancy (Simpkins, 2005). Mental health effects on adolescent mothers include increased use of alcohol and drugs, depression, poor self esteem, feelings of helplessness, self-harm, suicide attempts, and psychosis (Erdmans & Black, 2008). Narrative analysis of detailed data from an individual with a history of severe sexual abuse in childhood illustrated the effects of abuse on a woman's experience of pregnancy. This woman described poor diet, significant pelvic pain, nightmares, dissociation, fainting, excessive working and childbirth fear (Smith, 1993). Other forms of abuse in childhood are also associated with emotional distress, drug use and self harm during pregnancy (Minnes *et al*, 2008; Babiker, 2009).

3.4. Summary

The extensive research in the area of social and relational factors on mental health during pregnancy suggests that a predominantly medical and diagnostic framework for understanding women's mental health is limited and unlikely to point to potential solutions to the origins of the problems. Although there is an increasing quantity of research examining mental health in pregnancy, there is a widespread lack of public and patient involvement in producing research in this area, which is dominated by research within the medical model and by top-down and expert-driven knowledge production. Many quantitative studies rely on researcher-defined categories and use standardised measures that aim to reduce women's distress to numerical and criterion or norm-referenced representations of experience. The lack of comprehensiveness and clarity provided in much of the national guidance arises from limited inclusion of research based on standards that rely on a positivist/objectivist framework for assessing research quality and importance. This

may contribute to a broad lack of professional confidence in knowledge about mental health during pregnancy. Although current policy encourages service user involvement in research and service development, there are few opportunities for women with experience of mental health problems during pregnancy to significantly influence professional guidance and training.

The mainstream academic literature lacks a clear platform for women's voices about their own experiences of mental health, maternity and health services to be heard, rather than their symptoms measured (Jomeen, 2012). The following chapter will examine the existing qualitative research that explores women's experiences of mental health during pregnancy, and aims to develop a greater depth of understanding of this area than it has been possible to provide on the basis of the literature summarised in this chapter.

CHAPTER FOUR

FOCUSED LITERATURE REVIEW: WOMEN'S EXPERIENCES

4.1. Introduction

The approach taken in this research prioritises knowledge that is developed through participatory processes, emphasising that knowledge about women's experiences should not be limited by professional or academic ways of understanding. To remain consistent with the overall approach to this research, it was important to examine existing literature that was appropriately broad in its focus, so as to remain inclusive in developing our understanding of women's experiences of mental health. As part of a participatory research project, the literature review process was discussed with the members of the research team who were mothers with firsthand experience of mental health problems during pregnancy. None of the community co-researchers wished to have direct involvement in identifying and reviewing the academic literature, but were interested to hear of the outcome of the review.

4.1.1. Aim of the review

The aim of this literature review was to focus on qualitative research that prioritises accounts of women who have firsthand experience of mental health problems during pregnancy. Because of the importance placed upon non-professional understandings, this literature review has been undertaken with a view to developing a focussed understanding of how women experience poor mental health during pregnancy, without being limited by the imposition of specific diagnostic categories. This decision was also informed by debates in the literature regarding the relative

usefulness of diagnosis in mental health research (for example: Boyle, 2007; Moncreiff, 2007, Harper, Cromby, Reavey, & Cooke, 2007).

4.1.2. Approach to reviewing the literature

Although some authors have undertaken reviews of qualitative literature that aim to synthesise the findings from the papers reviewed, this approach is not without its complexities. There are arguments in the literature regarding the relative value of undertaking such an exercise. A potent argument relates to the importance of bringing together the qualitative research on a subject to inform practice and policy, rather than leaving unintegrated pockets of knowledge to exist in isolation and relative obscurity (Walsh & Downe, 2005). However, others suggest that synthesis can destroy the integrity of the original research and can reduce the complexity and richness of data generated into one coherent account that loses much of the range of meaning incorporated in the many (Sandelowski, Docherty & Emden, 1997). In this literature review, the research identified and reviewed is undertaken from a range of theoretical and epistemological perspectives, using diverse methodologies. The research topics are varied, and the methodological approaches do not produce findings that can be easily synthesised. Zimmer (2006) suggests that synthesis is most appropriate when the included literature uses similar methodologies and is underpinned by approaches to knowledge that share assumptions.

Sandelowski and Barroso (2007) identify the need to analyse the reviewed literature to determine the type of analysis or synthesis that is appropriate. They outline a typology for classification of research reports depending on the level of transformation of data within the reported analysis. The typology represents a continuum from completely untransformed data, such as an oral history, through to complex interpretive explanations, such as a grounded theory generated by the

researchers from the data. Sandelowski and Barroso argue that qualitative metasynthesis is an interpretive process that integrates and synthesises findings from research reports that fall at the end of the highly transformed and interpretive end of the continuum. The authors suggest that metasummary is a more quantitatively oriented approach for literature that falls primarily on the less transformed end of the continuum. Further detail regarding the analysis of typology represented within the identified literature for this review is provided in the findings section below. To summarise for the purpose of this introductory section, literature identified within this review fell across the continuum of data transformation. Neither metasynthesis or metasummary, as described by Sandelowski and Barroso, fit both with the variation within the identified literature, and the theoretical position employed within this research. The authors suggest that ‘the data-as-constructed view is antithetical to the qualitative research enterprise as we portray it here’ (p. 140). They describe the ‘data-as-constructed’ position as holding that data is never truly raw, but is constructed in the process of generation. They argue that their approach to validity within the process of synthesising data requires the reviewer to be committed to producing an account of the literature that reflects a truth about the real world. In this way, their approach to metasynthesis can be seen to prioritise a realist epistemology. Mays, Pope and Popay (2005) similarly identify their ‘subtle realist’ perspective as acknowledging that ‘while there may well be multiple descriptions or explanations of phenomena, these ultimately relate to some underlying reality or truth’ (p. 7). They argue that critique of the attempts at synthesis is informed by a relativist perspective and that ‘Relativists would suggest that differences in theory and method are fundamental and militate against integration of research’ (p. 7). The authors point to the increasing popularity of mixed-method research and argue that synthesis is a

logical extension of this approach. However, they do not tackle the complexity of fundamental epistemological differences across research reports included in a literature review or give a sound theoretical justification for employing a mixed method or synthesising approach.

Rather than assuming that the published literature reflects an underlying truth that exists in the 'real world', it can be seen to illustrate what academics and professionals position as important in relation to mental health during pregnancy.

The aim of undertaking this review was to explore the current academic knowledge of women's experiences. This information was used to inform the research team about how antenatal mental health is currently understood within the literature as this has broadened our perspective as we undertook our own research. The findings of this review also provide a point of comparison and theoretical context for the findings of our research.

4.2. Literature Search

Due to the importance of accessing a wide range of literature, the search included the following databases: AMED, BNI, MEDLINE, PsycINFO, CINAHL, EBSCO Academic Search Elite and EMBASE. The definition of mental health problems was kept deliberately broad and as inclusive as possible. Rather than impose professionally defined limits on the search by focusing on a particular diagnostic category, and with a view to accessing an inclusive set of relevant literature, the search used the terms: experience AND (pregnan* OR antenatal OR prenatal) AND ('mental health' OR 'mental illness' OR depression OR anxiety OR emotional OR distress OR 'personality disorder' OR obsessive OR bipolar OR psychosis) AND qualitative. This search generated the following number of results across the databases.

CINAHL: 145

EBSCO: 52

EMBASE: 112

MEDLINE: 459

PsychINFO: 33

AMED: 12

Inclusion criteria for the review were: published, peer reviewed, empirical qualitative research studies undertaken with women, reported in English language journals. The studies were included if they reported original, qualitative research that provided data and analysis of firsthand accounts of women's experiences of poor mental or emotional health during pregnancy. Where dissertations were identified in the database searches, the abstracts were scanned for inclusion criteria, and further searches were conducted for publications by the named author.

The search results were scanned by title to identify relevant papers. Where the title was unclear, the abstract was reviewed to examine the publication for relevance.

Duplicates across databases were manually identified and removed from the set to be reviewed.

This process resulted in the identification of a total of 29 citations which either met the inclusion criteria for the review or which did not include sufficient information in the abstract to provide a clear rationale for exclusion. These 29 papers were included for review of the full content, at which time further papers were excluded due to lack of relevant content. The reasons for exclusion were as follows:

- One publication was a review of the existing literature, and did not report original findings.

- Two papers were excluded because they reported quantitative research and did not contain firsthand accounts of women's experience of mental health during pregnancy.
- Two articles were excluded because they reported findings from qualitative studies in which couples were interviewed about women's experiences during pregnancy, and the women's own experience was not the primary focus of analysis.
- A further eleven papers were excluded because the reported data and analysis did not focus on women's experiences of mental health during pregnancy. Whilst the focus of these papers could be considered relevant to women's mental health, they did not directly address women's experiences of mental health during the pregnancy. The subjects of these studies were: women's experience of domestic abuse during pregnancy; incarcerated women's experience of doula support during pregnancy; adolescent women's experience of pregnancy and motherhood; Kurdish women's experiences of their first pregnancies; women's experience of pregnancy following in vitro fertilisation; the experience of pregnancy among women who are street sex workers; and a qualitative validation of the Edinburgh Postnatal Depression Scale.

These papers were read fully and evaluated regarding whether the findings reported were relevant to an examination of women's experiences of mental health during pregnancy.

The remaining 13 papers were included in the review. The dates for inclusion in the review were not limited, however, it perhaps reflects the trends within pregnancy-focused research that all identified qualitative research reporting on women's

experience of mental health during pregnancy were published after 1999. The search was undertaken during November 2010. Papers were searched for any secondary references, following the same process of exclusion outlined above. The full text of remaining articles was examined, but none were identified that met the review criteria. See figure 4.1 for details of literature search process. Following the initial literature search in 2010, further periodic searches were conducted without identifying additional research that met the review criteria. One additional qualitative report was examined (Haga, Lynne, Slinning, & Kraft, 2012), but was found to be primarily focused on postnatal women's experiences of emotional wellbeing, with very limited discussion of depressive symptoms during pregnancy and was therefore not incorporated into the current review.

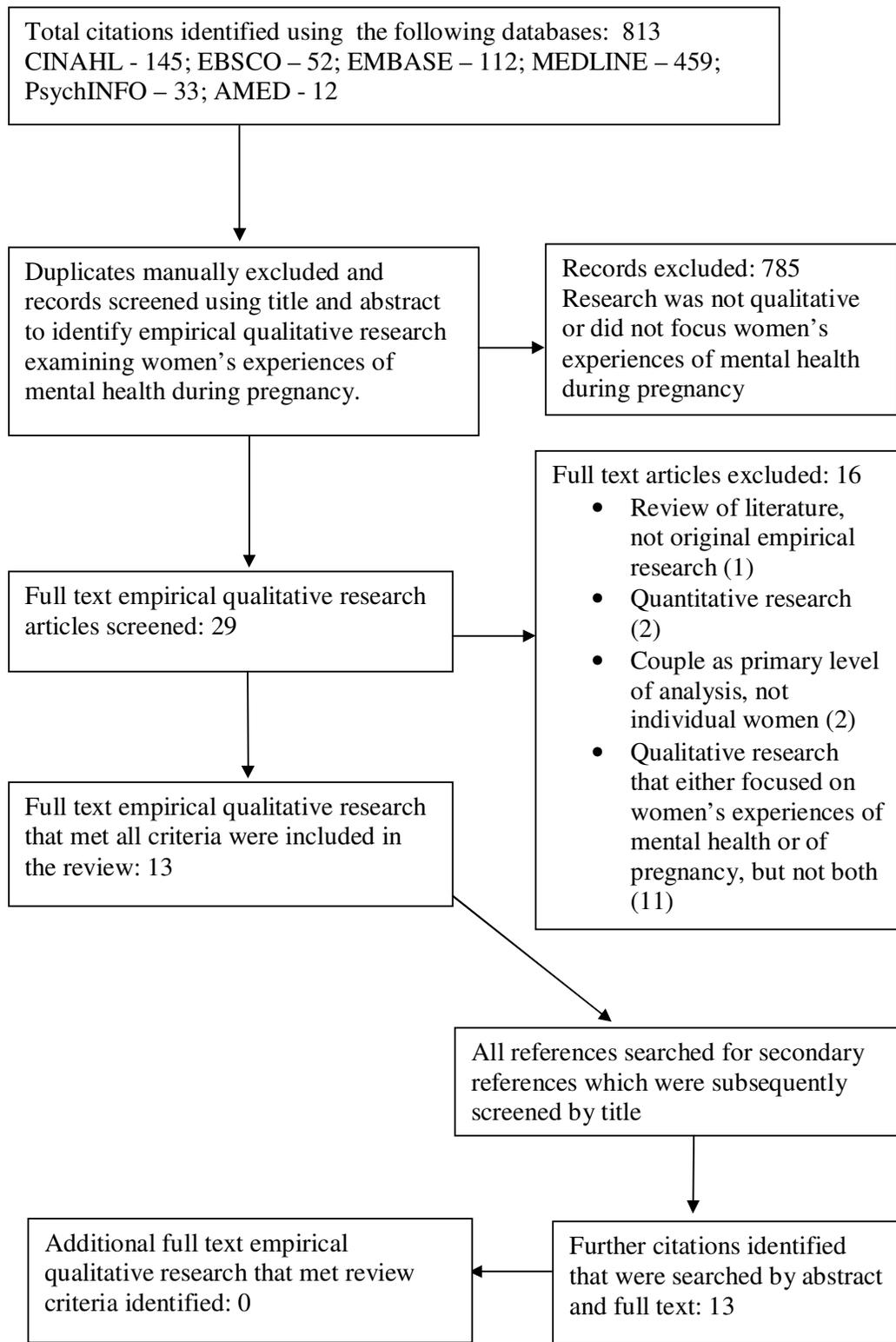


FIGURE 4.1 - FLOW DIAGRAM OF THE LITERATURE SEARCH

4.3. Critical Evaluation of the Literature

The research included in the review has been evaluated against a set of quality standards outlined by Kuper, Reeves and Levenson (2008), Yardley (2000), Willig (2001), Elliott, Fischer and Rennie (1999), in the Health Technology Assessment by Murphy and colleagues (1998) and the Critical Skills Appraisal Programme (2002). Within this broad range of frameworks for evaluating qualitative research, there are a number of overlapping criteria which point to a developing consensus in evaluating the quality of qualitative research. In particular, research in this review was examined for:

- Clarity of reporting, including providing information about the research context to enable evaluation of transferability of results
- Transparency in the reporting of method and process of analysis
- Appropriateness of method, sampling and analysis to address the research questions
- Attention given to issues of researcher assumptions, reflexivity and relationship with research participants
- Consideration given to ethical issues of research involving human participants
- Clarity and coherence in description of epistemology and claims about trustworthiness of the research
- The presence of articulated and congruent description of measures taken to ensure trustworthiness
- Comprehensiveness of the analysis and data
- Whether the analysis is presented with sufficient data to enable the reader to evaluate the fit between data and analysis

4.4. Findings

4.4.1. *Typology of literature*

The literature included in this review includes reports of relatively straightforward thematic analyses of data content, conceptual and thematic descriptions, and complex theoretical or process models built from authors' interpretation of data. The literature identified fell across three categories of typology as identified by Sandelowski and Barroso (2007). The continuum includes reports of findings that have different levels of transformation from the original data. These are outlined below, beginning from the least transformed data:

- Thematic survey – research findings that provide descriptions of themes and patterns as identified by the researchers (Coles & Jones, 2009; Côté-Arsenault & Mahlangu, 1999; Furber, Garrod, Maloney, Lovell & McGowan, 2009; Raymond, 2007; Sanders, 2008; Tseng, Hsu, Liu, & Chen, 2008)
- Conceptual/thematic description – research findings that describe one or more concept or theme developed from the data or imported from theory (Eriksson, Jansson, & Hamberg, , 2006; Nilsson & Lundgren, 2009; Rose *et al*, 2010; Schwerdtfeger & Wampler, 2009)
- Interpretive explanation – research findings that provide a fully integrated explanation of the phenomenon or a developed theory/model (Bennett, Boon, Romans, & Grootendorst, 2007; Côté-Arsenault & Freije, 2004; Lutz, 2005)

Although there are substantial differences in relation to topic, epistemology, method and transformation of data, it has been possible to identify a number of common themes that emerge across the range of literature reviewed. The existence of these

commonalities is of interest due to the diversity within the literature, and suggests that women's accounts of their experiences of mental health in pregnancy may share a number of important features. These features may be considered to reflect objective reality, constructions arising from the process of data generation or the dominance of particular discourses or social representations of pregnancy and mental health within culture. This review does not offer these findings as a representation of the truth. The areas of commonality are the focus of this review. The review does not intend to comprehensively summarise or synthesise the findings of all of the identified research, although these are briefly outlined in Table 4.1.

The research identified in this review primarily focuses on specific diagnoses or life events and experiences such as depression, childbirth fear, intimate partner violence, physical health problems, history of child sexual abuse and previous pregnancy loss. Little research focuses on mental health within pregnancy as defined by women themselves. One paper reported research focused on women's experiences of 'mild to moderate distress' as self-identified by women to their midwifery professionals (Furber *et al*, 2009). One paper reported research focused on retrospective self-identification of 'feeling low or depressed' (Raymond, 2007). Appendix A provides a summary of the research included in this review.

4.4.2. Overview

The literature identified in the review fell into two broad categories according to the general topic of the research. The studies either focused on current mental health problems, or current and previous experiences that have had a negative impact on women's mental health. Most of the research on current problems focused on a particular category of mental health problem. Three studies examined women's experiences of depression (Bennett *et al*, 2007; Raymond, 2009; Tseng, 2008), two examined women's experiences of intense fear of childbirth (Eriksson *et al*, 2006; Nilsson & Lundgren, 2009), and one examined women's experiences of self-defined mild to moderate emotional distress (Furber *et al*, 2009). Of the research that explored the effect of particular experiences on women's mental health during pregnancy, four of the studies focused on women's experiences of abuse. Two of these papers reported women's experience of intimate partner abuse during pregnancy (Lutz, 2005; Rose *et al*, 2010), and two reported women's experiences of childhood sexual abuse or previous sexual trauma (Coles & Jones, 2009; Schwerdtfeger and Wampler, 2009). In addition to the research focusing on the impact of abuse experiences on women's mental health, two papers reported women's experiences of pregnancy following a previous pregnancy loss (Côté-Arsenault & Mahlangu, 1999; Côté-Arsenault & Freije, 2004) and one reported women's experiences of pregnancy following diagnosis as HIV positive (Sanders, 2008). All of the research focusing on the effect of previous or current experiences on women's mental health during pregnancy addressed experiences that were described by the authors as traumatic (abuse, pregnancy loss and diagnosis with HIV).

4.4.3. *Methodological approaches*

Of the 13 studies included in this review, 11 reported individual interviews with women as the only source of data. The only exceptions to this were the two studies focused on women's experiences of previous perinatal loss (Côté-Arsenault & Mahlangu, 1999; Côté-Arsenault & Freije, 2004). The earlier of these studies used data from a self-report questionnaire with a number of short answer open questions, and the later research was an ethnographic study that included data from interviews, observations, questionnaires and artefacts including professional manuals, newsletters, video tapes and a CD-ROM. The interviews were described variously as 'semi-structured' (Bennett *et al*, 2007; Coles & Jones, 2009; Furber *et al*, 2009; Raymond, 2009; Rose *et al*, 2009; Schwerdtfeger & Wampler, 2009); 'in-depth' (Bennett *et al*, 2007; Lutz, 2005; Tseng *et al*, 2008), 'open' (Eriksson *et al*, 2006) and two interview protocols were not named, but were described as taking an approach that began with one or two questions and continued with a series of prompts depending on the direction taken by the interviewee.

The research designs and epistemological approaches also varied across the literature reviewed. There were two studies undertaken using a traditional Grounded Theory approach (Bennett *et al*, 2007; Eriksson *et al*, 2006); one using a Dimensional Analysis approach to Grounded Theory (Lutz, 2005); three studies used thematic analysis (Coles & Jones, 2009; Côté-Arsenault & Mahlangu, 1999; Raymond, 2009), three studies used phenomenology (Nilsson & Lundgren, 2009; Sanders, 2008; Schwerdtfeger & Wampler, 2009), one used a focused ethnography (Côté-Arsenault & Freije, 2004), one used framework analysis (Furber *et al*, 2009), one used content analysis (Tseng *et al*, 2008), and one used a qualitative approach that was not specified (Rose *et al*, 2010).

Epistemological approaches were not specified in six of the studies. Three studies were described as phenomenological (Nilsson & Lundgren, 2009; Sanders, 2008; Schwerdtfeger & Wampler, 2009), one was constructivist (Raymond, 2009), one was social constructionist (Eriksson *et al*, 2006), one was symbolic interactionist (Lutz, 2005) and one was constructivist/symbolic interactionist (Bennett *et al*, 2007). The methodological approaches, data sources and epistemological positions of the studies are summarised in Table 4.1.

Authors	Methodology	Data	Epistemology
Bennett <i>et al</i> , 2007	Grounded theory	In-depth, semi-structured interviews	Constructivism/ Symbolic interactionism
Coles & Jones, 2009	Thematic analysis	Semi-structured Interviews	Not stated
Côté-Arsenault & Mahlangu, 1999	Thematic analysis	Questionnaire	Not stated
Côté-Arsenault & Freije, 2004	Focused ethnography	Observations, interviews, questionnaires & artefacts	Not stated
Eriksson <i>et al</i> , 2006	Grounded theory	Open interviews	Social constructionism
Furber <i>et al</i> , 2009	Framework analysis	Semi-structured interviews	Not stated
Lutz, 2005	Grounded Theory - Dimensional Analysis	In-depth interviews	Symbolic interactionism
Nilsson & Lundgren, 2009	Phenomenology	Interviews	Phenomenology
Raymond , 2009	Thematic analysis	Semi-structured interviews	Constructivism
Rose <i>et al</i> , 2010	Not specified	Semi-structured	Not stated
Sanders, 2008	Phenomenology	Interviews	Phenomenology
Schwerdtfeger & Wampler, 2009	Descriptive phenomenology	Semi-structured interviews	Phenomenology
Tseng <i>et al</i> , 2008	Content analysis	In-depth interviews	Not stated

TABLE 4.1 - SUMMARY OF RESEARCH METHODS, DATA AND EPISTEMOLOGICAL PERSPECTIVES

Although there were different topics of investigation, and diverse methodological and epistemological approaches, there were many overlapping themes within the research identified in this review. The themes will be discussed below, followed by a critical review of the literature identified.

4.5. Common Themes

The approach taken to presenting findings from the literature reflects the Thematic Survey category of typology outlined by Sandelowski & Barroso (2007). This was identified as the most common category of typology following analysis of the reviewed literature. A diagram of the themes reflecting the patterns and connections between themes is given after the thematic survey (Figure 4.5). Table 4.2 provides an overview of which themes appear in which of the papers included in this review.

The first part of this section will summarise the descriptions given by women of their mental health problems. This will be followed by an examination of the contexts and conditions that women describe existing in relation to their mental health. These include:

- Women's previous experiences, such as abuse, trauma and loss
- Their relationships
- Whether they describe feeling supported or unsupported in their lives
- Their socio-economic conditions
- Their experiences of negative judgements by others

The third section will address women's descriptions of the impact of their mental health upon their sense of self and identity, their own internalised stigma, shame and self judgment, and their relationships with their babies.

Fourthly, women's accounts of their strategies for managing their mental health will be examined, followed by the implications for practice that are presented across the literature.

Theme	Bennett <i>et al</i> , 2007	Coles & Jones, 2009	Côté- Arsenault & Mahlangu, 1999	Côté- Arsenault & Freije, 2004	Eriksson <i>et al</i> , 2006	Furber <i>et al</i> , 2009	Lutz, 2005	Nilsson & Lundgren, 2009	Raymond <i>et al</i> , 2009	Rose <i>et al</i> , 2010	Sanders, 2008	Schwerdt- feger & Wampler, 2009	Tseng <i>et al</i> , 2008
Descriptions of mental health	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Socio-economic adversity									✓	✓			✓
Lack of support	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓		✓
Self-criticism/judgement	✓	✓			✓		✓	✓	✓	✓		✓	
Judgement by others	✓		✓				✓	✓		✓	✓		✓
Strategies for managing (+ & -)	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Confounded expectations	✓			✓	✓		✓	✓					✓
Dual identities							✓				✓	✓	✓
Relationships	✓		✓	✓		✓	✓		✓	✓	✓	✓	✓
Pregnancy/mental health interactions	✓	✓		✓		✓	✓	✓				✓	✓
self and identity	✓		✓	✓	✓		✓	✓		✓	✓	✓	
Implications for practice	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	
Abuse		✓				✓	✓		✓			✓	
Alcohol & drugs						✓	✓			✓	✓		
Relationship to baby	✓	✓	✓	✓	✓		✓	✓		✓	✓	✓	✓
Causes of distress		✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓
Stigma/shame	✓						✓	✓	✓		✓		
Being a good mother	✓	✓			✓		✓	✓	✓	✓	✓		✓

TABLE 4.2 - SUMMARY OF THEMES ACROSS PAPERS INCLUDED IN THE LITERATURE REVIEW

4.5.1. *Women's accounts of their mental health problems*

Although much of the research focused on a particular diagnostic category, or a particular category of experience, there were many areas of commonality in the ways that women described their experiences.

All of the research reviewed gave descriptions of women's experiences of mental health problems. However, women's experiences were often presented in professionalised language, as summarised by the authors. These descriptions frequently used objective diagnostic categories such as anxiety, depression and posttraumatic stress disorder. Where the data was directly represented in the report, participants often used more dramatic and colloquial language. Whilst Bennett and colleagues (2007) described women's experiences of travelling into despair and managing depression, they reported women's descriptions including 'downward spiral', 'wandering around in a blur', 'teetering', 'going crazy', 'falling apart', 'crash and burn', 'into the pit of hell' and 'over the edge'. Although the detail of language use was not the focus of this research paper, it is of interest that this group of participants presented their symptoms using a range of physical metaphors. This was not apparent in other research within the literature review; however it presents a striking use of descriptive language where women's mental health exists in parallel with the embodied condition of pregnancy.

Women's experiences of low mood were described in less catastrophic language, but many of these descriptions related to associated physical experiences, including feeling burdened by the physical load of pregnancy, fatigue, lack of energy and sleeping problems. Women also described feeling loss of freedom, emotional instability, body image dissatisfaction, forgetting and reduced capacity leading to irritability and fragility of mood (Tseng *et al*, 2009). It is important to note that these

descriptions were presented in an English language journal in translation from the original interview transcript in Chinese language. As in all qualitative research, the authors will have also selected quotations for relevance in the report, and may not have prioritised inclusion of the variety of respondents' descriptions of their experiences.

Because the focus of several of the studies related to different kinds of abuse, either during or prior to pregnancy, many of the papers described women's experiences resulting from trauma. Women's experiences following sexual abuse in childhood were described as distress; intrusive memories of abuse; guilt; anger, vigilance, feelings of vulnerability. Researchers' analysis suggested that pregnancy care can increase feelings of powerlessness and vulnerability for survivors of sexual abuse (Coles & Jones, 2009). Similarly, women who had previous experiences of sexual trauma, either during childhood or adulthood described intrusive memories of the trauma, overwhelming emotions, sadness, guilt, anger, loneliness, stress, unclean feelings, changes to their experience of sexuality, loss of self-esteem and mistrust in social relationships (Schwerdtfeger & Wampler, 2009).

Descriptions of feeling vulnerable were common within the literature. Research relating to intimate partner abuse and previous pregnancy loss both identified feelings of vulnerability and fear. Some participants in research relating to intimate partner abuse disclosed fears of harm to their baby due to violence (Lutz, 2005).

Women who had previously lost a baby during the perinatal period also described feeling vulnerable and anxious about the pregnancy, feelings of loss and grief, anger, depression, stress and trauma resulting from the previous loss (Côté-Arsenault & Mahlangu, 1999, Côté-Arsenault & Freije, 2004).

Anxiety relating to a range of issues was frequently presented in the literature. Women described anxiety in relation to pregnancy loss, but also anxiety and intense fear in relation to childbirth itself. Women who had an intense fear of childbirth described feeling physical manifestations of anxiety in addition to mood swings, absentmindedness, feeling trapped, and feeling isolated and lonely in having to face delivery of the baby (Eriksson *et al*, 2006; Nilsson & Lundgren, 2009). Women with a diagnosis of HIV prior to becoming pregnant expressed anxieties in relation to the impact of the pregnancy on their own health and the impact of their HIV positive status on the health of the baby (Sanders, 2008). Women who were undergoing treatment for depression were also anxious about the potential impact of anti-depressant medication on their babies' health, as compared with the potential harm to the baby of having a depressed mother (Bennett *et al*, 2007). Distress during pregnancy was identified as leading to problems with eating, constant worry about cleanliness and disengaging from the pregnancy (Furber *et al*, 2009).

Isolation and loneliness was also a common feature of women's experiences of mental health problems during pregnancy. This related to different circumstances in the various groups of participants. For some women who experienced intimate partner violence, the isolation related to controlling behaviour and abuse by their partners (Lutz, 2005). Women who experienced depression described loneliness and isolation in relation to social withdrawal (Bennett *et al*, 2007; Raymond, 2009).

Women who had experienced a previous sexual trauma also described loneliness (Schwerdtfeger & Wampler, 2009).

Experiences of loneliness and anxiety were common in the research reporting women's experiences of depression in pregnancy (Raymond, 2009; Tseng *et al*, 2008). Participants also described feeling unable to function, feeling out of control,

experiencing irrational emotions, intrusive negative thoughts and social withdrawal (Bennett *et al*, 2007). Those women who took part in research following self-identification as experiencing ‘mild to moderate distress’ described a wide range of mental health problems, including many of those identified within research focused on more narrowly defined clinical populations. The women with mild to moderate distress described problems of depression; stress; panic; crying; anxiety about the pregnancy due to previous perinatal loss; anxiety about the birth following previous traumatic delivery and anxiety about their future mental health arising from previous experiences of postnatal depression (Furber *et al*, 2009).

Although the literature includes research that focuses on particular experiences and diagnoses, there are significant areas of overlap amongst women’s descriptions of their experiences.

4.5.2. *Contexts and conditions*

The literature included in this review also shows a broad range of common themes relating to the conditions that women described as contributing to their distress and mental health problems.

4.5.2.1. Lack of support

Lack of support was one of the most common conditions that research identified in relation to women’s distress in pregnancy. Women identified a range of relationships in which they felt unsupported; these included those with professionals, family, partners, communities and friendships.

4.5.2.2. Lack of support from professionals

Some women diagnosed with depression found that some professionals seemed too busy to offer support (Bennett *et al*, 2007), and that professionals did not ask about

women's feelings, but rather focused on the health of the baby, resulting in the woman feeling like nothing but 'a baby carrier' (Raymond, 2009). Amongst women who had experienced a previous perinatal loss, some participants felt their emotional needs were not met by health workers during the current pregnancy (Côté-Arsenault & Freije, 2004). Women who presented to services with an intense fear of childbirth described feelings that there was no help available, that midwives did not understand the degree of their fears, and that staff were unsympathetic toward their fears (Eriksson *et al*, 2006; Nilsson & Lundgren, 2007). HIV positive women described feeling that they were treated differently to other pregnant women who were not HIV positive (Sanders, 2008). Some women who experienced intimate partner abuse felt unsupported by the police, and one woman described how the risk of violence toward her was increased by a police officer informing her abusive partner about her allegation (Rose *et al*, 2010).

4.5.2.3. Lack of support from family and friends

Women who participated in research focused on depression identified that they felt unsupported by members of their family and by friends. Some women identified that they did not actively seek support due to social withdrawal or covering up their depression to avoid experiencing associated stigma (Bennett *et al*, 2007; Raymond, 2009). Similarly, women with HIV described feeling isolated and unable to share experiences of pregnancy with other women due to avoiding disclosure of their HIV status (Sanders, 2008). Other women described feeling unsupported or criticised by family members in spite of seeking help and support (Sanders, 2008; Tseng *et al*, 2008). Women with extreme childbirth fears described that their family members dismissed their fears, and friends did not understand how frightened they felt (Eriksson *et al*, 2006; Nilsson & Lundgren, 2007). Women taking part in research

focused on previous perinatal loss expressed feeling that people were reluctant to raise the issue of loss for fear of causing upset to the woman, and therefore were not able to offer emotional support (Côté-Arsenault & Freije, 2004).

4.5.2.4. Lack of support from partners

Although it is predictable that women with experience of intimate partner violence reported feeling unsupported by their partners (Lutz, 2005; Rose *et al*, 2010), many other research participants described lack of support by their partners in a range of circumstances including previous perinatal loss, experiences of mild to moderate distress, childbirth fear, and depression (Côté-Arsenault & Mahlangu, 1999; Furber *et al*, 2009; Nilsson & Lundgren, 2009; Raymond 2009; Tseng *et al*, 2008). Some research identified that women felt their partners did not understand their emotional experiences (Furber *et al*, 2009), or were unable to relate to the woman's experience of a previous perinatal loss (Côté-Arsenault & Freije, 2004). Two of the papers that focused on the experience of depressed women also identify conflict with partners, actual withdrawal by partners, and fears of abandonment by partners as a source of distress for women during pregnancy (Raymond, 2009; Tseng *et al*, 2008).

Women's relationships were identified in the majority of studies as having an impact on their experiences of mental health during pregnancy. Qualitative research frequently identifies a range of diverse experiences within a group of research participants. It is important that not all of the women's experiences of relationships were negative.

4.5.2.5. Supportive relationships

Many participants within the reviewed research identified that a range of supportive relationships had a positive impact on their mental health during pregnancy.

Although it is demonstrated in the previous section that unsupportive and abusive relationships with partners as a source of distress for women, there were several studies that identified relationships with partners as a source of emotional or practical support (Bennett, 2007; Côté-Arsenault & Malangu 1999; Furber *et al*, 2009, Schwerdtfeger & Wampler, 2009).

Positive relationships with professionals were identified in a depression-focused study as a part of women's recovery (Bennett *et al*, 2007), and some women with HIV were able to change health care providers in order to find professionals who treated them with respect and offered supportive health care (Sanders, 2008). All of the women in a study focused on experience of pregnancy following a previous perinatal loss were able to identify five individuals, including mothers, partners friends, sisters and co-workers, to whom they would be able to talk about their pregnancy. However the authors identify that none of the people named on a list of the most helpful or supportive towards the women were nurses or doctors (Côté-Arsenault & Mahlangu, 1999).

4.5.2.6. Judgement by others

Relationships represented within the literature were not simply characterised as supportive or unsupportive. Seven of the thirteen included studies identified a further relational issue identified within the analysis of qualitative data from women with emotional and mental health problems during pregnancy. Participants within these studies expressed feeling blamed, judged or criticised by others with whom they interacted in their every-day lives. Participants in research focused on women's expressed expectations that they would be judged by others as lazy and attention seeking in relation to their difficulties with low mood. They also described fears of being negatively judged for taking anti-depressant medications whilst pregnant

(Bennett *et al*, 2007). Similar expectations and fears emerged in a study of Taiwanese women, who expressed fears of blame and criticism from their in-laws for not knowing how to take care of the baby (Tseng *et al*, 2008). Although this research was conducted in a non-Western cultural context, the described experiences parallel those from research conducted in the UK and North America.

Research focusing on intimate partner violence identified women's experiences of negative judgements from a range of sources. These included criticism from:

- Cultural and religious communities of women who ended relationships because of intimate partner abuse (Lutz, 2005)
- Family members, because of the abuse they experienced in their relationships (Rose *et al*, 2010)
- Abusive partners who taunted and ridiculed them (Lutz, 2005).

Specific judgement of women in relation to their experience of pregnancy included:

- Blame by a woman's friends and family for the loss of a pregnancy due to excessive work (Côté-Arsenault & Mahlangu, 1999)
- Fears of judgement by others as an inferior mother-to-be because of a woman's fear of childbirth (Nilsson & Lundgren, 2009)
- Negative responses and judgements by professionals regarding the choice to become pregnant following diagnosis with HIV (Sanders, 2008).

As the literature represents women's perspectives and experiences of their relationships, it is not straightforward to conclude that these reflect in a direct and accurate way the objective nature of women's relationships, but rather their subjective experiences. Some examples of criticism and judgement are reported in the literature as women's actual experiences, but some relate to criticism and judgement that was anticipated or feared. However, some of those fears appear to be

grounded in experience as described by research participants. For research participants with HIV, some of their fears and experiences of judgement by professionals are connected with their reported experiences of child protection proceedings and loss of children into care due to their addiction to narcotics (Sanders, 2008).

4.5.2.7. Drugs and alcohol

The effects of drugs and alcohol in relation to pregnancy were examined in four of the studies included in the present review. In the two studies that focused on intimate partner violence, research participants described use of drugs and alcohol by abusive partners and family members who were abusive during the women's childhoods (Lutz, 2005; Rose *et al*, 2010). Women who experienced abuse in relationships also described using drugs or alcohol as self medication, or because they were coerced by abusive partners (Lutz, 2005). Some women's experience of using drugs resulted in contracting HIV, and also in losing their children into care (Sanders, 2008).

Research focused on experience of mild to moderate distress during pregnancy identified that alcohol had been used as an escape from work pressures, and was no longer used due to the pregnancy. For this reason, women described alcohol as no longer being an available means to manage distress (Furber *et al*, 2009). Women's experience of drug and alcohol use as identified in the literature was diverse and varied between women's life circumstances. Some women who used alcohol to manage stress at work described different life pressures compared with women who were in abusive relationships or who contracted HIV due to drug addiction.

4.5.2.8. Socio-economic conditions

Although several studies implied that women may have been living in difficult socio-economic conditions, only three of the studies reported data relating to this. Two studies identified housing problems, smallness of accommodation, lack of access to outdoor space and isolation in rural locations as issues affecting women's mental health (Raymond, 2009; Rose *et al*, 2010). A further study identified debt and financial pressures arising from having another baby as a source of stress for pregnant women (Tseng *et al*, 2008).

The research literature examined in this review describes contexts and conditions within which women experience problems of mental health and emotional distress during pregnancy. Women's relationships are a common theme across many of the studies reviewed, and these clearly have an important bearing on how women feel either supported or abandoned, criticised and judged. In addition to issues arising in the relational context of pregnancy, are women's experiences of substance use and socio-economic conditions. These are pertinent, but not so widely or comprehensively examined in the research literature.

Beyond the contexts and conditions within which women live, are the range of impacts of women's experiences of pregnancy and their experiences of mental health problems. These issues are examined in the next section of the review.

4.5.3. *Impact of mental health problems on women's experience*

There are a number of common themes within the literature that describe the impact of women's experiences of mental health during pregnancy. These themes relate to the ways that women talk about their appraisals of the experience of mental health problems in pregnancy. Research describes women's expressions of confounded expectations of pregnancy; their questions and concerns about their sense of self and

identity, including a sense of dual identities or roles; their experiences of shame, stigma and negative self-judgements; their feelings about their relationship to their unborn babies, and their concerns about becoming a good enough mother.

4.5.3.1. Confounded expectations

Six of the 13 research papers in the current review identified ways in which women's experiences of pregnancy did not meet their expectations. Women who experienced depression during pregnancy described disappointed expectations of the pregnancy itself. These expectations were based on reading books, talking to other women, and their own experiences of previous pregnancies. The research identified an expectation that everything in the pregnancy would be 'all roses', and these expectations did not correspond with the experience of depression during the pregnancy (Bennett *et al*, 2007). Expectations of happiness during the pregnancy were also described by women as surrendered due to experiences such as intimate partner abuse during the pregnancy (Lutz, 2005), fear of childbirth (Eriksson *et al*, 2006) and disappointed hopes of practical support from their partners and families (Tseng *et al*, 2008). Women who experienced extreme fear of childbirth found their expectations of themselves were not met. Women described the loss of a sense of themselves as tough and capable women, and an emergent self-image as someone who is weak and excessively afraid (Eriksson *et al*, 2006; Nilsson & Lundgren, 2009).

In addition to the sense of confounded expectations, a large proportion of the literature reported the impact of emotional and mental health problems on women's sense of their own identity.

4.5.3.2. Sense of self/identity

Research identified a range of ways in which women's sense of self was affected by their experiences of pregnancy. Frequently the sense of identity that was shaken or lost related to the women's sense of themselves as women and potential mothers.

Women who experienced depression expressed doubts about their maternal ability, and an altered perception of the self (Bennett *et al*, 2007). Women who lost a previous baby had doubts about their biological ability to produce a baby, and lost a sense of their maternal identity (Côté-Arsenault & Mahlangu, 1999; Côté-Arsenault & Freije, 2004). Women who experienced extreme fear of childbirth expressed feelings of inferiority and their self-image as weakened compared to other women without the same level of fear (Eriksson *et al*, 2006; Nilsson & Lundgren, 2009).

Some women struggled to develop an identity as a mother and experienced a loss of worth as a woman while experiencing abuse by an intimate partner (Lutz, 2005; Rose *et al*, 2010). There were few positive appraisals of self described by women in relation to their mental health in pregnancy; however research identified some women's experience as prompting spiritual changes, development of self knowledge and assertiveness, and a sense that the pregnancy completes the sense of self as a woman (Côté-Arsenault & Freije, 2004; Sanders, 2008).

For some women, experiences of pregnancy generated a sense of dual or multiple roles or identities. Research focusing on domestic violence emphasised the parallel existence of two lives consisting of a public pregnancy alongside a private and hidden experience of violence and abuse. In addition to these two parallel lives, were duties experienced by women arising from membership of religious or cultural groups. These duties sometimes had a direct bearing on the woman's position in an abusive relationship embedded within a community that did not sanction her

departure from the relationship (Lutz, 2005). In addition to the hidden experience of intimate partner abuse women were also living with other hidden identities, including that of HIV positive status. Women who were HIV positive struggled to balance their health and substance use with the demands and priorities of motherhood (Sanders, 2008). Research indicates that women described their private and past experiences as a survivor of sexual abuse as both compartmentalised and integrated in relation to their more public experience of pregnancy. Women described the desire to protect their unborn children from future experiences of abuse, and to give their children a life that was different to their own, where pregnancy could be the beginning of a new and hopeful time in their lives (Schwerdtfeger & Wampler, 2009).

In addition to these more traumatic experiences of women in relation to loss and abuse, women also described existing in multiple roles within the family and society, and struggling to maintain and manage demanding roles such as mother, wife, daughter and career woman (Tseng *et al*, 2008).

The private expectations, disappointments and role conflicts experienced by women in pregnancy exist in relation to public and social perceptions and stigma. The literature illuminates the impact on women of social expectations and stigma in relation to aspects of their experience.

4.5.3.3. Stigma, shame and self-judgement

Women are described in the literature as experiencing stigma and shame in relation to a range of different experiences. Research participants in studies focused on depression describe shame and embarrassment about their mental health. Women describe expectations that they will be judged by others. As a consequence they maintain secrecy about their mental health, avoid talking about their depression due

to shame, and do not seek help and support because of embarrassment (Bennett *et al*, 2007; Raymond, 2009). Women expressed feelings of inadequacy, guilt and shame about their fears of childbirth (Nilsson & Lundgren, 2009), and described stigma about intimate partner abuse and HIV status (Lutz, 2005; Sanders, 2008).

The research literature reviewed contains a range of negative self-judgements as expressed by participants. These include:

- Feelings of failure due to the depression (Bennett *et al*, 2007)
- Self-blame for failing to protect their children where they felt that inappropriate clinical examinations had been undertaken (Coles & Jones, 2009)
- Feeling inferior, weaker, guilty and ashamed because of fear of childbirth (Eriksson *et al*, 2006; Nilsson & Lundgren, 2009)
- Embarrassment, shame and self-blame about experiences of abuse (Lutz, 2005, Rose *et al*, 2010)
- Descriptions of self-appraisals of weakness, worthlessness and dirtiness because of experiences of sexual trauma (Schwerdfeger & Wampler, 2009).

The literature illustrates how negative self-judgements about their mental health and life circumstances relate to women's perspectives on their abilities to be adequate mothers. Nine of the thirteen studies included in this review contain participants' expressions of anxiety and concern in relation to their capacity to be a good mother.

These anxieties are expressed in relation to:

- Concerns that depression could potentially harm the baby (Bennett *et al*, 2007; Raymond, 2009)

- Women's post-traumatic reactions to medical interventions and ability to protect their children from inappropriate examinations and professional touch (Coles & Jones, 2009)
- The ability to be in a good enough state to meet the new-born due to their dread of childbirth (Eriksson *et al*, 2006; Nilsson & Lundgren, 2009)
- The capacity to protect the baby from intimate partner violence and difficulties with bonding during pregnancy due to violence (Lutz, 2005; Rose *et al*, 2010).

Women had previous experiences of losing children into care due to addictions (Sanders, 2008), and struggling to be a good enough mother to their older children due to inexperience (Tseng *et al*, 2008). Therefore some research participants had previously experienced the difficulties that they were anticipating with their future children.

A predictably significant element of the research identified in this literature review related to women's feelings about becoming a mother. Many participants expressed particular concerns because of their mental health and the impact they felt it may have on their parenting. Alongside this were their reflections about their emerging relationships to their babies.

4.5.3.4. Relationship to the baby

Eleven of the 13 papers included in this review contained references to the development of women's relationship to the baby they were carrying. The research described concerns that connected the women's current difficulties with her fears about her current and future abilities to care for the baby. Where research focused on women's experiences of depression, participants expressed fears that their condition would harm the baby or that the baby may become depressed. Some women

expressed feeling sorry for the baby being born to a depressed mother (Bennett *et al*, 2007; Tseng *et al*, 2008).

Women who had experienced previous abuse identified that they wished to protect their baby from having similar experiences. This was especially concerning to women who knew that they were carrying a female child, and some women wished for male children for this reason (Coles & Jones, 2009; Schwerdtfeger & Wampler, 2009). The need to protect future children was also a concern for women who were in abusive intimate partner relationships (Rose *et al*, 2010). In these circumstances, women described wishes for the baby to have a better life, away from the abuser.

The pregnancy enabled some women to prioritise their own safety and the safety of the baby, thus prompting them to end the relationship where possible (Lutz, 2005).

Participants in several studies described difficulties with bonding with their babies as a result of their circumstances. Women expressing these concerns were participants in research focused on intimate partner violence and previous perinatal loss (Lutz, 2005; Côté-Arsenault & Mahlangu, 1999; Côté-Arsenault & Freije, 2004). Women who had lost a previous baby described confusion between the current baby and the lost baby, and described not being able to bond with the baby until late in the pregnancy, when they felt more confident about the baby's survival.

Women with intense fear of childbirth expressed ambivalent feelings toward their babies, as did women in research focusing on depression in pregnancy. Some depressed mothers described feeling pressured into having a baby by their husbands and families, and identified this as detrimental to their careers and freedom (Tseng *et al*, 2008). Some women expressed regrets about becoming pregnant and therefore having to confront their intense fear of childbirth (Nilsson & Lundgren, 2009).

Participants in both of the studies focusing on fear of childbirth expressed guilt

toward their unborn children, feelings of inadequacy and fears about their own and the baby's safety (Eriksson *et al*, 2006; Nilsson & Lundgren, 2009). Research focusing on women with HIV also identified fears about the baby's safety and health in relation to birth and potential HIV status. Some women with HIV also expressed ambivalence about the pregnancy, due to potential risks to their own health (Sanders, 2008).

Although several of the studies described women's feelings of ambivalence, there was also a strong theme of the importance of the baby to the participants' sense of herself as a woman and a mother. Amongst these participants were women who had lost their older children into care, and considered this pregnancy as an opportunity to regain their identity as a mother and replace their lost children. Women in this research expressed wanting the baby for love and companionship (Sanders, 2008). Women who experience poor mental health or emotional problems in pregnancy described a wide range of effects on their sense of themselves, and their emerging relationships with their babies. For many women, there was a feeling that their expectations of pregnancy as a happy time were disappointed. Many women described feeling alone and unsupported in facing their pregnancies, and this sense of isolation existed alongside ambivalent feelings about themselves and their babies. The research literature identified a range of strategies that women employ to manage their distress arising from the complex and difficult conditions and responses experienced during pregnancy.

4.5.4. Strategies for managing distress during pregnancy

The majority of papers included in this review described a range of strategies that women employed to manage their distress. These strategies varied according to the conditions in which the women were living. They included overcoming barriers and

seeking help, self-care, using interpersonal strategies within their relationships to reduce risk of abuse and violence, avoidance and distancing from painful emotions and frightening thoughts.

Research identified stigma as a barrier to help-seeking for some women. However, research participants identified that overcoming barriers and seeking appropriate help was an important strategy for managing their distress. Both women with diagnoses of depression and HIV identified that making a connection with a supportive health professional was important in coping with their circumstances (Bennett *et al*, 2007; Sanders, 2008). Research focusing on women's journey through depression identified that proactive strategies such as seeking information, making a plan, assessing progress and balancing risks were important in regaining control that had been experienced as lost at the onset of depression (Bennett *et al*, 2007). Seeking information and developing self awareness were also identified as important strategies for managing distress amongst women who had experienced a previous perinatal loss, who had intense fears of childbirth, who experienced mild to moderate distress and who were in abusive relationships (Côté-Arsenault & Freije 2004; Eriksson *et al*, 2006; Furber *et al*, 2009; Lutz, 2005).

The literature identified a range of approaches to self-care that women described as helpful in managing their distress. These included changing exercise and diet, writing, positive thinking, managing routines, and using relaxation and other holistic approaches (Côté-Arsenault & Freije 2004; Eriksson *et al*, 2006; Furber *et al*, 2009; Schwerdtfeger & Wampler, 2009).

In addition to self care, women sought support from their community networks.

Women with experiences of previous perinatal loss sought out support other women who had similar experiences (Côté-Arsenault & Freije 2004). Those with mild to

moderate distress identified strategies of socialising and talking about feelings (Furber *et al*, 2009). Similarly, confiding in a close friend and talking within supportive networks were amongst the strategies employed by women with experiences of domestic abuse or sexual trauma.

Conversely, strategies of avoidance, minimising of the negative experience, covering up and maintaining emotional distance were described by participants in a range of circumstances. Women in abusive relationships described shutting down their emotions, avoiding contact with the abuser, emotional detachment, keeping quiet, suppressing their own feelings and concealing or minimising the extent of abuse (Lutz, 2005; Rose *et al*, 2010). Research focused on women's experience of depression in pregnancy identified similar strategies of covering up, self-silencing to maintain the relationship where the woman feared abandonment by her partner and not showing off the pregnancy due to partner's negative feelings about it (Raymond, 2009). Women with intense fears of childbirth described using distraction and avoidance of thinking or talking about the fear (Nilsson & Lundgren, 2009). Research participants who had experienced previous perinatal loss also used strategies of avoidance, secrecy and maintaining an emotional distance from the baby until they felt it had developed through the most risky period (Côté-Arsenault & Mahlangu, 1999; Côté-Arsenault & Freije, 2004).

It is clear from the literature that a diverse range of strategies are employed by women in managing their distress, and these vary depending on the circumstances in which the women find themselves. For some women their social and relational contexts enable seeking help and support from others. However, it is apparent that not all women feel in a position to access support, either because of their perception of stigma associated with their situation, or because of ongoing risk to their safety

within abusive relationships. It is important to recognise that different women will use different strategies to cope with their circumstances, and to provide support to enable them to access safety and care where possible.

Alongside the examination of strategies employed by women to manage their distress during pregnancy, the literature provides a wide range of implications for practice arising from the research and analysis undertaken.

4.5.5. Implications for practice

A number of implications for practice are identified within the literature. These implications include:

- Training for professionals
- Developing positive relationships between antenatal women and professionals
- Screening and interventions for mental health during pregnancy
- Service development
- Awareness-raising for women
- Developing opportunities for women to access peer support from other women who have similar experiences.

4.5.5.1. Professional training

Professional awareness and knowledge was identified in relation to different circumstances that women may experience during pregnancy. Awareness raising was indicated for professionals in relation to knowledge of depression (Bennett *et al*, 2007), understanding of the effects of sexual trauma and the need for universal precautions in medical consultations for women who have been sexually abused (Coles & Jones, 2009); training for health professionals in responding to women's

intense fear of childbirth, mild to moderate distress in pregnancy and experiences of intimate partner violence (Eriksson *et al*, 2006; Furber *et al*, 2009; Rose *et al*, 2010). Well developed communication skills were identified as an important skill for professionals in responding appropriately to women's distress (Schwerdtfeger & Wampler, 2009).

4.5.5.2. Relationships with professionals

Research participants identified a range of difficulties in relationships with professionals, including feeling judged and misunderstood. Research also indicated that positive relationships with professionals were important for promoting women's mental health during pregnancy. Several papers concluded that the development of positive, non-judgemental and trusting relationships were an important element of women's care during pregnancy (Bennett *et al*, 2007; Coles & Jones, 2009; Nilsson & Lundgren, 2009). Research highlighted the importance of normalising of experiences and supportive care being responsive to the different needs of individual women after pregnancy loss (Côté-Arsenault & Mahlangu, 1999), and for professionals to treat women with respect and care (Nilsson & Lundgren, 2009; Sanders, 2008). Issues of respect were raised in research where women had described feeling stigmatised by professionals in relation to HIV status and their fears of childbirth not taken seriously. In the case of intense fears of childbirth, authors concluded that it was important for women's fears to be understood and explored within a trusting relationship, rather than offering medical interventions such as birth by elective caesarean (Nilsson & Lundgren, 2009).

4.5.5.3. Screening and intervention for identified mental health problems

Comprehensive screening and assessment of mental health was recommended, including screening for depression and post-traumatic stress disorder in general antenatal care settings (Furber et al, 2009; Shwerdtfeger and Wampler 2009). Where mental health problems were identified, services such as individual and group support were suggested. Identification and treatment of depression and post-traumatic stress disorder were emphasised as an important element of services offered to women experiencing intimate partner abuse, alongside referrals to specialist counselling (Rose *et al*, 2010). Approaches were recommended in relation to developing services for women who experienced mental health or emotional problems during pregnancy. These included monitoring and multi-disciplinary care management (Furber et al, 2009); implementation of universal precautions regarding medical examination and touch given the proportion of women in the population who have experienced sexual abuse (Coles & Jones, 2009), and services that promote opportunities for women to connect with each other, with professional support (Raymond, 2009).

4.5.5.4. Information for women

The provision of information for women was suggested to encourage their recognition of mental health problems and to promote help-seeking (Bennett *et al*, 2009). Research also suggested that women who had experienced a previous perinatal loss would benefit from clear communication of test results, and review and discussion of current recommendations for health during pregnancy, so that they are informed and can feel confident about making decisions about their choices (Côté-Arsenault & Mahlangu, 1999).

4.5.5.5. Peer and partner support

The role of peer support was identified for women experiencing distress arising within a range of circumstances. Peer support during pregnancy was recommended for women experiencing depression (Bennett *et al*, 2009; Raymond 2009); previous perinatal loss (Côté-Arsenault & Freije, 2004) and intimate partner violence (Rose et al 2010). Professionals were also encouraged to support women's partners to enable them to offer support to women experiencing emotional distress during pregnancy (Bennett et al 2009; Furber et al, 2009; Schwerdtfeger & Wampler, 2009).

4.5.6. *Summary of themes*

As outlined above, themes identified in reviewed research include women's experiences of mental health problems during pregnancy, the factors that have an impact on these experiences, the impact of the problems themselves and the strategies women have described for coping with their mental health problems. These themes are shown in Figure 1.3, below.

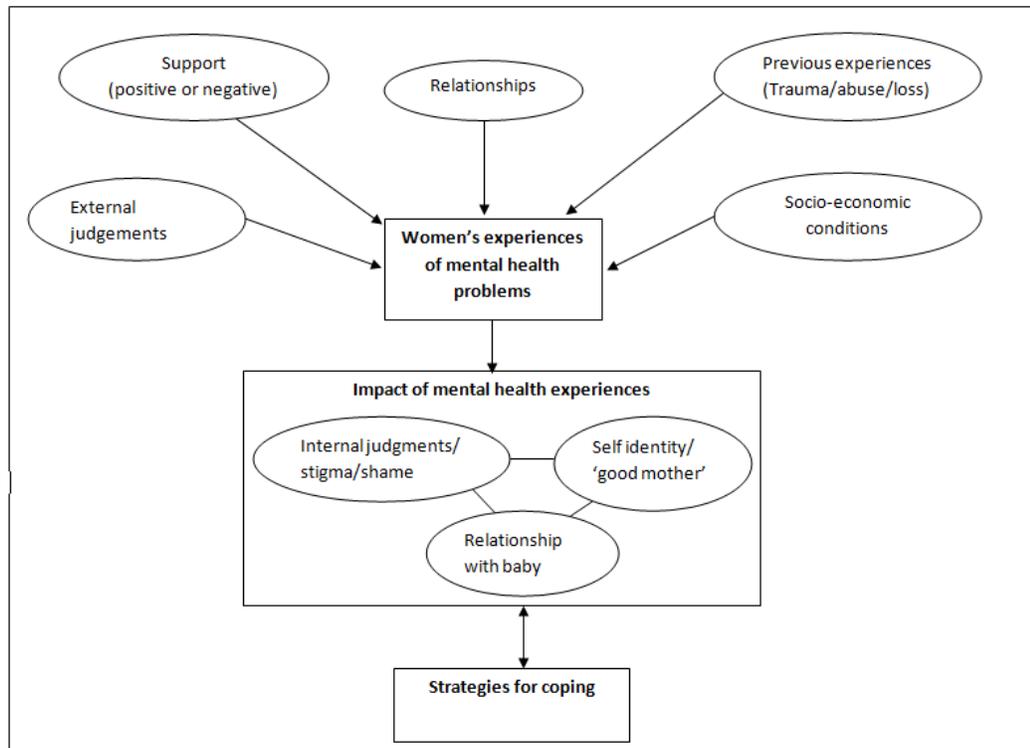


FIGURE 4.3 - COMMON THEMES IDENTIFIED IN QUALITATIVE RESEARCH FOCUSING ON WOMEN'S EXPERIENCES OF MENTAL HEALTH PROBLEMS DURING PREGNANCY

4.6. Critical Evaluation

When the above literature was reviewed in detail, a large proportion of it was found to have limitations in relation to methodological rigour and quality of reporting. The research was examined in relation to the list of criteria outlined at the beginning of this chapter, and an overview of this evaluation is summarised in Table 4.3.

Quality standard	Bennett <i>et al</i> , 2007	Coles & Jones, 2009	Côté- Arsenault & Mahlangu, 1999	Côté- Arsenault & Freije, 2004	Eriksson <i>et al</i> , 2006	Furber <i>et al</i> , 2009	Lutz, 2005	Nilsson & Lundgren, 2009	Raymond <i>et al</i> , 2009	Rose <i>et al</i> , 2010	Sanders, 2008	Schwerdt- feger & Wampler, 2009	Tseng <i>et al</i> , 2008
Clarity of reporting	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓
Transparency	✓		✓	✓	✓	✓	✓	✓	✓			✓	
Appropriateness of qualitative method	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Appropriateness of sampling		✓	✓		✓	✓	✓		✓	✓		✓	
Appropriateness of analysis	✓	✓	✓	✓	✓	✓	✓	✓	✓			✓	
Reflexivity and relationship with research participants	✓			✓			✓	✓				✓	
Consideration given to ethical issues and review	✓	✓		✓	✓	✓	✓	✓	✓		✓	✓	✓
Epistemological clarity and coherence	✓				✓		✓					✓	
Trustworthiness	✓			✓	✓	✓	✓					✓	✓
Comprehensiveness of the analysis and data	✓			✓	✓		✓		✓			✓	
Reporting of data and fit with analysis	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓
Total	10	5	6	9	10	7	11	7	8	2	4	11	5

TABLE 4.3 - OVERVIEW OF THE CRITICAL EVALUATION OF PAPERS INCLUDED IN THE LITERATURE REVIEW

As shown in Table 4.4, several of the studies included in this review provided strong evidence for methodological quality. Of the 11 listed quality criteria, two studies were rated as meeting all criteria (Lutz, 2005; Schwerdtfeger & Wampler, 2009). A further three papers met 9 or 10 of the 11 criteria (Bennett *et al*, 2007; Côté-Arsenault & Freije, 2004; Erikson *et al* 2006). Three studies met 7 or 8 of the criteria (Furber *et al*, 2009; Nilsson & Lundgren, 2009; Raymond, 2007). The remaining studies showed considerable methodological or reporting problems, meeting just over half (Côté-Arsenault & Malangu, 1999) or fewer of the specified quality standards. The standards that were most commonly met included:

- Appropriateness of a qualitative method to address the research questions
- Overall clarity of reporting and provision of research context
- Reporting of data and fit with analysis
- Appropriateness of the analysis to address the research questions
- Consideration given to ethical issues, and this being reported

However, as can be seen in the above table, not all of the papers met these criteria.

4.6.1. Sampling

Several papers reported approaches to sampling that were either not appropriate for the methodology used, or which presented potential problems for trustworthiness of the findings. For example, one study employing a grounded theory method did not use theoretical sampling, which produced limitations in the analysis and theory development (Bennett *et al*, 2007). One study described using purposive sampling, but reported only inviting all pregnant women who were referred to a specialist midwife, and interviewing those who responded to the invitation (Furber *et al*, 2009). Another study described sampling as purposive, but used a sample that was

recruited through advertising in online bulletin boards and a city newspaper, offering a financial incentive. This study attracted participants who were only able to offer a very retrospective account of their experiences, often more than 10 years previously, and included a significant proportion of participants who had also experienced loss of custody due to child protection proceedings due to illicit substance use. (Sanders, 2008). There may be some questions relating to the retrospective reporting of experience due to potential 'self-reconstruction' in accounts functioning as a protection of self-esteem and a cognitive bias that presents a consistent sense of the individual to self (Smith, 1994). These issues were not raised in the report of this research and pose some concerns relating to the credibility of the findings. A further study described participants as meeting criteria for depression based solely on their Edinburgh Postnatal Depression Scale score (Tseng *et al*, 2008), although the EPDS was not intended as a diagnostic measurement (Cox *et al*, 1987) and should be used for screening prior to clinical assessment (Harvey and Pun, 2007).

4.6.2. Analysis

Several papers did not successfully demonstrate a comprehensive analysis either through lack of clear reporting or presentation of a superficial level of analysis. Much of the reviewed literature presents a predominantly descriptive analysis of the data, and further analysis, interpretation or theorising is not presented. Where an analysis was considered to be superficial, it was presented within a limited framework of analysis where it was clear from examples given that there was further scope for analysis. For example, one study presented 3 primary categories of themes that were not broken down into any further detailed analysis, but reported as clustered under these three primary themes (Furber *et al*, 2009). For some studies, there was data and analysis presented under separate categories which appeared to

overlap significantly in terms of content and categorical description (Nilsson & Lundgren, 2009). Analysis was not always presented in ways that were credible in relation to the broader description of the research. For example, one study presented experiences of antenatal depression in relation to a primary theme of unbalanced commitment and transition to motherhood where 8 out of the 12 participants were already mothers from previous pregnancies. This primary theme did not fit well with presented categories and data relating to social circumstances (Tseng *et al*, 2008).

4.6.3. Reflexivity and the role of the researcher

The most common issue relating to trustworthiness of this body of research was the relative invisibility of researchers within the report and the research process. In recent years, there has been increasing recognition within academic approaches to qualitative research that the perspective of the researcher has an important bearing on the different processes involved in conducting research (e.g. Willig, 2001; Parker, 2005; Symon & Cassell, 2007; Alvesson & Sköldberg, 2009). Frequently the absence of transparency regarding researcher perspective appears to come from an assumption that researchers are able to approach research from a position of scientific objectivity. This has been challenged from a range of different perspectives, which may dispute the approach that is best to address the problem, but which find agreement in the position that lack of reflexivity presents a problem to the trustworthiness and credibility of the research (e.g. Elliott *et al*, 1999; Yardley, 2000; Willig, 2001). Without a clear and transparent approach to researcher reflexivity, there are considerable questions about how the researchers' implicit assumptions may have affected the research findings. The absence of transparency regarding this makes it very difficult for the reader to fully appraise the quality of the research and to judge for herself the impact of the researchers' identity and assumptions.

Only five of the thirteen papers reviewed gave any mention of the role of the researcher in generating data and shaping the analysis. Bennett and colleagues (2007) acknowledged the issue, but did not give any transparent account on the impact of their perspectives on the research. Côté-Arsenault and Freije (2004) gave some discussion of each of their positions as ‘insiders’ or ‘outsiders’ in relation to the researched group, but did not offer further examination of the impact of these positions on the research. Lutz (2005) acknowledged the importance of researcher reflexivity, and gave an account of procedures in place to address this issue in the research, but did not give sufficient detail for the reader to be able to make any appraisal for herself. Nilsson and Lundgren (2009) also outlined the importance of reflexivity in phenomenological research, but did not provide further detail regarding how this related to their research and findings. Schwerdtfeger and Wampler (2009) identified that researcher subjectivity is an issue in phenomenological research, and described a process of ‘bracketing’ to enable the research to proceed without the introduction of bias by the researchers. The importance of transparency is raised by many authors in relation to criteria for evaluating the quality of qualitative research (e.g. Elliott et al 1999, Yardley 2000, Willig 2001), and this is clearly a problem across the majority of the literature reviewed here.

4.6.4. Epistemology and trustworthiness

Clarity regarding the epistemological framework on which the research was undertaken is a further area in which much of the reviewed research was weak. Epistemological coherence is widely considered to be of particular importance in examining the quality of qualitative research (see Willig, 2001; Moses & Knutsen, 2007; Rose, 2009). Without clarity regarding the assumptions about how knowledge is produced in research, it is difficult to appraise the appropriateness of strategies

employed to ensure trustworthiness. Only seven of the thirteen studies reviewed deal directly with questions of epistemology. Raymond (2009) and Bennett and colleagues (2007) bring an explicitly constructivist epistemology to their research. Lutz's (2005) study is situated within a symbolic interactionist perspective. Eriksson and colleagues (2006) identify their epistemological position as social constructionist. Nilsson and Lundgren (2009), Sanders (2008) and Schwerdtfeger and Wampler (2009) all describe their approaches as phenomenological. All of those authors who address epistemology in their publications provide various levels of internal consistency, often through the lack of evident contradictions, but occasionally with clear explication of their rationale. Sanders' paper does not provide sufficient detail to make an appraisal of the internal consistency regarding epistemological stance and strategies to ensure quality and trustworthiness.

Much of the research included in this review provided some mention of measures taken to ensure and demonstrate trustworthiness. These descriptions are provided in Table 4.4.

Although all but one of the papers reported measures taken to ensure trustworthiness, some authors gave more thorough and comprehensive accounts and others embedded a very brief description in their publications. For example, Bennett and colleagues (2007), Côté-Arsenault and Freije (2004), Lutz (2005), and Schwerdtfeger and Wampler (2009) each provided extensive detail and a thorough description of the various strategies employed to demonstrate quality within their research. These measures taken to ensure quality were congruent with the authors' stated epistemologies. The only exception was Côté-Arsenault and Freije, who did not explicitly state an epistemological position. Overall, these papers present the most credible and trustworthy accounts of the research undertaken.

Details	Trustworthiness
Bennett <i>et al</i> , 2007	audit trail, reflexivity and peer debriefing through triangulation of researchers, participant validation (number of participants not reported)
Coles & Jones, 2009	participant validation (1 of 18 participants), independent coder for random sample of transcripts
Côté-Arsenault & Mahlangu, 1999	Not reported
Côté-Arsenault & Freije, 2004	reflexivity, triangulation of data sources, triangulation of analysts, recursive modification of themes by reviewing data and analysis memos
Eriksson <i>et al</i> , 2006	Researcher triangulation, constant comparison
Furber <i>et al</i> , 2009	Researcher triangulation, constant comparison
Lutz, 2005	Participant validation (number of participants not reported), audit trail, reflexivity, external consultants, theoretical saturation
Nilsson & Lundgren, 2009	Reflexivity
Raymond, 2009	Constant comparison in data generation and analysis
Rose <i>et al</i> , 2010	Discussion to achieve consistency in coding between analysts
Sanders, 2008	verification of transcription, use of consultants to reduce bias
Schwerdtfeger & Wampler, 2009	bracketing, participant validation (number of participants not reported), thick description, reflexive journal, internal & external auditors
Tseng <i>et al</i> , 2008	researcher journals, coding checks, peer debrief, participant validation (3 of 12 participants)

TABLE 4.4 - MEASURES REPORTED TO ENSURE TRUSTWORTHINESS

Some papers included in this review gave brief details of means authors employed to ensure quality. Not all of these were well described or provided sufficient detail to generate confidence in the findings of the research. Constant comparison was used by several authors, but the descriptions given of this strategy were varied. Eriksson and colleagues (2006) described a process of constant comparison within the analysis of data whereby comparison was initially undertaken between sections of data, and subsequently between categories/dimensions and the original data. This is the approach to constant comparison as outlined by Henwood and Pidgeon (2006).

Other accounts of constant comparison were described as clarifying understanding during interviews, seeking out alternative perspectives through purposive sampling and in data analysis (Raymond, 2009). Furber and colleagues (2009) described using constant comparison to link codes across interviews, but did not provide further detail. Within this sample of papers it can be seen that qualitative researchers may hold different understandings of processes used to demonstrate quality, and this presents some difficulties for evaluating the quality of the research.

Ten of the articles identified that analysis was undertaken, reviewed or discussed amongst more than one researcher, consultant or auditor. The reasons for the use of multiple perspectives varied between papers, and this was likely to reflect the articulated or implicit epistemological position of the authors. For some authors, triangulation was considered to be a strategy to facilitate reflexivity and deepening of analysts' understandings of the data, rather than demonstrating objective truth (Côté-Arsenault & Freije, 2004; Eriksson *et al*, 2006; Lutz, 2005). Other papers gave an account of triangulation between analysts, peer debriefing or the use of external consultants to achieve consensus and consistency within the coding structures (Bennett *et al*, 2007; Coles & Jones, 2009; Rose *et al*, 2010). Other authors employed auditors or consultants to reduce researcher bias, which was consistent with the phenomenological epistemology in both cases (Sanders, 2008; Schwerdtfeger & Wampler, 2009). The remaining two papers referred to peer debriefing as a way to ensure credibility or to maintain rigour, but did not provide a clear rationale for this strategy (Furber *et al*, 2009; Tseng *et al*, 2008). The process of bringing alternative perspectives to the process of research and analysis can provide a means of demonstrating quality, given that the rationale is articulated and internally consistent.

4.6.5. *Summary of critical evaluation*

The quality of the research included in this literature review was widely varied. Table 4.4 provides an overview of the relative strengths and weaknesses of the papers in this review. The research represented here is compared and summarised in relation to common themes that were reported across the range of identified papers. Although methodological and reporting concerns have been raised regarding a number of the articles, it is intended that this overview provides a stronger perspective of the current knowledge that is represented in the literature than can be inferred from the reviewed research papers individually. This assertion does not imply that the themes presented here represent the truth about women's experiences, but rather an amalgamation of the ways in which those experiences have been represented by academic and professional researchers into mental health in pregnancy.

4.7. Summary of the Review and Direction for Future Research

Women's experiences of mental health during pregnancy have only been examined using qualitative methods in recent years. No qualitative research was identified addressing this subject prior to 1999, and this suggests that the importance of this topic is attracting increasing recognition amongst professionals and academics.

The common themes that appear within the identified literature relate to:

- women's descriptions of their experiences
- the contexts and conditions within which these experiences exist, including
 - relationships with community networks, families, partnerships, professionals and services
 - Material and social conditions of living

- Previous experiences
- The impact of mental health experiences upon the women's sense of themselves and their developing relationship with their babies
- Strategies women use for coping with their mental health and circumstances
- Implications for professional practice

A range of women's experiences were described within the research, which would merit further exploration. However, the authors' perspective most frequently reflects a dominant professional and academic position taken on the subject, and the voices of participants are only presented from the perspective of the 'experts'. If it is acknowledged that people with firsthand experiences of the topics under examination also hold important expertise, then it is essential that they have a greater influence in designing, undertaking and disseminating the research.

Simultaneously with the dominance of the professional or academic authorial voice, very little consideration was given to reflexivity issues, or examination of the impact of author assumptions on the research findings in the reviewed literature. This research will place a greater value on working reflexively as team with different experiences and backgrounds, not least firsthand experience of mental health problems during pregnancy.

A significant gap in the literature has been identified in relation to direct discussion of mental health during pregnancy as understood by women with those experiences. With only one exception (Furber *et al*, 2009), research focused explicitly on mental health tends to use categories as defined by researchers, rather than by women themselves. Questions unaddressed within the literature include women's understanding of what contributes to poor mental health, what might help to support good mental health, and particularly what strengths and resources women can draw

upon within their communities. These gaps identified in the literature will inform, but not restrict the emphasis brought to this research. The primary aim of undertaking this research within a participatory framework is to work in collaboration with women who have firsthand experience of mental health problems during pregnancy, and to provide a platform for their voices within the professional and academic dominated research field.

CHAPTER FIVE

METHODOLOGY

5.1. Introduction and Rationale for Using a Participatory Approach

Participatory research is ‘action-oriented research activity in which ordinary people address common needs arising in their daily lives and, in the process, generate knowledge’ (Park, 2001, p.83).

Developing a rationale for undertaking research using a participatory approach consists of multiple elements, including ethical considerations, research outcomes, and potential to inform action and practice. Although this project was initially planned to include at least one cycle of an action research process, the timescale for undertaking this as a PhD within a context of regulated public health services and academic requirements proved unrealistic. As a result, this thesis reports the findings of the initial participatory research phase that prioritised genuine collaboration and comprehensiveness of data and analysis above progression through the action research phase.

Participatory research is argued to promote greater equality. Fals Borda (2001) described the development of participatory research as an attempt to address the gap between academic and popular knowledge. He considered the impetus for participatory research as arising from awareness of the shortcomings of academic knowledge and the exclusion of ordinary and underprivileged people’s access to knowledge and its production. Fals Borda emphasised the gap between scientists’ knowledge and priorities and those of non-scientists. He was concerned with the ethics of the monopolisation of knowledge by higher and educated classes. Equality

of access to the production of knowledge was argued to enable ordinary people to defend their interests by having access to the resources of knowledge and power.

Action research and participatory research are argued to present a challenge to traditional hierarchies of power and increase the influence of health service users in the development and delivery of services (Winter & Munn-Giddings, 2002)

Participatory approaches to research are intended to improve the relevance and scope of knowledge about research topics. Philosophical challenges have been made to the idea of scientific objectivity and neutrality on parallel grounds of possibility and desirability. Many researchers using participatory methods do so on the grounds of epistemological challenges to the notion of scientific neutrality and objectivity, and ethical grounds that such an approach supports the status quo in relation to power (Cecchin, 1987; Lang Little & Cronen, 1990; Fals Borda, 2001).

Involving diverse people in the production of knowledge can generate new perspectives, insights and priorities that can contribute to the broader understanding of the research subject (Gaventa & Cornwall, 2001). Developments arising from participatory research can generate knowledge beyond that which is conventionally recognised as knowledge. Beyond knowledge about the subject (representational knowledge), participatory research can also produce knowledge through interaction with others in the research setting (relational knowledge), and critical analysis of morality and values in relation to life conditions of participatory researchers (reflective knowledge) (Park, 2001). The tradition of participatory research emphasises the importance of how research can raise the critical awareness of the people involved (Freire, 1970/1996, Gaventa & Cornwall, 2001). Participatory research therefore has the potential to generate new knowledge, extending not only

to the representational knowledge of the research subject, but also our understanding of ways of knowing.

Participatory research is useful in generating action for researchers seeking practical and applicable knowledge (Fals Borda, 2001). Participatory approaches are also used to promote local ownership. Action that is embedded in the culture of local context is argued to be more meaningful and acceptable to local people, and more likely to be effective and sustainable compared with solutions imposed by outsiders.

Participatory research emphasises ways of knowing that come from rigorous research to inform action. Knowing and action are parallel tools for empowerment (Gaventa & Cornwall, 2001).

In summary, participatory research offers an approach to generating knowledge that privileges the perspectives of those who have direct experience of the subject under examination, and aspires to egalitarian, practical, reflective and intellectual outcomes.

5.2. Feminist Research and Critical Psychology

As outlined in the Theoretical Frameworks chapter, feminist and critical community psychological approaches have been a significant influence on the development of this research and the participatory methodology that has been developed. There is a great deal of common ground between feminist, critical psychological and participatory approaches to research, which is explored in the following section.

Developments in feminist research have emerged in response to structural inequality in society based on gender, devaluation of women's knowledge production and the need to privilege women's voices in research to identify and redress inequalities (Grbich, 2007).

In common with participatory and critical psychological research, feminist approaches to research focus on the relationship between researched and researcher and aim to recognise and reduce power inequalities within the relationship by increased transparency and personal disclosure by researcher. Traditional objective scientific method separates the knower from the known, and identifies knowledge as an end in itself. Oakley (1992) rejects this approach and proposes a feminist alternative with demands upon knowledge to serve social ends. This emphasis is shared by participatory and critical psychological approaches to research (for example: Gaventa & Cornwall, 2001; Fox *et al*, 2009; Stainton Rogers, 2009). Oakley argues that methods used to produce knowledge are part of the knowledge itself. Language is not only a means of acquiring data, it is data, and it is analysis. Oakley addresses class and status difference in producing knowledge and argues that the class of researchers and academics has a bearing on the analysis of data and consideration of political and material contexts. Within these feminist approaches to research we can see parallels with participatory research in relation to the processes of knowledge production, research relationships, and the purposes of producing knowledge. However, Grbich (2007) raises questions about aims of empowerment and emancipation within research, arguing that both assume a superior position by the researcher. The aim of reducing power inequalities can be difficult to achieve in practice due to cultural assumptions about knowledge and structural inequalities relating to academic status in society. It is important to consider the question of whose interests are served by research, and who has ultimate control of the data, analysis and dissemination. Stainton Rogers (2009) explores the complexities of ethical practice in critical psychological research and concludes that researchers must offer a high degree of transparency and openness to critique within their research

practice. Also in common with feminist researchers, Stainton Rogers emphasises the importance of researcher reflexivity in relation to the exercise of power within the research process.

Oakley (1992) identifies a paradox within the focus on the university as a mainstream site for the production of feminist knowledge. The value given to academically produced knowledge elevates the status of the knowledge produced. The dissemination of knowledge produced within university settings can be argued to be elitist and exclusive to those with access to particular resources and language skills. A difficult issue to address is the likelihood that many women who would be participants in this research are unlikely to be consumers of the research if only disseminated through traditional methods of research journals and professional/academic conferences. However, the research is undertaken as a PhD and therefore is situated within this context and the author is required to apply these standards for recognition of the research activities and completion of the doctorate. This presents an ongoing tension within the research and PhD process. The use of a participatory approach within a PhD required a number of compromises within the research and an attempt at balancing the competing interests of different agents within the research environment.

5.3. Development of the Participatory Research Team

It was established that it would not be necessary to obtain Research Ethics approval prior to recruiting the research team. Current National Research Ethics Service documentation was examined, including a joint statement from INVOLVE and NRES (January 2009). This clarified that involvement in conducting research did not constitute becoming a research participant and therefore did not require ethical approval. Contact was also made with the University and local NHS Research Ethics

Committee Chairs to clarify that co-researchers would not be research participants, and therefore approval would only be needed once a team was in place and a research protocol had been developed.

The process of developing the research team aimed to be as inclusive as possible. An information leaflet (see Appendix B) about the research was distributed to organisations that provide services to women with mental health problems during pregnancy. Meetings, groups and drop-in sessions were attended to discuss the project with service providers and service users in both statutory and voluntary sector organisations. It was explained that this research project had a broad focus on women's mental health and emotional wellbeing during pregnancy, but that decisions about the research questions and process had not been made prior to involvement of co-researchers. Although several women who were contacted during this process expressed an interest in the research, most did not feel able to undertake a voluntary role as a co-researcher. Several potential co-researchers said that they might be interested if they knew more details about the research. Due to the participatory nature of the research development process, it was not possible to give a clear description of the research process prior to developing the research team. Potential co-researchers seemed to be put off from involvement due to the lack of a clear plan to sign up to at the outset. Attending meetings and discussing possibilities was time consuming and did not immediately result in anybody engaging in further meetings to develop the research. This situation illustrates one of the complexities of undertaking a participatory research project that is initiated by professionals or academics, rather than emerging from community members' own interest in the research to be undertaken. The initial lack of a clear focus within the broad topic of

antenatal mental health was a result of this situation, and reflects a critique of participatory research that is not initiated by community members.

Further contact was made with the advisory group for the local Parent Infant Mental Health Service, who agreed to act as the advisory group for this research. The group was made up of professionals from statutory and voluntary sector agencies, with a small number of parent representatives. The group meets monthly, and is attended by the professionals, managers who provide the Parent Infant Mental Health Service, and two parents who have used the service in the past. The group agreed to offer advice on the local context of the project, possible sources for co-researcher and participant recruitment, and feedback on the developing research protocol.

Following initial difficulty in contacting potential co-researchers, the advisory group suggested contacting two women, one who had been involved with the advisory group and one who was a local breast-feeding peer supporter. The professionals who were in contact with these two women contacted them to ask permission to pass on their details. Initial meetings were arranged, and both women were interested in becoming involved in the research. One woman brought a friend to a second meeting, who was also interested in becoming involved. These three women have become members the research team. Two were pregnant at the time of beginning the research, and one had given birth to a daughter 18 months previously. All of the women described experiencing mental health problems or significant and distressing interpersonal and social difficulties during their current or previous pregnancies. The research team met on a number of occasions to discuss research ideas, and to review the developing protocol. The protocol was developed on the basis of these discussions, and written into a format that would be needed for submission to NHS Research Ethics Committee. This was subsequently presented to the advisory group

and other professional network meetings. Feedback was positive and no significant changes were made at this time.

5.4. Research Questions

The research questions developed for guiding the project were as follows

5.4.1. Questions for women:

What have women experienced as supporting their mental health during pregnancy?

What have women experienced as causing problems for their mental health during pregnancy?

What are women's experiences of services during pregnancy?

What do women think is needed from services and from their communities to support their mental health during pregnancy?

5.4.2. Questions for professionals:

What are their experiences of working with women with mental health problems during pregnancy?

What do they think supports and undermines women's mental health during pregnancy?

What do they think is needed to support women's mental health during pregnancy?

What do non-mental health professionals understand about mental health during pregnancy?

What training have non-mental health professionals had about mental health during pregnancy?

What training do non-mental health professionals need about mental health during pregnancy?

5.5. Design

This research was undertaken by a core working group, with advice and guidance from a wider advisory group and academic supervisors from the university. The core working group, made up of three mothers from the local community and me, has collaboratively developed the research design.

Decisions regarding the design and research questions were taken by the core research group. Qualitative data were generated within individual and group discussions. Qualitative methodologies were considered to be the most appropriate for this project due to the nature of the research questions and the type of data that could answer them (Murphy *et al*, 1998). There were no pre-existing hypotheses to be tested. The research questions related to the experiences and understandings of mental health by women and professionals, and could best be explored within a flexible and participant-focused methodology. Qualitative approaches are suitable in situations where the researcher wishes to avoid imposing a set of pre-determined ideas on the researched population (Henwood and Pidgeon, 1992, 2003). This is suitable within a participatory approach to research and is especially important where there are likely to be multiple and contradictory perspectives on the experiences being researched. As this research was exploratory and participatory, understandings of the community were anticipated to evolve throughout the process, during which a degree of flexibility was necessary. Qualitative methodologies routinely employ an iterative research strategy so as to be responsive to new understandings as they emerge (Mason 2002).

The use of Thematic Analysis (Braun & Clark, 2006) was agreed upon to meet the requirements of this project, including:

- Accessibility to members of the research team without specialist theoretical and methodological knowledge
- Flexibility of use with epistemological frameworks
- A bottom-up analysis built on the data rather than dominated by over-arching theory

Within this research, it was intended to balance individual data with group discussion data (Michell, 1999). A group setting for generating data can provide opportunities to observe dissent, agreement and the development of accounts as they are built in a social context (Kitzinger, 1994). The potential to generate data through group discussion was considered to be beneficial for exploring understandings of mental health in a social context, however, it was also anticipated that some participants might not feel able to openly express their perspectives in a group setting. Given the sensitive nature of the subject of mental health, the research group decided that it would be important to give participants a choice about how they were involved in generating data.

This research project was able to include data from pre-existing groups of professionals and mothers, which could reflect naturally occurring discussions. Ultimately, the majority of data was generated and collected in discussions with individual participants rather than in groups. There were two group sessions with mothers. These were made up of pre-existing groups of women who knew each other prior to the research. The first group was drawn from a weekly drop-in at a Children's Centre for women with post-natal mental health problems. The second group was held at a weekly drop in for pregnant teens, held at a voluntary organisation that provides support for young mothers. The two groups of

professional respondents were held at routine meetings of a midwifery team and a psychological therapies team.

5.5.1. *Trustworthiness*

The use of the notion of ‘trustworthiness’ in qualitative research reflects the importance of ensuring methodological and analytic rigour of the research, much as notions of reliability, validity and the accuracy and appropriateness of statistical analysis are of central importance in evaluating the quality quantitative research.

5.5.1.1. Epistemology and quality in qualitative research

Because many qualitative methodologies are founded on diverse assumptions about the nature of the world (ontology), and the nature of knowledge about the world (epistemology), they therefore cannot rely on one set of technologies for demonstrating that the research has some worth. In qualitative research, there are many different ways of demonstrating the usefulness, truth value, or quality of any particular study. There are numerous resources outlining different frameworks for establishing quality within qualitative research (Elliott, Fischer & Rennie, 1999; Yardley 2000; Willig, 2001; Parker, 2004; Kuper *et al*, 2008). The following section addresses the approach taken to quality within this study.

Amongst the many criteria that can be used to judge the quality of qualitative research, theoretical and epistemological coherence is an overarching consideration. Without this, even the means to establish quality can be inappropriate for the methodology in question (Willig, 2001). For example, if a researcher is conducting a discourse analytic study, based on the assumption that knowledge is co-constructed and context-dependent and that subject positions are produced in language within a set of socially constructed parameters, then it makes little sense to employ measures

of establishing quality that rely on assumptions that there are directly accessible truths to be discovered about the nature of a particular experience. These two different frameworks produce different means of establishing quality.

Some critiques of qualitative research (and particularly the postmodern, social constructionist and poststructuralist traditions within qualitative research) centre upon the charge of relativism in relation to the focus on multiple potential interpretations of data (for example Cromby & Nightingale, 1999; Parker, 1999). Relativism has been critiqued in terms of its failure to distinguish between the validity of different interpretations and the ultimate conclusion of this argument being that ‘anything goes’ (Willig, 2001). The dissatisfaction with this position is that it renders impossible the assertion of any moral absolutes, such as ‘sexual violence is wrong’. This is a problematic stance for researchers who are motivated by the promotion of social justice within and through research. Furthermore, a position of absolute relativism encounters similar problems to arguments about the possibility of objectivity in research. It assumes that the researcher does not have a particular stake, agenda or subjectivity within the research, but rather suggests a pure, disconnected, disembodied search for knowledge. This research is situated within a theoretical, conceptual and ethical framework outlined in Chapter Two. In this way, the researcher’s position is made explicit and open to scrutiny.

Rather than proposing strict or specific criteria for quality, Yardley (2000) described a set of principles for flexibly assessing the quality of qualitative research. She includes sensitivity to context; commitment and rigour; transparency and coherence and impact and importance. Sensitivity to context includes not only an awareness of the local and dominant cultures, but also sensitivity to the theoretical and ethical context within which the research itself is situated. Commitment and rigour relate to

expectations of comprehensiveness in data generation, analysis and reporting.

Transparency and coherence relate to the level of information provided to the reader to facilitate appraisal of quality, and the fit between the theoretical approach taken to the research and the methods used. Transparency will be addressed in more detail below in relation to reflexivity. Impact and utility were argued by Yardley to be of decisive importance in assessing the quality of research. This includes ethical and political issues about the effects of the research in both practical and theoretical domains.

5.5.1.2. Specific issues for establishing trustworthiness in participatory research

Tensions exist between different perspectives on research quality when using a participatory approach. Choosing to work within an academic setting places particular expectations regarding quality on the researcher which must be balanced with the expectations and criteria that are placed on the researcher by the community participants (Strega, 2005).

Reason and Bradbury (2001) outline five overlapping areas of importance in assessing the quality of participatory action research. They suggest that different projects are likely to focus more strongly on some of these areas than others. They describe the areas as 'choice-points', signifying the flexible approach to considering quality (and the likely differences between research groups/communities) rather than 'criteria'. Some of these areas relate to Yardley's (2000) principles outlined above.

Reason and Bradbury's (2001) five choice points:

1. Relationships and extent of participation/inclusion – research is judged on the basis of how inclusive, and how decisions within the process prioritise participation

2. Practical/reflexive outcomes – the research outcomes are examined in relation to their usefulness, as well as the extent to which the research has changed the understandings of the researchers about the research topic and their own involvement in the process.
3. Plurality of knowing – this is broken down into 3 subsections:
 - a. Quality through conceptual-theoretical integrity
 - b. Quality through extending our ways of knowing
 - c. Quality through methodological appropriateness
4. Purpose – is this ‘significant work’ and is explicit attention given to the question of whether the subject is worthy of research
5. Enduring consequence – can the research demonstrate lasting/enduring impact for researchers, participants and others?

Within this project, the points that are focused on most strongly relate to the level of participation within the participatory research team, and the importance of practical and reflexive outcomes. The primary aims of this project were to work with local women to explore mental health during pregnancy and to produce findings that could inform community and service development. Evaluation of the research quality through theoretical integrity, ways of knowing and methodological appropriateness was also important, and is examined within the discussion chapter.

Strega (2005) disputes the appropriateness of ‘validity’ within research based on an epistemology of ‘multiple, partial and perspectival’ knowledge (p. 228). She considers that more appropriate ways of judging research include:

1. Its usefulness and political implications for anti-oppressive practice (‘social justice validity’ from Deyhle & Swisher, 1997)

2. Whether it is made useful and fed back to the communities about and with whom it is undertaken (this is one rationale for using participatory methods)
3. The extent of researcher reflexivity and comprehensiveness of analysis of our own ways of perpetuating power imbalances, in this way resisting complicity

Across these different approaches, there are many areas of commonality, which can be used to guide researchers in evaluating the work, and guiding how it is conducted. Significant areas of consensus include the importance of comprehensiveness within the data generation and analysis; researcher reflexivity; reciprocity in relationships with the researched community including providing feedback; transparency in the method; and the usefulness of the research outcomes.

5.5.1.3. Strategies to improve trustworthiness in qualitative research

5.5.1.3.1. *Triangulation*

Triangulation is one technique in qualitative research that can enhance the rigour of the research. Various methods of triangulation have been suggested by Lincoln and Guba (1985) to improve credibility. Triangulation between sources has been used to improve the comprehensiveness of this study by comparing perspectives and themes that occur across varying contexts including different community members, professionals and the scientific literature (Murphy *et al*, 1998). In this respect combining individual and group discussions from different perspectives such as mothers and professionals adds further depth to the data.

Additional triangulation comes from the different perspectives of collaborators on the research team. The different members of the research team bring diverse perspectives to the research. Regular engagement in discussion regarding data generation and analysis has helped to ensure that a balanced approach is taken to

producing the research findings. This further enhancement to credibility is called peer debriefing (Lincoln & Guba, 1985), and collaborators have had extensive opportunities to review the data generation and analysis throughout the research process.

5.5.1.3.2. *Transferability*

The issue of transferability is significant, although this project aims to generate findings that are of value in the development of local projects and services. Due to its focus on the particular, qualitative research does not aim to produce findings that are generalisable to broad populations, but seeks to explore in depth the local and the particular. However, qualitative research is able to generate findings, methodological developments and theory that may be applicable in other settings; this is referred to as ‘transferability’. Through transparency, it is anticipated that findings may be transferable across settings. When the findings from this research are disseminated, reports, papers and presentations will include anonymised information about the setting and sample so that the findings can be evaluated in relation to transferability to other settings (Elliott, Fischer & Rennie, 1999)

5.5.1.3.3. *Trustworthiness of the data: trust and access*

An additional issue with regard to the trustworthiness of the data itself is dependent upon the extent to which community members are prepared to share their views with the researchers. Miller (2004) discusses the relational context of research with communities, including the question of trust and openness in data collection. He suggests that ‘outsiders to the communities that are the focus of our research cannot simply waltz in unannounced and start gathering data’ (p. 217). Miller emphasises the importance of the relationship of trust that the researcher develops with research

participants, and argues that this can be overlooked if it is seen as peripheral within a positivist research framework. This can occur where the researcher is constructed as an objective collector of observations rather than a person involved in negotiating relationships and generating data with the research participants.

Recognition of this issue has been central in planning this research. Collaboration with the community members and privileging of their accounts underpins the design of this research. Community members and professionals in statutory and community organisations have been involved or consulted in the planning of the research.

Consequently the research has needed to remain flexible to ensure that this has been a genuinely collaborative process. This issue has also determined the approach to the process of generating data. Data was generated in unstructured discussions with a small number of prompts to guide the discussion, and a high degree of flexibility to respond to participants' identification of important issues in relation to the broad topic areas. Researchers aimed to be open and engaged in the discussions, and it was valuable to carry out discussions alongside co-researchers who could draw upon their own experiences in relation to participants' data.

5.5.1.3.4. Comprehensiveness and analytic rigour

Yardley's (2000) approach to trustworthiness emphasises the importance of comprehensiveness in relation to data and analysis. It is important to have an approach to generating data that seeks a sufficient quality and quantity of data to shed light on the research topic. In addition to comprehensiveness in relation to data, it is important to ensure that analysis is thorough and examines the data using a rigorous and systematic approach. Analytic strategies including familiarisation, detailed coding and constant comparison were employed to ensure that the data was fully explored. A process of moving between data and the analysis to frequently

check the emerging analysis, described by Henwood and Pidgeon (2006) as the ‘flip-flop’ enables the researchers to critically examine their developing understandings. A further analytic strategy is to return again to the data once the analysis is well developed, and seek evidence that contradicts the analysis. This process enables further refinement and development, and can be used reflexively to examine the assumptions of the researchers.

5.5.1.3.5. *Reflexivity*

Mason (2002) defines reflexivity as ‘thinking critically about what you are doing and why, confronting and often challenging your own assumptions, and recognising the extent to which your thoughts, actions and decisions shape how you research and what you see’ (p. 5). Whilst she emphasises reflexivity as a process within qualitative research, in recognition of the impact of the researcher on research outcomes, Mason also advises against an over-emphasis on introspection. The aim of the research is not to primarily explore the researcher, but reflexivity remains important to demonstrate quality within the research through an examination of the impact of the researcher. The value of transparency regarding the role of the researcher provides the reader with information on which to assess the quality of the research (Yardley, 2000). Without engaging in a reflexive process throughout the research, it would be difficult to articulate the impact of the researcher on the research process and outcomes. This is an ongoing process, which evolves over the course of a research project (Bott, 2010).

Feminist research methods explore relationships of power and hierarchy within the relationship between researcher and researched. This process involves exploration of how researchers position participants as 'other'. Researchers can unexpectedly perceive participants as 'unlovable' as our knowledge of the participants develops and we become increasingly aware of the differences between us (Bott, 2010).

Although this is important in maintaining an awareness of our ethical responsibilities within the research relationship, it does not reflect my experience of the relationship with either professional or community participants. However, as Bott describes, it is not just from my perspective that this perceived distance may be important. Research participants will have their own perspectives on members of the team of researchers. My prior position as a clinical psychologist working in the area has shaped my perspective toward the research participants, some of whom might be considered as 'unlovable' by some researchers (for example, a woman who has been in prison, dependent on substances, and lost her children into care). The perspective I have brought to this research in relation to stigma and mental health, having worked in mental health services, will have shaped how I relate to some research participants, but may not shape how they relate to me. Bringing a particular philosophical and professional perspective to this activity has influenced the way that I understand the origins of distress experienced by professionals and mental health service users.

Familiarity with the research context raises different issues about relationships with research participants. In particular, there have been historic rivalries and allegiances between different groups of professionals within the local service context, and this has a bearing on processes of data generation. The collaboration with co-researchers has moderated the influence of my position as a clinical psychologist in relation to these relationships in the professional context. The co-researchers have been able to

ask difficult questions that previous professional relationships may have prevented me from asking. Co-researchers have been able to construct accounts with other local mothers that I would be unable to do because of lack of common experience and knowledge. Conversations with co-researchers about data from both professional and service user participants have enabled me to recognise the perspectives that I hold, and allowed us to develop the depth of our understanding of the data.

Mauthner and Doucet (2003) argue that reflexivity as a process aims to make the contexts of research visible. In common with many feminist researchers, they present qualitative analysis as not simply a neutral, technique-driven activity. The authors argue that it can be difficult to reflect on what shapes research during the process beyond reflecting on the researcher-researched relationship.

Mauthner and Doucet (2003) give an account of the value of having access to a group of peers to develop reflexivity in analysis. Although this group was presented as productive in generating a reflexive position on their research activity, in retrospect Mauthner and Doucet have recognised the limitations of their ability to reflect beyond personal identity issues and emotional responses within the process of analysis. This awareness has led them to identify a need to broaden reflexivity to include the influence of interpersonal, organisational and epistemological/ontological contexts on analysis. Within this research, analysis and data generation activities have involved discussion with co-researchers at each step in the research process. The participatory activity of data generation and analysis has enhanced reflexivity through illuminating the differences between co-researchers' perspectives. In this way, it has been possible to see the assumptions that I bring to the research, when they are not shared by co-researchers. The position of co-

researchers outside of the academic system has also helped me to develop my awareness and recognition of the organisational processes that have affected the research. As Mauthner and Doucet have argued, reflexive awareness of influences on the research process is likely to deepen over time and with the hindsight of distance once the research is complete.

Training and experience in clinical psychology provide skills in reflecting that are transferrable to research activities. The clinical encounter requires the psychologist to actively reflect on her impact within the clinical relationship, in developing a formulation of the presenting problem and evaluating progress in collaboration with the service user. This involves holding a position described as the ‘Internal Supervisor’ (Casement, 1985) while simultaneously interacting with the service user. These clinical activities parallel data generation and analysis, although frequently in a less formally articulated and structured process.

This research has involved reflections on the position and assumptions that I bring to the research, through articulating this in the theoretical frameworks chapter and writing reflective diary entries about influences, perspectives and contexts that have shaped the research.

5.5.1.3.6. *Reflexive research journal*

It was hoped that all researchers would document the process of investigation, from planning, through data collection, coding and analysis as a record of the development of the research. However, on discussion with co-researchers, this was not considered to be a priority for them. The purpose of providing a reflexive account of the research process was connected with the academic assessment and appraisal of the research, therefore this was only carried out by me. The reflective journal functions as a resource within the research and as an ‘audit trail’ (Lincoln and Guba, 1985) to

ensure the transparency of the process of the research, so that credibility, dependability and confirmability can be evaluated.

5.6. Ethical Considerations

A favourable opinion was given by the Essex 1 NHS Research Ethics Committee (Appendix C), and management approval was obtained by the Research and Development departments of the 3 NHS Trusts in which the research has been conducted. The process of obtaining approval from the NHS Research Ethics Committee involved a number of challenges that specifically related to the participatory approach to the research.

All co-researchers except me were Honorary Research Associates at University of East Anglia. I was registered as a PhD student at University of East Anglia, and employed by Norfolk & Waveney Mental Health Foundation NHS Trust and Norfolk & Norwich University Hospitals Foundation NHS Trust. All researchers were subject to Criminal Records Bureau (CRB) checks and Occupational Health clearance, although due to prior checks carried out within my existing employment, I was not required to undertake additional clearances.

An information sheet was given to potential participants prior to requesting their consent to participate in the study (Appendix D). The sheet details the participant's right to withdraw from the study at any time, and to refuse to answer any questions, without giving any reason. It was emphasised that no aspect of their health care would be affected by their decision whether to participate, or by their withdrawal from the study. Signed consent forms (Appendix E) were obtained from each participant.

All discussions were audio-recorded, and the transcribed recordings will be destroyed once the study is complete (after the viva examination and amendments to

the thesis). In transcription, each participant was allocated a number to enable analysis of continuity. These numbers have not been used to link data with participant identity. Identifying information (such as names and places) was removed at the time of transcription. Potential threats to confidentiality have been considered and minimised prior to including verbatim extracts in the thesis or papers submitted for publication. The identity of some participants may be exposed to readers with local knowledge, due to the small number of professionals in particular specialist roles. Therefore it has not been possible to give details of professionals' roles, genders and place of work, as in some cases there is only one person in such a role in the local area. The Data Protection Act has been adhered to, and all forms of data (audio and transcribed) were stored in a locked filing cabinet and a password protected electronic storage drive at the University of East Anglia. Participants were not named on any transcript, but were given a unique identifier, such as IM1 (Individual Mother 1), GM1a (Group Mother a, within Group 1), IP1 (Individual Professional 1), and so on. A master list of these codes and participants to whom they refer has been stored in a locked filing cabinet at the University of East Anglia. The issue of confidentiality and anonymity was addressed at the beginning of each individual and group discussion. Participants were assured of the measures undertaken to protect their anonymity. The intended use of the data was described to the participants so that each participant could make an informed decision regarding participation and level of disclosure. It was highlighted at the beginning of each discussion that there are circumstances in which confidentiality could not be maintained, particularly in relation to the requirements of the Children Act (1989), in the event of disclosure of harm to children. There were no disclosures during the

data generation that were considered to raise concerns about the safety of children or any other person.

All participants were informed at the beginning of the data generation sessions that information could be given about how to access services in the event of distress arising from the session. In the event of distress arising from participation in the discussion, the participants were reminded that they were under no obligation to continue with the discussion. Two participants cried at times during data generation, but did not wish for further debrief at the end of the discussion. One of these participants requested additional information about local services at the end of the discussion and was given information about self-referral to Improving Access to Psychological Therapies (Wellbeing) services. At the time of every discussion, I was available for advice and debriefing with co-researchers where necessary. Time was set aside at the end of every session for reflecting on the experience with the co-researchers. After several of the discussions during which participants described abusive experiences or expressed distress, it was possible to take time to discuss the impact on co-researchers.

5.7. Procedure

The team of researchers liaised with local services to recruit participants from the community of mothers who had experienced poor mental health or emotional wellbeing during pregnancy. The potential participants were given written information about the research by either the researchers or by their professional contact, and were given at least 24 hours to consider participation before being asked to sign consent forms. For those who were considering agreement, the researchers were available to answer any queries about the research prior to taking consent.

Professionals working with pregnant women within statutory and voluntary agencies were approached and recruited through existing networks and subsequently through snowballing following initial contacts with potential participants. Professional participants were also given information sheets and asked to consider participating, with a minimum of 24 hours to consider this (in accordance with local ethics committee guidelines) before being asked to sign consent forms.

Regular peer debriefing continued alongside the data collection and analysis, and discussion with research supervisors to enhance trustworthiness of the analysis (Lincoln and Guba, 1985) were carried out after all of the discussions were conducted and analysed.

5.7.1. Sampling decisions

Maximum variation and theoretical sampling were used to guide the rationale for sampling decisions within the community as the research progressed. Decisions were informed by emerging themes from preliminary analysis of the initial data, together with developing familiarity with the community being researched. The aim was to incorporate into the study design an appreciation of the issues from as diverse a range of perspectives as possible within the timescale of the research. Unlike quantitative research, a random or representative sample was not emphasised within this approach, and while seeking to explore commonalities, the sampling decisions sought to appreciate potential diversity among the populations (Henwood, Griffin and Phoenix, 1998).

5.7.2. Participants

Sixteen professionals were recruited from services working with pregnant women within statutory and independent sector agencies. Initial participants for the

professional sample were sought from the researchers' existing professional networks. This stage of recruitment was followed by 'snowballing', whereby existing contacts were asked to suggest other people who had knowledge of the research issues. The approach to snowballing aimed to contact a range of professionals in different roles and different services, including the statutory mental health and maternity services and voluntary sector services for pregnant women. Unfortunately no general practitioners or psychiatrists were recruited to take part in the research. The professional groups who participated in the research are listed in the following table.

An outline of the professions of individual participants is given in Table 5.1.

'GP' indicates that data was generated in a group, and 'IP' indicates that data was generated in an individual session.

Unique identifier	Position
IP1/GP2b *	Clinical Psychologist
IP2	Specialist Health Visitor
IP3	Community Mental Health Nurse
IP4	Antenatal and Health Promotions Worker
IP5	Primary Care Mental Health Linkworker
GP1a	Specialist Midwife
GP1b	Midwife
GP1c	Midwife
GP1d	Midwife
IP6	Consultant Obstetrician
IP7	Specialist Health Visitor
GP2a	Clinical Psychologist
GP2c	Psychotherapist
GP2d	Clinical Psychologist
GP2e	Clinical Psychologist
IP8	Specialist Midwife

** This participant took part in an individual discussion and was present at a subsequent group meeting where data was generated.*

TABLE 5.1- LIST OF PARTICIPANTS: PROFESSIONALS

Detailed information about individual professionals, such as gender and specific role/workplace, is not given because this could compromise anonymity in a small community where this information would enable identification to anyone with knowledge of local services.

Seventeen participants were recruited from the local population of antenatal and recently postnatal women. This research aimed to be inclusive and develop a comprehensive understanding of the many experiences of mental health in pregnancy, and therefore the aim of sampling was for maximum variation. The researchers contacted both statutory and third sector services and community groups to recruit participants. These included primary care, maternity services, mental health services and community services for women with young children. As some potential participants may not have been in contact with services, the research was presented in the local press and on local radio to make interested potential research participants aware of the study and give information about how to contact researchers. In addition to raising awareness in local media, the community co-researchers shared information with their personal networks and a small number of participants were contacted in this way.

‘CM’ indicates that the woman chose to have her partner present during data generation, ‘GM’ indicates that data was generated in a group, and ‘IM’ indicates that data was generated in an individual session.

This table provides a summary of some basic information about research participants. However, this does not reflect the diversity of experience within the sample.

Unique identifier	Age	Number of children	Age of youngest child/number of weeks pregnant	Living with partner?	Housing
CM1a	32	2	9 months old	yes	Owner occupied
CM2a	25	1	6 months old	yes	Private rented
GM1a	24	2	<6 months old	no	Private rented
GM1b	27	1	16 weeks old	yes	Council rented
GM1c/IM5*	40	3	<6 months old	yes	Owner occupied
GM1d	36	4	<6 months old	yes	Council rented
GM1e	25	2	<6 months old	yes	Private rented
GM1f	22	2	<6 months old	yes	Council rented
GM2a	18	Pregnant	32 weeks	no	Shared/private rented
GM2b	16	Pregnant	14 weeks	no	Living with friend
GM2c	17	Pregnant	24 weeks	no	Hostel/lodgings
IM1	32	2/pregnant	17 weeks	no	Council rented
IM2	29	1	18 months old	yes	Private rented
IM3	27	Pregnant	21 weeks	no	Private rented
IM4	27	2	15 weeks old	yes	Council rented
IM6	29	Pregnant	16 weeks	yes	Owner occupied
IM7	37	1	13 months old	no	Living with mother

** This participant took part in a group initially, and then expressed a preference to speak with a researcher on an individual basis.*

TABLE 5.2 - LIST OF PARTICIPANTS: PREGNANT AND RECENTLY PREGNANT

WOMEN

The recruitment strategy of seeking participants in contact with a range of different services, or without ongoing contact with services has resulted in recruiting participants with a range of experiences including:

- Women with serious, long-term mental health problems relating to traumatic early life experiences, some of whom have ongoing secondary level mental health service contact
- Women with mild to moderate anxiety and depression, who have had a short burst of primary care services such as CBT within local Wellbeing services
- Women who are prescribed psychiatric medication, and women who are not
- Women who use alcohol and non-prescribed drugs and women who do not
- Women with extensive and supportive social and family networks, and women who are extremely socially isolated
- Women with professional training and employment and women who have never worked
- Women with serious financial problems and women who feel financially secure
- Owner occupiers in affluent areas and women in hostels or insecure private rental accommodation with concerns about neighbourhood safety and damp, cold, unhealthy housing conditions
- Women with education ranging from degree-level professional qualifications to those who left school at age 14
- Women with older children in their teens, and women who were pregnant with their first baby
- Women who had had multiple miscarriages and still-births, and women who had never lost a pregnancy
- Women whose older children had been taken into the care system, and women who had all of their children still living with them
- Women aged from 16 to 40 years

- Women in long term, supportive relationships and women who were in and out of violent relationships, sometimes requiring accommodation in a women's refuge
- Women with physical and mild learning disabilities and women without any disclosed disabilities
- Women who were born in the local area, who relocated from other parts of the UK, and who migrated to the UK from other countries
- Women with strong religious affiliations and women without

Although this list provides an overview of the diversity amongst the participants, it is important to note that all participants were of homogenous ethnicity (White). Those who disclosed information about their intimate partner relationships only described heterosexual relationships. Attempts to recruit participants from more ethnically diverse backgrounds, through professional contacts with specialist community roles, were not successful. Existing professional networks were not able to facilitate contact with lesbian and bisexual mothers. Colleagues with roles in LGBT communities did not identify any mothers who may have been interested in taking part in the research.

5.8. Data Generation

The data generation consisted of focused discussions addressing the research questions. An initial set of discussion topics (Appendix F) was developed, based on the research questions and experiences of co-researchers from the community. This was reviewed with the advisory group prior to data collection, but was not significantly amended during the process of data collection and analysis.

The research team decided to use focused discussions rather than more formal or structured interviews for generating data. The primary rationale for using focused

discussions is in keeping with the participatory approach to this research. It was considered that the opportunity for informal discussions would generate data that was richer, more comprehensive, and more responsive to the interests of participants than data that would be generated in response to a structured list of questions as predetermined by the research team. The process of collaboratively generating data with participants is in keeping with a philosophical approach that conceptualises knowledge as co-constructed within a social context, rather than as something pre-existing to be extracted from the participant. The emphasis on privileging the perspectives of the participants allowed the researchers to encourage further exploration of themes and issues as they arose within the discussions. The iterative nature of qualitative research ensures that research is thorough, and responsive to participant input throughout (Charmaz, 2006).

Members of the research team have different and complementary skills, and it was important to ensure the best use of this range of skills to develop the research process and ensure the highest quality of data generated. Some members of the research team have specific local knowledge, and knowledge and skills gained by experience of pregnancy, parenthood and mental health problems. The university-based member of the research team has knowledge and skills gained by experience of undertaking qualitative research and research interviews, and from working as a qualified clinical psychologist in adult mental health services. Because of this mix of skills, the best quality of data was likely to be gained by working together to develop data gathering skills across the whole team and a greater level of consistency across the data set. Initial development of the process included opportunities to share skills and knowledge in co-training meetings prior to discussions to generate data. A number of preliminary sessions were undertaken by the research team to develop the

approach to data generation. The process of discussions was developed with ongoing feedback, discussion and amendment to the process by the research team after completed discussions.

Data generating discussions were facilitated by all members of the research team. Discussions involved either individual or small groups of participants and two members of the research team where possible. A number of discussions were conducted by only one researcher either because another co-researcher became unavailable once the appointment had been made, or because a participant requested to be seen individually. Due to delays within University Human Resources, the Criminal Records Bureau checks and Occupational Health clearances were not completed until all of the data had been gathered. This meant that if a participant preferred a one-to-one discussion, this was arranged with the member of the team with pre-existing employment and clearances. Details of the research team members involved in the data generation are listed in Appendix G.

5.9. Analysis

The approach to analysis of the data was based on methodologies from research using thematic analysis, and informed by grounded theory (Braun & Clarke, 2006; Henwood & Pidgeon, 2006).

5.9.1. Transcription and familiarisation:

The audio recordings were transcribed as soon as possible after each discussion. Data were transcribed verbatim, with the exception of excluding identifying information (names of people, organisations and places). This was done by me as part of the process of familiarisation with the data. The text was read through again as a whole prior to commencing coding.

5.9.2. *Coding and indexing:*

Members of the research team met individually with me to read through the transcripts, familiarise ourselves with the data and carry out initial coding. The members of the research team who had been involved with data generation with each participant were the researchers who carried out initial coding. There were a few exceptions where one member of the research team had not been involved in many data generation sessions, and wanted to have more involvement in coding and analysis. The members of the research team involved in data generation and initial coding are given in Appendix G.

Detailed coding followed the method outlined by Frankland and Bloor (1999), beginning with attaching codes to transcript texts using open coding. Rather than focus on individual lines as the unit of analysis, the research team coded meaningful units of data. This approach avoided using arbitrary units as defined by transcription and document formatting rather than focusing on meaning (Chenail, 2012).

Similarly to the process of conducting discussions, this process helped to develop familiarity and shared skills in analysing data, drawing upon the different strengths of the research team, including contextualised knowledge and procedural knowledge. It was not expected that all researchers' perspectives on the data would be identical; however, commonalities and differences were examined with the intention of developing a greater reflexive understanding of the ways in which researcher positions impact upon the analysis. This is a form of triangulation that was not intended to reach an objective truth, but rather to enhance reflexivity and improve the comprehensiveness of the analysis (Murphy *et al*, 1998).

After initial coding was complete, notation on the transcripts was used to inform cross sectional indexing. Sections of the data were numerically identified (including

participant identity, transcript page number and line number) and indexing was carried out by pasting data and initial codes into Excel spreadsheets to facilitate comparative analysis (Mason, 2002). Although the original intention was that this could be carried out by members of the research team together at meetings, when the length of the process was reviewed with co-researchers, they all preferred for this to be done and fed back to after completion. Therefore, I was responsible for all data indexing, and this part of the process did not involve the co-researchers. For an example of a section of an index spreadsheet, see Appendix H.

The coding and indexing process remained provisional through the early stages of analysis. This was a cyclical process, so that new codes emerging through the analysis and from subsequent discussions informed the progressive elaboration of the initial codes.

5.9.3. Core analysis

The first stage of core analysis focused on themes emerging from initial coding and indexing from community discussions related to:

1. Participants' understandings of mental health and factors that undermine and promote good mental health during pregnancy
2. Women's experiences of services and professionals' views of services
3. Views regarding existing strengths and resources such as local statutory and independent sector services, and community resources
4. What is needed by local women to support good mental health during pregnancy and beyond

This process involved meetings between co-researchers to review spreadsheets and compile summaries of data content and themes. When this activity was discussed with all three co-researchers, one member of the team expressed feeling unable to

take part in this element of the project due to her dyslexia and the quantity of written text to be managed. When we discussed the possibility of taking time to read through the text aloud to enable her to be involved, she said that she would prefer not to be involved in this stage of the process. One of the co-researchers was able to meet more frequently than the other, and was therefore more involved in this process. The process of building thematic summaries of the data involved reading together through all of the indexed data compiled within the spreadsheets and agreeing on themes within overarching categories of data. It was agreed between co-researchers that this activity would focus on the initial questions driving the research. An example is given in Appendix I, in which the data relating to the question ‘What do mothers say is needed to promote their mental health during pregnancy?’ is built up from the spreadsheet to combine all of the relevant data under headings that summarise the full data set. This activity was undertaken in relation to all parts of the indexed data set from both mothers and professionals.

Excel spreadsheet functions were used to bring sections of the data together according to the coding labels attached to each chunk of data. For example, where several chunks of data were labelled as ‘community support’, these were examined alongside each other and categorised within the summary as relating to peer support or other types of support within the community. Under the heading of peer support, this was compiled into different functions of peer support within the summary, according to what participants said about their wishes for peer support. These included the opportunity to access different opinions; having someone to talk to; being listened to; having support as a mother-to-be, not just in relation to mental health and; generally accessing emotional support from peers.

The second stage of core analysis involved moving from the thematic summaries of data and mapping connections between aspects of the data. During this process, further decisions were made regarding changes to the themes and sub themes that were captured during indexing, but reconsidered in further discussion with a co-researcher. Some versions of separate themes collected in the indexing spreadsheet were either separated into more than one theme, or collapsed from more than one theme into one.

Following the process summarising and compiling all of the indexed data, one co-researcher and I drew out visual maps of all of the overarching categories using one flip chart page for each category. We wrote the different sub-themes from the summary onto post-it notes and located the different themes and sub-themes in relation to the overarching category (for an example, see Appendix J). In this example, the themes within the category from mother's data about 'what doesn't help' their mental health during pregnancy were mapped out showing all of the sub-themes that were in the indexed data under themes. These hand-drawn maps were subsequently replicated by me using computer software for the purpose of presentation, as will be shown in chapters 6 and 7 of this thesis. Following this process we used the maps to share the analysis with the other co-researchers who had been less involved in this part of the process to aid further discussion of findings.

5.10. Presentation of Findings

Blaxter (1993) emphasised the importance of analysing data for similarities and differences, both between and within participants to enable a consideration the context of the account. It was one of the aims of analysis to explore similarities and differences, contradictions and relationships within the data. This included addressing the similarities and differences between professional and community

members' data, with a view to understanding the perspectives of providers and users of services.

Henwood and Pidgeon (2003) highlight the importance of moving from categories to an account of their inter-relatedness and placing them in the wider theoretical context. In this case, this includes consideration of what the locally focussed analysis can suggest about the wider theoretical context of antenatal mental health, and its relevance to informing mental health promotion.

Findings from the analysis of mothers' and professionals' sets of data are presented in Chapters 6 and 7. The Discussion chapter will explore the connections between the two sets of data and relate these findings to the wider theoretical and ecological contexts of women's mental health during pregnancy.

CHAPTER SIX

FINDINGS FROM MOTHERS' DATA

6.1. Introduction

Data from discussions with women about their experiences of mental health during pregnancy are presented in seven primary categories. These are:

- Women's experiences of mental health problems
- Factors that undermine women's mental health during pregnancy
- Effects of mental health problems during pregnancy
- Factors that promote women's mental health during pregnancy
- Strategies for coping with mental health problems during pregnancy
- Women's experiences of services during pregnancy
- What women felt was needed from services to support their mental health during pregnancy

The data relating to women's experiences are presented first in the chapter in order to provide a context for subsequent data. However, the following diagram (Figure 6.1) shows the connections drawn between the different main categories of data as listed above.

This chapter reflects the variation in experiences described in the data. Figure 6.1 shows the connections between influences upon women's mental health; the experiences of mental health problems; the effects women described arising from their mental health problems; and the resources, internal and external that they have drawn upon. The section addressing women's experiences of services reflects both the positive aspects of this as a resource, and the difficulties women had experienced

in relation to services. Finally, the chapter concludes with women’s views on what they need from services in relation to their mental health during pregnancy.

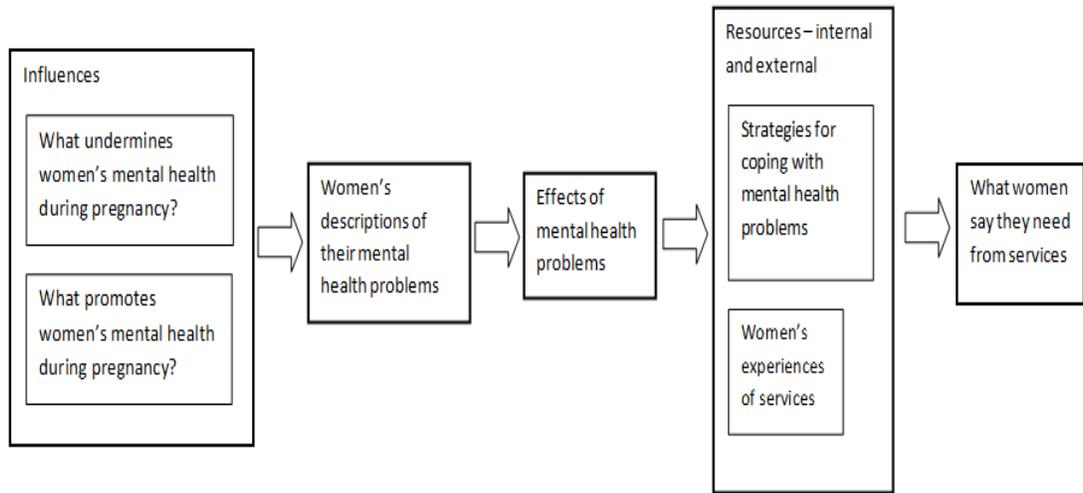


FIGURE 6.1 - OVERVIEW OF ANALYSIS OF WOMEN’S DATA

At the beginning of each section, a mind map is shown to summarise the data within that section. Although further interesting aspects of women’s experience emerged from analysis of the data, this thesis is focused on the research questions outlined at the beginning of the research process.

Data is presented as it was transcribed verbatim, with the following symbols:

.. short pause during uninterrupted speech

... longer pause during uninterrupted speech

--- omitted data, to provide continuity within the meaning of the data from the participant when the transcript included sounds from the interviewers or other participants in a group, such as short utterances, prompts for further clarification or expressions of acknowledgement such as ‘mm hm’.

[] brackets are used to indicate where identifying data such as names of people and places have been removed, where data was missing from the transcript because it was inaudible on the recording, to clarify the topic about

which the participant was speaking immediately before the quote, and non-speech sounds within the recording, such as crying.

() At the end of each quote, the anonymous unique identifier for each participant is given. Where women were part of a group, the identifier is given as 'GM' (group, mother) followed by the number of the group and a letter to identify which member of the group they were. Where women gave data as an individual interview, the identifier is given as 'IM' (individual, mother) followed by a number. Where women were interviewed with their partner present, the identifier is given as 'CM' (couple, mother), followed by a number.

6.2. Women's Experiences of Mental Health Problems

The first part of this chapter is focused on contextualising the data. It gives an overview of the kinds of experiences and the diversity of descriptions given by participants about their mental health.

Participants described diverse personal experiences of mental health problems. The descriptions ranged from everyday struggles with emotions to long-term and serious problems that had a significant impact on their abilities to function in life.

I've felt that at times it's been quite.. kind of um, almost debilitating, a bit life limiting for me (IM6)

I get over loaded, and then that, I'll have a crisis.. because you can only take so much, and you can only give out so much --- and when you've given everything, you've got nothing left, and you can't cope with normal everyday things --- and... you just.. break (IM4)

Many women used diagnostic labels such as anxiety, depression, bipolar and personality disorders, alongside more descriptive terms to give a more personal account of how they felt.

if I can't find the knife in the kitchen, I'll just get really angry ---and I won't wanna wash it up, and I'll just think, 'well why hasn't no one done the washing up', and I'll just go really.. agitated about it (GM2b)

I just thought, 'whoa, I'm not in control of anything' and that's how I felt (CM2)

I think sort of inside I'm a complete mess, but I mean, luckily I'm the sort of person that can hide that it's a complete mess (IM3)

A 'mind map' of the overall categories of problems described by participants is shown in figure 6.2.

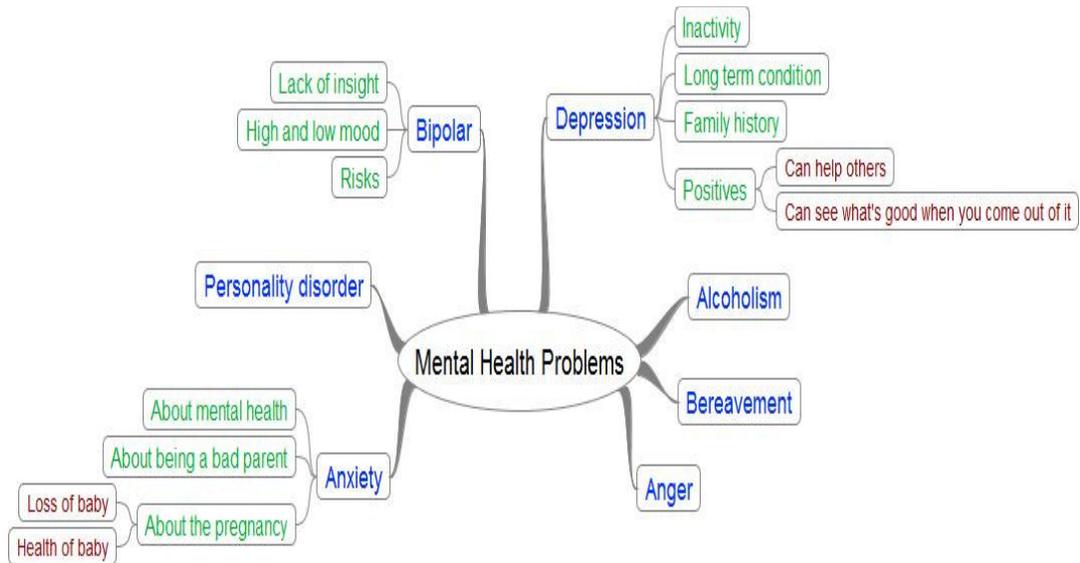


FIGURE 6.2 - WOMEN'S DESCRIPTIONS OF THEIR MENTAL HEALTH EXPERIENCES DURING PREGNANCY

In the case of diagnostic labels, such as depression, women often gave detailed descriptions of the quality of their personal experience, beyond the label, frequently employing physical metaphors.

I think when you get down about something, then everything can just come down on top of you and you get yourself into a rut and that's exactly what I was like (CM2)

I'll feel myself, suddenly just sinking and then I'll just sit there and cry my eyes out (IM1)

In addition to primarily negative experiences of depression described by all participants, one woman also expressed another side to her experience of depression, where she was able to see positive aspects of her life arising out of the contrast with times when she was feeling depressed.

when I'm out of it [depression], everything, everything positive becomes magnified, you know, like that picture, is like, massively bright colours, um... I can, when I'm, when I'm not depressed, I can see pretty much positive in everything (IM7)

Women's relationships to their mental health were reflected in the use of descriptions of their mental health problems as something they 'have' or 'had', something that is theirs, such as 'my depression' (IM7) or 'my anxiety' (IM6).

I had depression, sort of, a long time ago, um, and it, that, in my teens I had depression (IM3)

Participants also used descriptions to signal something they are or were. Women used expressions such as 'I was very depressed' (CM2) or 'I was suicidal' (IM1). In most cases these expressions of being something related to a state that they

experienced, similar to ‘I was pregnant’ (IM7) or ‘when I was five’ (IM2), rather than a description of a more stable identity, which was uncommon.

I know a lot of it is me, and how I.. feel (IM6)

On one occasion a participant began to express her mental health as a more stable identity trait, and then corrected herself.

I am an anxious, I get quite anxious anyway (IM3)

In other cases, participants described their experience of mental health problems as something that they do or did, or find/found it difficult to do.

I still do it now, I sort of walk around with a barrier (IM3)

I felt, I just could not calm myself down (IM6)

In many cases, participants used language to externalise their experiences of mental health in different ways. These included mental health problems as something that happens to people, something they act on and find ways to manage.

being pregnant makes it harder to keep.. depression away (IM3)

I was always trying to fight it, and there’s still quite a big element of that, but --- it’s sort of seen as such a negative thing, ‘we need to get rid of it, get rid of it’ (IM6)

In the above examples, anxiety and depression were referred to as abstract objects to be kept away or as negative ‘things’ to be fought rid of. Mental health problems were also seen as something that can be imposed on people by others, or by themselves, or that can be inherited through birth.

she kept saying he weren’t gonna be healthy, which then put a lot of anxiety into me (GM1a)

spend weeks thinking, worrying myself stupid ... and getting myself into a right stew sometimes (IM2)

I think there's a possibility it could be genetic, because it just seems strange to me how, like my dad's an alcoholic, my mum's an alcoholic, I'm an alcoholic, brother's got drinking problems, what he says, and he's got mental health, I've got mental health, mum's got mental health and my dad's got mental health (IMI)

The data reflects the pervasive nature of women's experiences of mental health problems, which have been described as coming from many different directions and occupying many positions in relation to women's experience. Only on rare occasions did women describe their mental health as something over which they felt they had any control. Some of the data shows ways in which women have struggled with the meaning of their mental health problems and their relationships to the experiences that they had.

There were no instances of women questioning a diagnosis they had been given, even where they were unhappy with the diagnosis, it was accepted as truth about themselves.

before I had my diagnosis [personality disorder] I was desperate to get this diagnosis just to know what was wrong with me, and now I've got it, don't want it (IMI)

This was the case even when the woman had other, less medical ways of understanding her emotional experience.

I tend, I do tend to go into a lot of unstable relationships, every single one of my relationships has been unstable, and violent, and that's because you tend to think that's all that you're worth in the end. (IMI)

From a psychological perspective, this account gives an explanation of the contextual and relational nature of some negative mental health experiences, however, the woman was left with an experience of an unwanted medical diagnosis. Some women described their mental health problems in relation to the experiences of stress and distressing experiences in their lives.

my doctor said, '[IM7], you're not depressed, you're just a f.. is it a frustrated.. angry wife, that's not depression, that's just, you know, stress' (IM7)

I went to [nearby city] hospital, and they said I was suffering with sleep deprivation, which is like one of the top... things on mental health, like.. so from there on, it's only the fact that I went to the hospital that I got help, otherwise, I, I think I was going mad (GM1e)

They [coroners] kept holding him [her brother] so long, obviously we couldn't see him, cause of, you know.. and then I think, I rushed in to getting back to work, and not properly grieved for him (CM2)

Other women described feeling emotionally sensitive and not understanding or being able to identify the reasons behind the feelings.

very up and down --- one moment you can be really happy, and the next you're crying for no reason, absolutely no reason at all (GM2c)
it's a just a funny feeling, you just kind of wanna be left, like left on your own, you want.. it's just really weird (CM2)

Although a small number women were not able to identify the origins underlying their difficulties with mental health, this lack of understanding was in the minority within the data.

6.2.1. Summary

Women used predominantly diagnostic terms to label their mental health problems and expanded these with more descriptive details reflecting the lived experience of the problems including physical metaphors to describe their experiences. Many women gave accounts of their relationship to the mental health problem including the sense that it was something that they had, something that they did, something that had been imposed on them a transient state. Many women gave accounts to suggest that they understood the origins of their mental health problems, although some participants expressed difficulties in describing, explaining and understanding their mental health.

6.3. Factors that Undermine Women's Mental Health During Pregnancy

Many women volunteered ideas about the origins of their mental health problems before a question was asked about what made it worse. Whether this question was directly asked or the information was volunteered without a prompt, women's ideas of what undermined their mental health generated a comprehensive map of a range of factors. This is shown in figure 6.3 below.

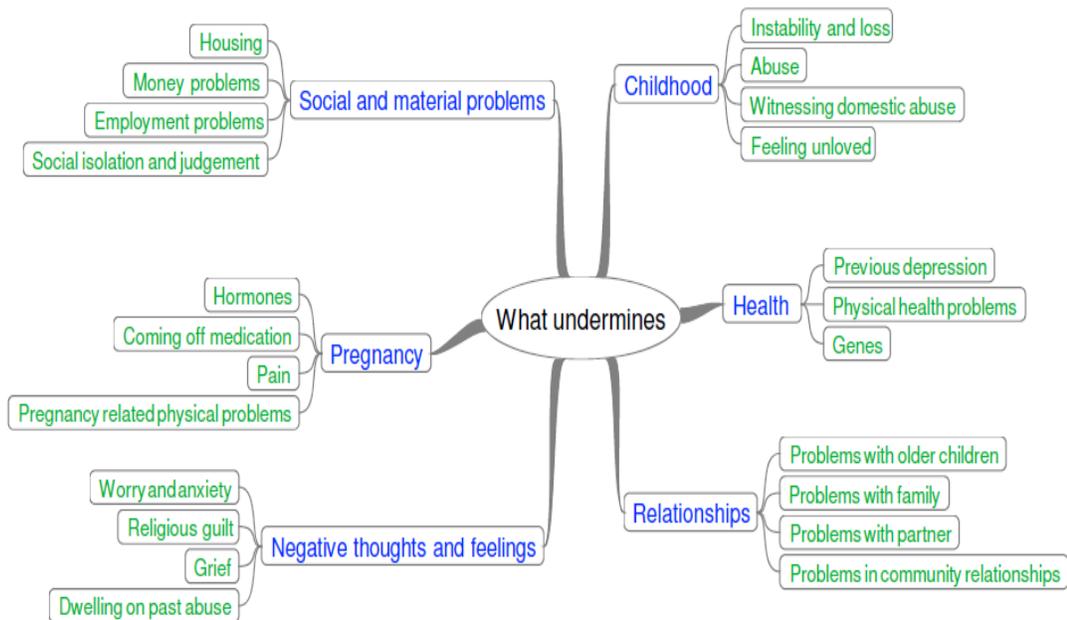


FIGURE 6.3 - WHAT UNDERMINES WOMEN’S MENTAL HEALTH DURING PREGNANCY

Women’s accounts of the factors that undermine their mental health during pregnancy fit well with a wide ranging model that incorporates experiential, relational, social, biological and intrapsychic aspects of experience. Participants’ descriptions of these factors have been collected together under six major headings: Childhood experience, health related factors, relationships, internal processes such as negative thoughts and feelings, experience of the pregnancy, and social and material problems relating to their lives.

6.3.1. Childhood experiences

Many women spoke of their painful childhood experiences in direct relation to how they understood the origins of their mental health problems.

with my bad childhood there weren't really any support or help offered to me then --- so, it just all got.. quite.. a lot on me, so, that gave me depression (IM3)

Negative childhood experiences were divided into four main categories, which were instability and loss, feeling unloved, being abused (including physical, sexual and emotional abuse), and witnessing domestic abuse within their families.

6.3.1.1. Instability and loss

Women described childhood experiences of unstable family life and losses of loved family members.

that goes back from like, from my sister being ill, and my granddad dying, cared about him a lot, my sister, I cared and loved her a lot --- and they've all gone, taken away, and the babies as well (IM5)

In addition to losses by bereavement, participants described the loss or absence of support from family members through work and parents' mental health problems.

One teenaged woman had been a carer for her mother who was diagnosed with bipolar affective disorder.

dad worked a lot.. like I mean a lot, lot --- high demand.. I remember one year he had to travel, couldn't take us, I was so sad when my dad went, cause I really didn't .. get on with my mum, especially being little, cause she didn't want to do anything, cause she's so.. sad.. you know (GM2c)

Other participants described parents who had been depressed, alcoholic and suicidal.

we talk a lot because we've both been through the same experiences, we've both got mental health, we're both alcoholics, um, we've both been abused in childhood and stuff (IM1)

to have your two.. pillars in your life [parents], threaten, you know, take, trying to take their own lives (IM7)

The lack of stability in childhood also related to poverty, insecure housing, and frequently moving home.

when we were children, we were always in and out of refuges, women's refuges, and that, and moving all over the place, and stuff, so they tried helping her, but she'd always go back (IM1)

I came home to a different house, my mum picked me up and took me to a flat, instead of our home.. um, and it was very difficult (IM4)

6.3.1.2. Abuse

Several women described experiences of different kinds of abuse during their childhoods. The majority of abuse experiences were different forms of abuse within the family, although one participant also described bullying at school.

6.3.1.2.1. Physical abuse

Two women described frightening experiences during which they believed their fathers were going to kill them. One woman's father was violent to the whole family, including an incident when he threatened her mother and siblings with a loaded gun. Another woman recalled repeated occasions when her father would become very angry, go red in the face, begin to shake and then lash out at her. The participant's account sounded very frightening, in spite of having previously described her childhood as 'normal'.

I remember just about passing out and Dad taking his hand off my mouth [sniff], because I'd gone quiet, well apparently my eyes had rolled to the

back of my head... and I was off, and, uh... Dad.. took his knee off my chest and looked at me and said, 'well, at least you're quiet now' (IM2)

This participant was concerned about becoming an abusive parent when she had her own baby, and described frequent worries during pregnancy about her ability to parent her son. Other women also described repeating patterns from childhood when they formed adult relationships.

I done exactly the same thing, like, with the kids dad, he's, he's been extremely violent to me, and threatened to kill me, and was even violent towards the kids, and um... I stayed, I was with him for five years (IM1)

A significant concern arising in the published academic literature relates to the impact of maternal mental health on the lives and health outcomes of the children that women have. This concern in the literature is reflected in the data from women themselves. The effects of internalising and pathologising women's experiences of violence and abuse locates the problem within the woman, for which she subsequently gives an account of herself as culpable in failing to break the pattern.

6.3.1.2.2. *Sexual abuse*

Three participants described familial sexual abuse, one of whom also described sexual abuse by a neighbour. Abuse within families included fathers, an uncle and a cousin who was an older child at the time of the abuse. Women described not receiving support in relation to a number of different experiences during childhood, which included not receiving help when they disclosed that they had been sexually abused.

I was sexually abused right throughout my childhood, for about ten years --- um, and because I sort of went to the police and got no help from them, I spoke to school teachers and got no help from them (IM3)

I tried to tell my mum, who .. laughed at me and told me not to be so stupid and tell lies (IM2)

This failure of adults to respond to children's disclosures of abuse potentially results in the abuse continuing for years, and children having no place to go for safety from sexual violence. One of the participants who experienced sexual abuse in childhood also described not understanding that sex was not a normal part of life in childhood.

when I was about [sigh].. twelve or thirteen, I was having sex with my friends who were sixteen or seventeen --- I just thought that's what you did, you know, that would, that's what boys and girls do.. then .. obviously that man that wants it.. you know, that's what you do (IM2)

She said that she was subsequently abused by other older men while she was still a child. One participant said that although she talked about the abuse frequently, this was not believed and was labelled as 'attention-seeking'. After this she became 'aggressive and angry' (IM3) toward adults in her life, which she felt subsequently had a negative effect on her ability to engage with education. The effects of childhood abuse can be seen here to have a broad impact on later life and subsequent experiences during pregnancy.

6.3.1.2.3. Emotional abuse/feeling unloved

All of the above descriptions of abuse in childhood also constitute emotional abuse, where a child does not feel valued and protected. However, there were other women who also described feeling emotionally uncared for as children, without other experiences of abuse. For some women, these experiences had had an impact on their adult lives and relationships.

I didn't want him to feel the way I felt when I was little, when my, when [younger half-brother and sister] come along.. you know, I didn't wanna be

made to feel like the pushed out one, and I didn't want [older step-son] to be, I didn't want [older step-son] to feel like that, either (CM2)

For these women, the presence of a favoured sibling or siblings contributed to their feeling unloved within the family.

6.3.2. Physical health, previous mental health and genes

Some women described their previous experiences of physical and mental health problems as having additional negative effects on their mental health during the pregnancy. For one woman this was related to physical pain and obesity.

I had awful backache, and my legs ached, and I just ached.. [laugh] proper ached, and I stood, and I was holding my stomach and I was feeling [baby] kick me, thinking, 'thanks a lot mate, you know, join in with this' (IM2)

This woman expressed feeling that her baby was kicking her as a way of contributing to the struggles that she was facing with her physical discomfort and emotional distress during the pregnancy. An interconnected cycle of physical and emotional distress is reflected in her experiences of physical pain, stigma and interpretation of the meaning of her baby's movements.

Other women described their history of mental health problems as an aspect of their health that contributed to emotional distress during the pregnancy. This was also reflected in their experience of maternity care services and allocation for consultant-led care.

because I had depression as a teenager I had, that, what, well whatever reason, that made pregnancy high risk, just because of depression (IM3)

Previous mental health problems were seen as exacerbated by pregnancy and contributing to the difficulties during the pregnancy.

being kind of.. pregnant, brings the whole one out about how I feel that everything could potentially be dangerous --- and when I found out I was pregnant, I .. sort of returned to quite high levels of anxiety, because I felt that so much could happen to me (IM6)

Other women located their difficulties with mental health during pregnancy in the arena of genes and brain chemistry.

you're born with Bipolar... people who are gonna have it are born with it, um.. what it is, is a chemical imbalance in the brain, uh, which renders you unable to control your own emotions (IM4)

even my brother suffers with mental health as well, so I think there must be some sort of genetic thing or something (IM1)

The experience of pre-existing physical and mental health conditions was clearly connected by many of the participants to their problems with mental health during the pregnancy.

6.3.3. Relationships

Although some women's relationships were identified as a factor that supported their mental health during pregnancy, many women described difficulties within their relationships that contributed to their experience of mental health problems.

6.3.3.1. Older children

Many of the women who took part in the research were having, or had recently had their first baby. However, there were some women who struggled with managing the pregnancy and the needs of their older children. For one woman, her older children had been taken into care due to her previous mental health problems, suicidality and inability to protect the children from a violent partner. With the new pregnancy, this

participant was struggling with anxieties about the physical health of her new baby and her ability to care for him. For another woman, there were anxieties about care for a new baby and her ongoing difficulties in caring for her older child with special needs.

he's learning delayed, and he's got ADHD and a multitude of other things --- he's classed as, well, he's a child with, um, yeah, registered special needs, um, complex, just basically complex child --- so that's sort of gonna make it a bit more.. difficult anyway, sort of having him, and a newborn (IM3)

Another woman had difficulties with her teenage son's behaviour, which she thought was related to his anxiety about her pregnancy, after a series of late miscarriages. Some women felt inadequate as mothers because they did not give the same attention to the foetus as they had given to the older child, due to the demands of caring for their older child. Some felt they were less able to give attention to their older child due to the physical limitations of pregnancy.

when I just had [eldest], I was the mum I always wanted to be.. but then when I was pregnant, cause I couldn't do all the things with her [crying, big intake of breath].. I then just felt really bad that I couldn't play, and she wasn't getting.. the best from me (CM1)

The multiple demands of having more than one child, and experiences of difficulties with older children appeared to increase the emotional difficulties experienced by women during pregnancy. Women expressed feeling that it was difficult to live up to expectations that they and others held about their ability to parent.

6.3.3.2. Family of origin

Women described negative experiences within their family lives in childhood and adulthood as contributing to their mental health problems. Some women described

parents as critical, blaming and interfering. Some teenaged women had not felt able to tell their parents until late in the pregnancy due to fear of anger and judgement. Other women found it difficult to disclose to their family about their mental health, due to prejudices expressed by family members about others with mental health problems.

I'll never forget my dad actually made a comment about my uncle, going 'huh!' you know, he, just mocking him that he'd had to go into hospital for it, so I knew that that's what he thought of it, so I'd never, I'd always put, a big like.. put the act on when I went to see my dad (CM2)

I've had a lot of grief off of my mum and my sister about taking tablets for depression (IM7)

Some women talked about their mothers interfering in different aspects of their lives, from telling them how to decorate their houses, to telling them that they should not have another baby. For one woman, her mother pressured her to have a termination of the current pregnancy.

my mum's already given me instructions that I'm not.. to have another baby, for a good five or six years --- she wants me to have a career rather than a family, and that's not what I want, I want both essentially (GM1b)

Women also described their mothers as blaming them for having health problems relating to the pregnancy.

she'd just come down and lecture me about why I was in hospital, and what I was doing wrong and what I should be doing (GM1b)

Within this group discussion, one woman began to talk about her experience of her mother as interfering and criticising, which sparked a long exchange about the difficulties and tensions in relationships with mothers and mothers-in-law.

One young woman in a group for teenagers had been a carer for her mother due to mother's mental health problems, and was currently estranged from this relationship.

in my mum's case, I was quite worried because, well, I ain't there, and no one's looking after her, and anything could happen (GM2c)

Other women also described deciding not to continue relationships with their mothers due to the impact on their own mental health, one participant said she had done this on the advice of her hospital consultant who considered the relationship to be causing unhealthy levels of stress. Although some women described a helpful and supportive relationship with their own mothers, there was also a large proportion of women who described their mother's behaviour as detrimental to their mental health.

6.3.3.3. Partner relationship

Similarly to participants' descriptions of their relationships with family members, there were also significant variations between women who described their relationship with a partner as very supportive or as contributing to their emotional distress and mental health problems.

For women who described the partner relationship as unhelpful, there were problems with abuse and violence, gambling, infidelity and controlling behaviour including suicide attempts. For some women, there were combined negative experiences of intimate partner relationships, including lack of support and other problematic behaviours.

I wasn't allowed any money, I was given six pounds a week.. [laughs], um, I used to bring in sort of two hundred pounds (IM7)

Women described partners who did not offer support either relating to the baby, or relating to the woman's emotional needs.

I did let the dad know that there was more than likely gonna be a problem, um, and his words were, 'well find someone else to take it on then', and so he's completely, sort of, put it, put her out of his life (IM3)

her dad, he, he just go, 'oh, go and talk to your counsellor', which doesn't help either (IM5)

For other women there was not the level of dismissal of their emotional needs as described above, but a sense that their partner was not able to help them emotionally. For one woman this related to his own difficulties caused by an autistic spectrum disorder. For another woman, she was aware that her husband was frightened by her panic attacks and did not know how to help her.

Beyond difficulties in the direct relationship with partners, some women described stress arising from relationships with a partner's former girlfriend.

she was threatening me, saying that she, she knows, she knows --- where I worked, and she, I better watch my back, and even when I'm heavily pregnant, and then she turned up at my flat before, um.. but, she, she was just really unstable (CM2)

Other participants described conflict and hostility from their partner's family, including a grandmother who was angry about the pregnancy, and parents-in-law who were controlling and critical toward them.

the first words out of her [grandmother's] mouth was, 'so when do you get an abortion?' (GM2c)

all of a sudden his dad turned on me and he said.. um, 'the place is a' excuse my language, 'shithole', --- 'you've never picked up the Hoover, you've never ironed, uh, you've never done any washing, you've never done any ironing' and I was like.. 'well who the hell do you think does it then?'(IM7)

One woman had fled her home to a women's refuge due to violence and threats from a former partner and his friends and family.

6.3.3.4. Community relationships

Many women described feelings of isolation and lack of support in their lives. For some women this related to lack of support in their close family and domestic relationships as described above. Other women talked about general feelings of isolation within their communities. Accounts of this experience reflected both the negative impact of mental health on relationships and the lack of supportive relationships on women's mental health.

I grew up in [town], but I haven't really got any.. friends --- so, cause obviously, cause I was quite depressed when I was a teenager --- um, I didn't really mix with other people (IM3)

not having anyone to talk to.. will just torment you even more.. because then you're having to question and answer everything yourself --- which doesn't help (IM5)

For one woman, isolation was an effect of entering a women's refuge away from her home, and loss of connection with friends and informal support networks.

Participants described not only the absence of supportive relationships within their communities, but also the negative impact of relationships with friends, neighbours and strangers. Women described experiencing criticism and negative judgement, for example, in relation to being a pregnant teenager or other lifestyle choices.

everyone does it, even when you're walking down the street and you've got your big bump, and.. everyone just stares at you.. (GM2a)

we went out for a meal on Friday night, and I had lasagne and chips, and I sprinkled a little bit of salt on my chips, and this woman went [intake of breath] you're not meant to have salt' (IM6)

Women described encountering strangers who made assumptions, limited their choices and interfered with advice that was unwelcome.

they come around with a bottle of wine, they miss you, don't they, and you think, 'oh, I'd like to be able to say no thanks, rather than you deciding that I'm not gonna have, you know, a glass of wine' (IM6)

it's meant to be a nice experience, being pregnant, it's meant to be one of the best things, and I absolutely hated it, because everyone was so quick to say 'do this, do that', and then you've got the next person saying 'oh well I wouldn't do it like that, I would do it like this' (GM1e)

Participants gave examples of negative relationships with community members and neighbours that felt hostile and intimidating, including harassment for being overweight and frequent reporting to housing authorities.

I keep having to have inspections and people come round to the house because she's reported me for all sorts of stupid things, um, I'm meant to be.. make, make too much noise, um, shout all the time, yet, she's supposedly hears it, yet [other neighbour] doesn't hear a thing from me (IM3)

In this instance, the woman described limiting her use of her garden due to feeling of surveillance and harassment from her neighbour and feeling frightened when she passed her neighbour walking down the street where they lived.

In common with much of the literature on mental health during pregnancy, many women who experienced mental health problems described feeling a lack of support

in many of their relationships, in addition to experiences of fear and judgement within their communities, their family and intimate relationships.

6.3.4. Negative thoughts and feelings

The majority of women described external (such as relational and material) and physical health related conditions that undermined their mental health during pregnancy. Less commonly, participants described experiences arising from their negative thoughts relating to religious guilt, grief from previous losses and dwelling on past abuse. Connected with this category, but related directly to the experience of pregnancy were worries about their ability to parent, and worries about the health of the baby. This will be addressed in the next section of this chapter, which is focused on pregnancy related concerns raised by women in relation to their mental health. Participants described negative thoughts and feelings that were not directly associated with the current pregnancy, but with other experiences in their lives. Only one woman talked about religion in any detail, and for her this was associated with both positive and negative effects on her mental health.

you end up putting yourself.. last, which is gonna make you miserable.. um.. but then Christianity says.. you know, you should be putting.. other, you know, you should be putting other people first.. and God first (IM7)

This woman was aware of the complexities of the impact of her religious beliefs and the ways in which she was pulled in different directions by trying to meet the related expectations she perceived.

Although some women acknowledged complex and mixed emotions in relation to their thoughts, other women described the impact of their thoughts as only negative in relation to their mood and mental health. In the case of feelings of grief and ruminations about previous painful experiences, these internal mental events were

exclusively negative and perceived to be arising from experiences that were beyond women's control. Participants drew clear connections between their mental events and their emotions and behaviour. This was the case with experiences of family bereavement, loss of previous pregnancies and childhood experiences of a parent with a mental health problem.

I think I got to a point of thinking, 'no, if you can't be bothered to help me, then.. sort of you can get.. lost sort of thing, and became --- aggressive and angry (IM3)

I lost my brother a year before, my younger brother, so I think that was always at the back of my mind (CM2)

I had a lot of anger, towards her because I thought, well, I blamed her for me becoming an alcoholic (IM1)

However, in some cases, participants may have recognised that there were alternatives to the way that they managed their thoughts about the past. For one woman the impact of her awareness of alternatives emerges as a form of self-blame for the ongoing distress that is triggered by memories of abuse. This participant described herself as getting bored and thinking about the past, and in common with many other people who were abused in childhood, identifies the effects of abuse and ongoing rumination as her own responsibility and a problem within herself.

just dwelled too much on the past, that's my problem, um... like I was.. abused a lot during my childhood, and I had a very difficult childhood, um.. and I tend to dwell on it (IM1)

Participants described their thoughts as contributing significantly to their emotional distress and poor mental health. In many cases these thoughts were associated with earlier experiences of loss and abuse.

granddad used to beat Dad, Dad used to beat me and my sister --- am I gonna be beating my son --- am I gonna be that type of parent that gets my kids taken off me --- or that kills him one day? (IM2)

In addition to thoughts relating to the past, many women expressed troubling thoughts about their pregnancy.

6.3.4.1. Thoughts about the pregnancy

Participants described specific thoughts and anxieties about the pregnancy, including anxieties about the health of the baby and fears of losing the pregnancy. In some cases these fears related to previous pregnancy losses, with the pregnancy itself triggering memories of past loss and anxieties about future losses.

before I had [daughter], I lost two, um, at twenty two weeks, um, both had to be delivered, and both were buried, and.. the fear of going through it again (IM5)

For other women, their anxieties related to information they had been given about risks to the baby, and increased worry related to lack of available information in relation to health fears for the baby.

I've spent a lot, sort of the early part of the pregnancy bleeding, um, and then the gestation sac came away from the wall, --- which then didn't heal, and that's turned into an amniotic .. band, so I'm sort of, that's all gone a bit.. pear shaped at the minute --- I've only had sort of Google and the internet to go by--- and there's a band of tissue that goes straight across the baby --- that can sort of, that can, if it completely snaps can sort of wrap around her limbs and cut them off --- I've not actually managed to speak to any consultants about it, so then obviously that, sort of then stops you.. your sort

of stress gets to the point where you can't sleep, cause it's all you think about (IM3)

This woman experienced anxieties about the health of her baby, encountered difficulties in accessing support and information, which led to developing stress and rumination about the possibility of pregnancy loss and infant disability. In this case, access to further information and support may have ameliorated the anxieties and effects including sleep loss.

6.3.5. Pregnancy-related experiences

A small number of women drew direct relationships between their physical experience of the pregnancy and their experiences of mental health problems.

6.3.5.1. Hormones

A group of young women discussing their mental health during pregnancy, and one woman who described herself as having a diagnosis of bipolar disorder briefly mentioned hormones as having an impact on their emotions and relationships. There were no other instances of women describing hormones in pregnancy as significant in their emotional wellbeing.

they're definitely having an impact on the relationship as well --- well, you get really moody with 'em, whereas.. before you wouldn't (GP2a)

6.3.5.2. Coming off medication

Two women described deciding to come off medication due to concern about the effect on the foetus during their pregnancies.

I'm unmedicated --- you can't have medicine, well, not my one anyway, while you're pregnant (IM4)

For both women, there were other resources that they felt were helpful in managing their mental health in the absence of medication. One described setting up an informal network for support in a crisis, and the other described skills that she had learned in Cognitive Behaviour Therapy.

I wanted to come off them anyway, and um, he and I decided together that we would work out a way that I could cope without being on them --- so I've set up my own support circle, where I can phone somebody, or have somebody come round to my house if I'm in a crisis --- it's not as effective, but it does work, it's better than being completely alone (IM4)

This woman felt that her medication was more effective than support, but felt that she could manage with support while she was off her medication during the pregnancy. The other woman who talked about medication, described her experience of skills developed in CBT as helping her to manage without medication in the long term.

with the cognitive behaviour therapy, I feel like I'm.. and also I feel a lot now that I'm not on any medication now, and I'm doing alright and I'll.. if I have a setback, then I feel like I need to be able to cope with that, without taking the medication (IM6)

6.3.5.3. Pregnancy-related physical problems

Women described a range of physical problems that were related to the pregnancy, and had a negative effect on their emotional wellbeing during the pregnancy. There were issues with pre-existing diabetes, back pain and obesity, and pregnancy related itching, pain, nausea, fatigue, urinary tract infections and sleeplessness.

there were just days when I .. couldn't go on, cause I was in so much pain.. um, because she and my son were both back.. babies, they' liked to look out

and see the world.. [laugh] --- with their spines against my back, all the time, um, the pain in my back was excruciating (IM4)

I was covered in like in a real red rash, a really itchy rash.. and it was almost like my skin was like, um, really, really tight, and they just wouldn't give me, they said they couldn't give me any antibiotics because I was carrying [child], they wouldn't give me certain creams that could work, because of the risks (CM2)

Women described a negative interaction between the pregnancy and their mental health, describing thoughts that the pregnancy had exacerbated a pre-existing problem.

just all the different new symptoms and everything like that, made me, where I'd before, been putting everything into little boxes in my head about, 'oh yeah, I think that's anxiety, that'll be..', and I couldn't do that anymore (IM6)

at the end of my pregnancy, and I was manic, and I knew that I could do something, but I couldn't, because my body wouldn't do it.. cause it was just too big and cumbersome (IM4)

Some women who described negative effects of physical symptoms expressed feeling that the pregnancy was horrible, and that they perceived that nobody understood how difficult it had been for them. Where there were physical problems, combined with lack of support and pre-existing mental health problems, women described more intense distress and anxiety relating to pregnancy related symptoms.

6.3.6. Social and material conditions

Women described a range of conditions in their lives that reflect the demographic and economic profile of the town where they lived. The characteristics and context

of life in this town were described in the introductory chapter, and reflect a high level of socio-economic deprivation, with poor housing stock, high rates of domestic violence, lone parenting, children on safeguarding register, low birth weight, smoking during pregnancy and teenage pregnancy greater than the national average. Women's reflections on these conditions and the impact on their mental health are shown in the data provided by research participants.

6.3.6.1. Isolation

The most common social condition that women described as disturbing and distressing was the lack of support and feelings of isolation within their communities and in relationships with services.

there is no place where you can go to be emotional really (GM2c)

not having anyone to talk to.. will just torment you even more.. because then you're having to question and answer everything yourself (IM5)

I took myself to the hospital when I was pregnant, and to a refuge when I was pregnant, and.. it was hard for me because I had to move all away from everybody I knew, I wasn't allowed to talk to none of my friends (GM1e)

it's quite a lonely.. time, is to be pregnant full stop, cause there just doesn't seem to be... doesn't really seem to be all that much, sort of, support or help or really interest (IM3)

Many women described loneliness, having nobody to confide in, and having no emotional support while they were pregnant. These experiences reflected many of their accounts of early life with poor relationships and lack of responsiveness to their needs for protection and support.

6.3.6.2. Employment

Many research participants were not in employment. Difficulties associated with work due to child care responsibilities were described as a reason for stopping work.

he was about, just coming up to two when I gave up work, and became his full time carer, and then obviously as, sort of, more of his mental health issues come up, it's just got to a point where it's just easier for me to look after him, than to hunt down people that look after special needs children (IM3)

For women who had a working partner, financial difficulties resulting in long working hours had an impact on the level of support that was available within the relationship.

I haven't seen much of my other half because he's been working seven days a week, and, out of an entire month, he only gets one weekend off, and he works long, sometimes seven thirty or eight in the morning and I won't see him til.. nine at night (GM2c)

A small number of working mothers talked about stresses arising from work during the pregnancy and described struggles with managing work due to nausea and loss of sleep.

often late for work, cause I just couldn't.. get up and get myself ready, cause I was just so sick in the morning (CM2)

Two women described unsupportive employers.

even though she knew I could only do Friday and Saturday night, or Saturday and Sunday day shifts, she was saying that I'd have to work during the week, and stuff like that, and it just, that was just really stressful (CM1)

Whether or not research participants were employed, they described difficulties arising from the competing demands of work and pregnancy or parenting of older children while they were pregnant. One woman described having an emotionally supportive, employed husband, who was able to provide financially for the family while she was pregnant. This woman was also receiving maternity pay based on her previous professional earnings. This was an exception within the research sample, in which many of the women were in receipt of income support or incapacity benefits, which reflects the broader social context of the researched locality.

6.3.6.3. Money

Consistent with the above account of difficulties with employment, many women described financial hardship, including struggling to pay for food and saving money from benefits for second hand clothing for the baby.

I only get, from the [charity] I only get one [supermarket] ten pound voucher and that's for food and that's it, that's all I live off of for a week (GM2c)

This young migrant woman described her scan photograph as one of the only things that made her feel emotionally better.

I think in a way it's sad that you have to pay for them --- you have to pay two pounds per picture --- and um, well, it doesn't sound a lot, but then again, when you don't have that much and you're saving (GM2c)

Finances were also described as difficult in relationships where women were not earning their own money, or if earning, were not in control of their money.

I do feel guilty for not earning, but there's also, you know, if I was still at work we could do.. a lot more things, and .. you know, we could do something better than Butlins... you have four days, or... just things like that really, and

I could just buy whatever I wanted if I had my own money... where, I don't have my own money (CMI)

For many participants, financial difficulties were described as restricting their independence, personal control and access to minimal resources that they felt would improve their emotional wellbeing during the pregnancy. Two of the seventeen participants said that they did not have financial worries.

6.3.6.4. Housing

Alongside difficulties with lack of financial resources, women described availability of appropriate and secure housing as contributing to their emotional distress. This related not only to the quality of the housing, but the level of overcrowding, the perceived safety of the neighbourhood and conflict with neighbours.

there's so many, and there's loads of different cultures.. as well that walk past --- um, people that are drunk, people that are stoned, so --- I just choose not to.. go outside --- there's always one fight or another going on, on the road --- so it's not exactly a very positive place to be (IM3)

Rather than only reflecting participant anxieties, during the course of the research, local news featured stories of violence in the neighbourhood where this participant lived, including the death by stabbing of one young person on the adjoining road. Many participants expressed that they had little control over their housing situation, either because of their relationship or because of their financial circumstances and tenancies. Among women in local authority housing, data reflected local professional knowledge that there were large numbers of residents seeking housing and housing exchanges.

his parents had decided they were going to.. do our house up for us, which was an issue, because I didn't want to live in that house anyway, it was his old marital home.. um, it was quite a depressing house (IM7)

she, she wrote out, you know, some options and such, a lot of the girls have been to [named] lodgings.. I didn't want to go there, cause it seems much of a ho.. sort of like a hostel, sort of thing, to me (GM2c)

I had a lot of upheaval, once, while I was pregnant, um, the council made us homeless, so we ended up moving from one place to another, and I moved four times in total while I was pregnant, and the last time was two days before she was born (GM1b)

it was really bad, and it, it got ridiculous, especially in the one room, and it was just obvious that the flat had loads of problems, but you just obviously weren't aware of it until, you know, winter time came round, and it was a nightmare, and I wanted to go and get let out of the, the contract early, and they were saying 'no' (CM2)

Other participants relied on family members when they felt their housing or relationship situation had become unbearable, staying with mothers and grandmothers. One participant had been a young carer for her mother who had mental health problems. When the relationship broke down she was thrown out of the house. Women were temporarily housed in Bed & Breakfast accommodation, or living in overcrowded private rental flats.

6.3.7. *Summary*

Far from a straightforward link between pregnancy-related hormones and women's mental health, the data showed women's understandings of their mental health problems arising from a complex and interconnected range of current and historical

experiences, relationships, health problems and social and material conditions. The stresses arising from the demands of family life were exacerbated by lack of support in personal and professional relationships.

6.4. Effects of Mental Health Problems during Pregnancy

A significant concern raised by many research participants related to the impact of their mental health problems on other aspects of their lives. These concerns extended to their behaviour, relationships and connected internal processes such as thoughts and fears. A negative cycle can be seen between women's primary mental health problems and increased anxieties and difficulties that are likely, in turn, to increase distress.

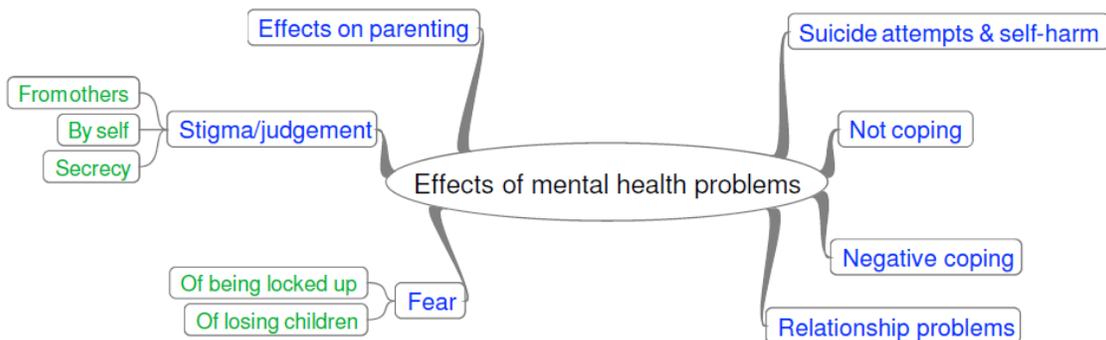


FIGURE 6.4 - EFFECTS OF MENTAL HEALTH PROBLEMS DURING PREGNANCY

6.4.1. Suicide and self harm

Perhaps the most significant concern raised by women about the effects of their mental health related to the direct risks that poor mental health posed to their own life and physical health. As raised in the CMACE report (2011), a small but not insignificant number of women commit suicide during the perinatal period. Within

this research, four women talked about previous thoughts of suicide and suicide attempts, either earlier in their lives or in adulthood and after having earlier children. Although one woman acknowledged that her previous attempts may have been ‘a cry for help’ (IM1), she also explained that she no longer felt she wanted to die. Another woman considered that her baby was protective against her suicidal intentions while she was pregnant.

if it wasn't for this baby that I was carrying, I didn't think, I think I would have been depressed, and so depressed, that I would have possibly have considered ending it, and that hasn't happened for years and years and years (IM7)

A small number of women described harming themselves without the intention of ending their lives, but as a means of coping with emotional distress.

I do know I have to, sort of like, stop myself from self-harming and that, cause I self-harmed for quite a long time (IM1)

I saw someone from my doctors, like a psychiatrist, cause I do get down quite a lot, I used to self harm, so.. I did feel really down, and uh, she said it's just normal (GM2b)

This teenaged woman's account reflects both the common experience of self harm reported by young women, and the professional's response to the frequency of accounts of distress she encountered in her practice.

No women disclosed within the research interview that they had current suicidal thoughts or were actively self harming as a means of coping, however, a woman who was diagnosed with Bipolar Affective Disorder described her risk of suicide as fluctuating with her mental state. She explained that sometimes people with this

diagnosis could sometimes take potentially fatal risks due to mania and delusional beliefs that they cannot be harmed.

it becomes very dangerous in that I do too much, think I can take on the whole world by myself and survive (IM4)

This data reflects the levels of risk to women relating to their mental health. Beyond immediate risks posed by harm to themselves, women described the impact of poor mental health on their ability to cope with everyday challenges in their lives.

6.4.2. Not coping

Women frequently described themselves as finding it difficult to cope, and acknowledged the impact of this situation for themselves and for others. Many women did not specify how they were struggling to cope, but did describe the subsequent effects of recognising their difficulties. Several women expressed fear of consequences of asking for help from professionals. Asking for help from family members carried some unhelpful consequences, such as pressure not to continue with the pregnancy.

when I was, found out I was pregnant with [son], my mum was insistent that I couldn't have another pregnancy.. so I had the pressure from her, that I shouldn't have another baby, and, because I couldn't cope (GM1e)

This woman decided to continue with the pregnancy, however, another woman whose two older children were in foster care and awaiting adoption at the time of the research interview had recognised that the negative impact of her mental health had terminated an earlier pregnancy.

because there was a s.. like another pregnancy after [son], where I knew my mental health was too bad --- I wouldn't cope, and I did terminate that pregnancy (IM1)

There were also specific aspects of how coping became difficult due to mental health problems. These included feeling overwhelmed with life events including difficulties with moving house, managing involvement from parents-in-law and managing money.

6.4.3. Negative coping

Instead of describing an inability to cope and feeling overwhelmed, some participants gave accounts of trying to cope in ways that they acknowledged were not helpful for themselves and their relationships. These negative coping strategies included drinking alcohol, avoidance and negative thinking.

my mental health actually deteriorated quite badly, and I developed alcoholism as well (IM1)

yeah just put it under the carpet for a little while --- I'll let a bit out later (IM3)

These ways of coping with distress can further undermine a woman's mental health and present risks to the unborn baby. Women described worries about the impact of anxiety on the health of the baby during pregnancy, producing a negative cycle of worry about the effects of anxiety, and worry about worrying.

I'll get quite anxious, but then obviously, getting anxious doesn't help baby (IM3)

6.4.4. Relationship problems

Participants gave accounts of the negative impact of their mental health on both partner relationships and friendships.

cause I was quite depressed when I was a teenager --- um, I didn't really mix with other people (IM3)

you get really paranoid as well, and have a go at 'em for no reason (GM2a)

Women drew direct connections between their emotional and mental health problems and difficulties in forming and maintaining positive, supportive relationships. Beyond personal relationships, a woman's history of abuse by men had a significant impact on her degree of trust and comfort in meetings with male gendered strangers, including doctors and the researchers.

I don't trust people very easily that's why I'm glad, I'm glad you're not a bloke --- because otherwise I wouldn't be here now (IM1)

This data reflects another negative cycle in women's lives, in which difficulties, conflict and lack of support in relationships were seen as contributing to their mental health problems and also arising from them.

6.4.5. Fear

Participants talked about fears of potential outcomes that might arise from their experience of mental health problems. The majority of these fears related to loss of control in their lives, and vulnerability to intrusion arising from the judgement of powerful of others.

6.4.5.1. Being locked up

Women had concerns about loss of freedom under the powers of authorities of detention under the Mental Health Act.

you've got the other fear of like, being at [local mental health] hospital, and think to yourself, 'well, if I say this or say that, he might think I'm a total fruit loop and end up putting you in section or something, then you lose your kids (IM5)

This fear was closely connected with fears of removing children from families and women's subsequent reluctance to openly discuss their mental health with professionals.

6.4.5.2. Loss of child custody

During recruitment of participants, colleagues informed me that some young women said they would not take part in the research because of fears that talking about their mental health would prompt safeguarding procedures.

These concerns were not always unfounded. One of the participants described the loss of her older children into care due to her mental health problems and inability to protect the children from an abusive partner.

because I've had two children taken away, I'm scared of actually saying anything to them (IMI)

Several women were prepared to take part in the research and expressed similar concerns to the young women who were too concerned to talk to a researcher about their mental health.

they're gonna like, take your kids away, if you say you really feel rubbish (GMIe)

These participants still expressed a reluctance to openly discuss their mental health with professionals because of their worries. Because limits to confidentiality were explained at the beginning of data generation conversations, it may be that women were prepared to discuss their concerns about disclosure, without giving full details of the content relating to their mental health, which they may have otherwise disclosed if total confidentiality had been assured.

6.4.6. Stigma and judgement

In addition to specific fears about loss of freedom or loss of access to their children, women described a range of other material and social consequences that they feared in relation to disclosing to others about their mental health. These ranged from potential discrimination in employment to a more general sense that disclosure would affect the opinion that others held about them.

trying to get a job after that, you know, you put on your CV, the reason you weren't working for six months was cause of depression, they're just not gonna... they'll just say, 'well, because you weren't qualified' they're not gonna say, 'because you've got depression on your CV (IM7)

I don't like to mention.. about that, cause I feel that people look at you in a different sort of way (IM5)

Negative judgement relating to women's mental health extended beyond the expectation of judgement by others into their feelings about themselves. This self-criticism related to previous standards they held about themselves in their strengths and abilities.

I felt like I couldn't talk to the doctor, I feel, and I know it sounds really silly and I've been told, that, I felt it was a sign of weakness to try and... tell somebody I was depressed (GC2)

When these previously held, and previously met standards became more difficult to maintain, this resulted in further negative appraisals.

I can't be bothered to do.. lots of things now, which I would have done before, and.. you know, I hate the way the house looks, but then I just think, 'oh I just can't be bothered'.. and it's.. that wasn't what I was like (GC1)

Recognition of the impact of the changes to everyday functioning had resulted in this participant reflecting on a changed sense of herself.

Women described questioning themselves and the reality of their experience as a result of their awareness of their mental health problems. The experiences of fear of negative consequences and shame arising from a changed view of self identity were related to greater degree of public secrecy about mental health problems.

For some women, the reluctance to disclose their mental health experiences meant having to cope without support.

I basically have deal, deal with things on my own (IM5)

Women recognised that the impact of not disclosing their emotional distress, and therefore lacking support was counterproductive, but difficult to overcome due to fear of the potential consequences.

you just keep quiet about it, so it plays on in your mind, and it sort of winds you up even more (GM1d)

I sort of walk around with a barrier --- um... and I think... I think I find, at the minute I find it a lot harder to ask for help (IM3)

In common with data about relationships, the impact of worry about mental health and negative coping strategies, it can be seen that women's fears of the consequences of disclosure, of external and internal judgement further undermined their ability to access support and to manage their distress. These experiences additionally contribute to their distress arising from negative self appraisals and lack of confidence in their resources to cope with their mental health.

6.4.7. Effects on parenting

In addition to women's uncertainties about their ability to cope with mental health problems and ability to seek support, were the concerns that participants expressed

about the potential impact of their mental health on their children. This ranged from very general expressions of concern about future parenting capacity to more specific concerns such as the ability to manage the care of a disabled older child and the baby.

whether I was mentally capable of having a child (IM2)

For one woman, this concern about her current pregnancy reflected the objective reality of her older children being removed due to harm caused to them by neglect and her inability to protect them from violence. She was concerned about developing postnatal depression after the birth of her baby and subsequently having to disclose this to health professionals.

they're saying that um, my mental health has had a huge impact on them, and drinking and stuff, and now they're gonna need psychological help (IM1)

In most cases within this data, participants described anxieties about the impact of their mental health on parenting style, including over protective and anxious parenting, particularly of older children during the current pregnancy.

I have to physically follow the bus, that she was in, so that I knew that if anything, you know, I couldn't drive all the way there and wait for them.. um I had to know that.. the bus had got there safely (CM1)

6.4.8. Summary

Participants described wide ranging of effects of mental health problems during their pregnancies. The nature of the effects shows the cyclical nature of mental health problems and emotional distress, where reflection on the impact of their mental health functions to further undermine women's confidence, relationships and access to support during pregnancy.

6.5. What Promotes Women’s Mental Health during Pregnancy

Women described considerably fewer factors of their everyday experience that they felt helped their emotional wellbeing during their pregnancies. It is important to note that women were invited to take part in this research *because* they identified themselves as having problems with their mental health, and this is reflected in the data generated with research participants. This sample does not reflect the general population of pregnant women in the researched locality.



FIGURE 6.5 - WHAT PROMOTES WOMEN’S MENTAL HEALTH DURING PREGNANCY

6.5.1. Support

For the women who expressed that they had some support, this came from a range of different sources. Participants described different kinds of support that were helpful to them. Close relationships that provided general day to day support were identified as helping to promote positive mental health.

my mum comes round once a week, and she takes us out, and I get a break from my hubby, and from, sometimes from my son --- so she comes round once a week, she takes us out and I have a break (IM4)

This data contrasts with the experiences of many participants who described isolation and lack of support in their relationships.

6.5.1.1. Talking

Participants described the positive experiences they had of talking with different people, and positive roles they occupied in their lives. One woman had forged a role

for herself in supporting others in a craft group with other pregnant women. For several women, the existence of positive, pre-existing relationships were described as important in providing support during their pregnancies.

I had an older child, so I was already in.. a loop.. of people---so I had links to people I could talk to during my second pregnancy (CM1)

just having friends to talk to who are in a similar position --- you know, it makes such a difference (IM7)

It was important to some participants to have peers with whom they shared experiences and could understand each other. In other data addressing aspects of experience that undermine mental health, women described the absence of these relationships as contributing to the feeling that they were isolated and had nobody who understood them. Some women described feeling that professionals who did not share their experiences merely had 'book knowledge' that was felt to be less valuable than experiential and shared knowledge.

6.5.1.2. Reassurance and information

For participants who experienced anxieties relating to the pregnancy, availability of information and reassurance was valued when it was offered by peers who have similar experience to the research participants.

it's quite reassuring to.. really get information from other people, who are at the same point as you (IM6)

Some women described difficulty in finding reassurance and information from professionals, and relying on other sources such as internet chat rooms when they did not have other trusted women in their social networks with knowledge of pregnancy.

In many instances women gave examples of finding support, including information and reassurance, this was expressed as partial and not fully satisfying of their felt needs.

6.5.2. Medication

Two research participants described receiving treatment for long term mental health conditions. Both women had been prescribed medication prior to their pregnancies, and had changes to their medications during pregnancy. One had been prescribed an alternative drug that was safer to use during pregnancy, and the other stopped taking her medication during the pregnancy.

I was on medicine.. when I was pregnant with my son, uh, a different kind --- and it did help a little, but not hugely --- as much as if I weren't pregnant (IM4)

For the woman who stopped taking her medication entirely, she had to find other ways to cope with her distressing emotions while not taking her usual prescribed medications. In common with other types of external support, many of the women who took part in this research defined resources to support their mental health during pregnancy as weaker and as less helpful than they wished for.

Beyond relying on external support or medication, some women described different internal resources that supported their emotional wellbeing.

6.5.3. Positive thoughts

In contrast with external sources of support, women described a wide range of positive thoughts that boosted their emotional experience of pregnancy. For one woman this related to her religious faith, however the other women describing

positive thoughts related these to the pregnancy itself, and their connection to the baby that they were carrying.

when I thought about being a pregnant woman, and being a mum in the future.. it was the most amazing thing (IM7)

I think it's scans.. they make you feel like it's really happening --- and they.. really do, it's amazing to see 'em.. it's just breathtaking, completely (GM2a)

For most of the women who described their mental health as supported by positive thoughts about the pregnancy, this was their first baby, and was anticipated in the context of the absence of other valued roles or relationships in their lives. For some women this related to the development of a new role identity for themselves in the future.

I felt completely special.. um, I had an immediate bond with this, you know, this tiny, tiny thing from the moment I found out I was pregnant, I just, if it was just me and the baby (IM7)

For one woman whose older children had been taken into local authority care, her pregnancy represented a new start and new possibilities for the relationship with this baby.

social services have just been granted placement orders, so I know that they[older children] won't be coming back to me, but I know that this one --- this one's gonna be staying with me --- I just want to see him, and see what he looks like --- and give him a nice cuddle and stuff (IM1)

6.5.4. Confidence from previous experience

One woman who was having her second child described increasing confidence in her own knowledge as a result of a previous pregnancy. She gave an account of ability to be assertive with health professionals due to the knowledge gained from experience.

this time round I can argue more, because he's different from what [older boy] was, so I can argue... with a lot of things now... and actually get my point across (GM1a)

This woman's account relates to other women's appraisal of the value of knowledge gained from experience. For her, there was a greater sense of authority and ability to argue about her needs during the pregnancy.

6.5.5. *Summary*

It was noticeable in this data that there were relatively few participants who were able to identify elements of their lives that seemed to have a generally positive effect on their mental health. More women were able to identify means of coping while they were having problems, rather than being able to describe the aspects of their lives that promoted their mental health. This data stands in contrast with women's descriptions of experiences that undermined their mental health. In much of that data, women described an absence of positive relationships and experiences that were reflected through their absence in this data.

6.6. Coping with Poor Mental Health and Emotional Distress

When asked directly about what supports their mental health, rather than describing positive experiences in their lives, many women identified means of coping when they were experiencing emotional distress. In some cases this category overlapped with the category of what supports mental health, such as positive thoughts about the baby and using a supportive network. However, most strategies for coping were primarily described as a mental or physical activity used to manage distress at times when it occurred.

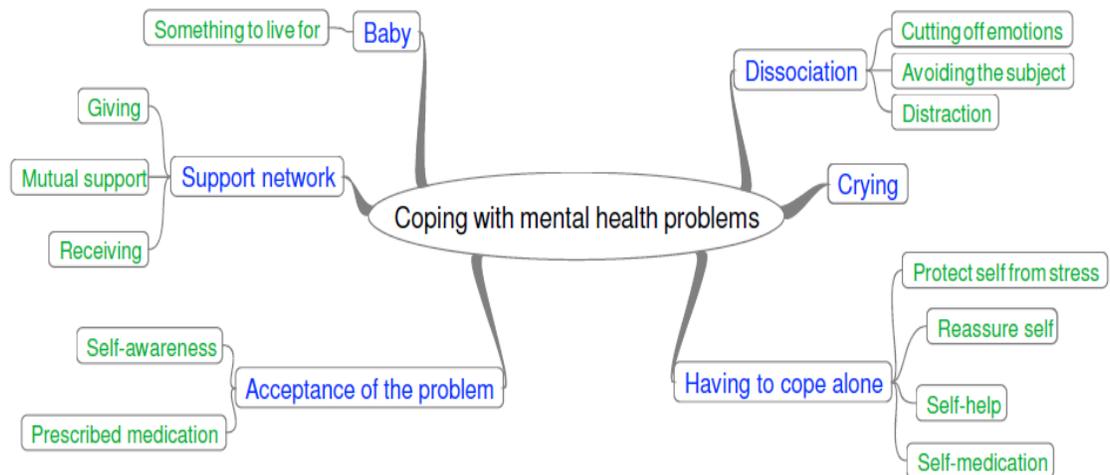


FIGURE 6.6 - COPING WITH MENTAL HEALTH PROBLEMS

6.6.1. Dissociation

A small number of women described mental strategies to separate themselves from painful experiences. Only one participant described this activity using the professionalised language of dissociation. She described developing an understanding of this through the experience of psychological therapy.

I know that I can talk like this through using the dissociation, I can talk like this, and I'll go out and I'll be fine (IM1)

She reflected on the usefulness of this strategy and its value in helping her to manage difficult emotions arising in situations such as the research interview. Other women described different ways of distancing themselves from painful experiences such as fearing the loss of another baby, or remembering previous events.

in my mind, I think I tried to blank out the fact I was pregnant, cause I thought if I don't get close to it, and I lose it again, I haven't got to worry, so that was my little not thinking about it really (GM1c)

I think, but then I think it's because I've got like, it all under a carpet, and I'll sort of, I'll let little bits out each time --- so I think, I think in that way I

find it easier to deal with things, cause I don't.. bombard myself with it all at once (IM3)

Other strategies to avoid engaging with difficult emotions included use of distraction with other activities and avoiding spending time alone when they would be likely to spend time reflecting on their past experiences such as painful memories of childhood abuse.

I've tried to keep myself busy, cause I know if I'm busy, I haven't got time to sort of dwell on them sort of things, or let them things bother me (IM1)

The process of using dissociation and distraction to distance themselves from painful emotions was among a range of tactics used by women who were managing their emotional distress by themselves. This was commonly expressed in relation to how participants managed difficulties.

6.6.2. Having to cope alone

In the context of many different difficult situations, women talked about the absence of support to help them when they felt in need.

sort of deal with it, um.. and the same with my pregnancies, no one helped deal with that --- sort of dealt with everything myself (IM5)

In coping alone, participants described what they did to help themselves in a range of circumstances. Strategies included reducing stress where possible, reassuring themselves, using self help materials or using prescribed drugs, street drugs or alcohol.

6.6.2.1. Protect self from stress

Participants described a range of situations in which they used avoidance, primarily to escape uncomfortable contact with partners, children, extended family and neighbours.

I'll either separate myself from him --- or I'll go out --- cause otherwise I end up snapping at my husband, and then we end up having a huge blow out --- which we have done in the past [laughing] (IM4)

6.6.2.2. Reassure self

In the absence of knowledge and information that feels reassuring about symptoms relating to the pregnancy, one woman explained that she had to wait for symptoms to pass and feel reassured by them going, rather than having anybody to turn to for reassurance and advice when needed.

what I need --- for someone to say to me, 'yes, that is all normal, that is all ok', whereas I've had to .. do that myself, by thinking, 'oh, it's gone now', and that's my reassurance, but.. um, I felt I've had to do a lot myself, you feel a bit, sort of out.. on your own (IM6)

One psychological perspective suggests that external reassurance is a significant part of the cycle that maintains anxiety, however, this research participant describes the absence of reassurance as leaving her feeling that she is on her own and struggling with emotions in isolation.

6.6.2.3. Self help

Participants described accessing information and knowledge from sources like books, CDs and the internet to help them to develop constructive strategies to help to manage their emotions.

I went to see her and she said, 'you're doing so many things yourself, there isn't really anything I can tell you, to help you', so I felt really disheartened, cause you're thinking, 'ah that might be the end' (IM6)

Thus although the woman had information, she had struggled to find this, and described disappointment with her GP and other health professionals, who she thought could have enabled her to overcome the anxiety more quickly and easily. Other participants described professionals who worked with them to explore resources for management of their mental health.

they say knowledge is power, the more you know about something, the better you are at coping with it and dealing with it (IM4)

Although these two women had found some information about how to manage their mental health problems, they each had a different level of support in doing so. They described quite different experiences of empowerment and feelings of support in relation to their health professionals.

6.6.2.4. Self-medication

In other circumstances, women found less constructive ways of managing their distressed emotions.

I basically have deal, deal with things on my own, um... I mean, when I say that, the, uh, misuse and that, it wasn't for a long period, it wasn't anything hard or anything like that, it was nothing.. major, do you know what I mean - -- it wasn't.. serious, but, I dealt with it myself (IM5)

The common theme arises across several accounts of women finding whatever strategies were available to them in managing and tolerating distressing emotional experiences in the absence of support from others.

6.6.3. *Crying*

Within the data, where participants described few other coping resources, several women described spending long periods of time crying by themselves.

I do find that having a good cry, does like help --- like I can sit there for like two, three hours on end, just crying about nothing (GM2b)

just by myself really --- not easy --- most times you just cry --- but then you feel a bit better (GM2c)

This was particularly the case with the young women who were involved in a group for pregnant teenagers. In this group the women described feeling a general lack of family and partner support, and struggles with accessing appropriate services for their needs. Although two of the women in this group left the session after a short time, the third woman, GM2c stayed for a further 90 minutes to talk about her circumstances, her loneliness and lack of security and resources in her life.

6.6.4. *Acceptance of the problem*

For a few women, there were expressions of reaching a point in understanding their mental health problems and finding way of managing their emotional distress by developing a degree of acceptance that this is a feature of their lives that will not go away, but a resignation to living as well as they can with it.

I know my mental health will be something I need to work on for the rest of my life --- this isn't just gonna disappear, so I know this is something that could always be a problem for me (IM1)

One woman realised that the process of trying to eradicate her anxiety contributed to its maintenance and the level of distress that she experienced in relation to it.

However she recognised that this was still a response that she was struggling with in spite of her sense that this is counterproductive.

I was always trying to fight it, and there's still quite a big element of that, but --- it's sort of seen as such a negative thing, 'we need to get rid of it, get rid of it', when actually that's making it.. worse (IM6)

These two women had both been able to access psychological therapy within the NHS. For other women acceptance involved seeking help from health professionals to find safe and appropriate medication to help to manage their symptoms during the pregnancy.

6.6.5. Support network

Although many women described coping on their own and feeling isolated and unsupported, a small number of participants said that they were able to cope with their distress by calling on assistance from family and friends. In addition to feeling supported by peers, one woman described benefitting from being able to support someone else who was experiencing similar difficulties.

it's been really good that she can then just.. tell me, how she's feeling, and stuff (CM2)

The development of a supporting role within an informal network of other women enabled this woman to take on a different perspective from one focused on her own perceived failings, to boosting her sense of ability to provide a positive experience for another new mother.

6.6.6. Developing bond with the baby

Finally, in common with the earlier section addressing experiences that support positive mental health during pregnancy, women described positive thoughts about

their baby as means of coping with their distress as it arose. While some women struggled with coping without the medications they had been using prior to the pregnancy, they focused on the importance of the baby and wish to protect and offer the baby a healthy start in life.

I think the thought, that like, you're going without your medication for the reason that there's a little life growing inside of you as well, helps, it does help (IM1)

Another woman identified the importance of a similar focus on prioritising the baby while recovering from an earlier episode of depression

as I was coming out of that.. sort of depression, I got pregnant with my son anyway --- so it was more of a case of had something to live for --- so I just.. sort of, put everything into him (IM3)

6.6.7. Summary

Much of this data emphasises the importance of support during pregnancy. Without support, women described different strategies for trying to cope with mental health problems alone, and for some young women there was a lack of either internal resources or external support, and resulted in struggling to do anything other than crying on their own.

6.7. Mother's Experiences of Services

These findings were structured according to primary distinctions between women's positive and negative experiences of services and professionals. Within this section, the overall theme (as reflected on both sides of the mind map below) is given as the heading, with positive and negative examples provided in the same sub-section.

Women mostly talked about NHS health services, and occasionally other third sector

services such as children’s centres and community organisations. Although several issues that were raised by women related to problems with available resources and staffing, many issues related to difficulties arising within existing resources, such as communication skills, staff attitudes and interpersonal relationships with professionals.

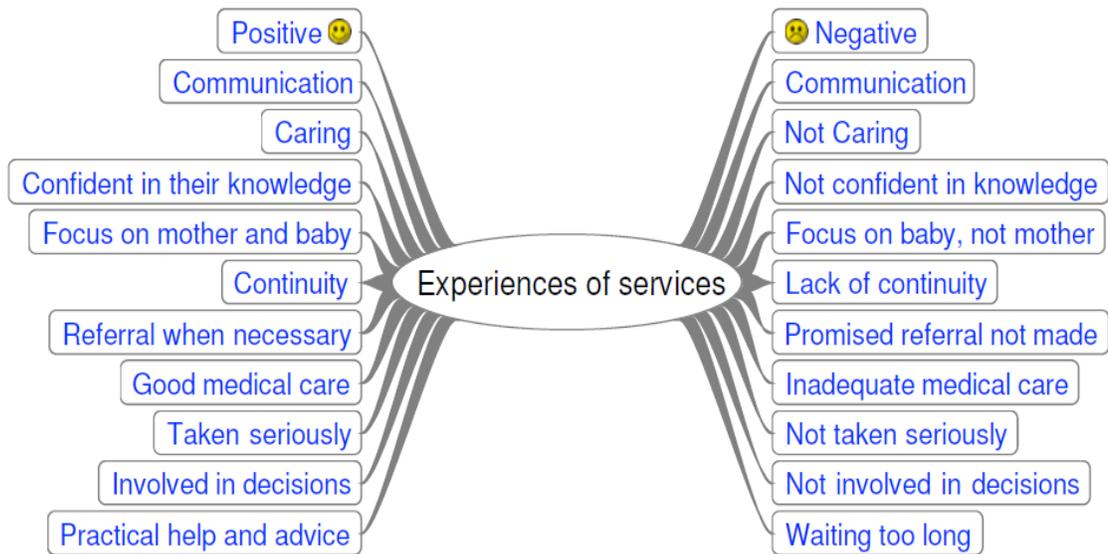


FIGURE 6.7 - WOMEN’S EXPERIENCES OF SERVICES

6.7.1. Communication

Some concerns raised by participants related to the exchange of information between service user and provider. This may have reflected a perceived inadequate assessment of the woman’s difficulties, or not being able to access enough information from the professional.

you go and see a consultant and they just try and push anti-depressants on you without asking if you’re depressed or not (IM3)

In one situation, a woman had medical complications with her pregnancy and described the difficulties arising from uncertainty and problems in communication as contributing to her distress about the problem itself. Unfortunately she described being most able to access information on the internet, which was balanced toward other women's descriptions of the severe and disabling outcomes of the condition for their babies.

trying to get profession, well midwives and doctors.. to talk to you obviously can be quite stressing as well, cause I've not actually had anyone discuss with me what the problem is (IM3)

Some concerns about the exchange of information related to the structure and demands placed on professionals to complete a task-focused agenda.

I don't think there's enough, there's not enough communication between the patients, and.. it's like the nurses haven't got the time (CM2)

This was often referred to by participants as 'box-ticking', and was usually described as giving the impression that the professional was just there to do a specified job, rather than engaging with the individual woman to understand her needs within a consultation.

when I had my booking in visit, there was no real advice, it was just lots of ticking of boxes (IM6)

Women commented on the approaches that different professionals brought to communication, and described feeling that this made a difference to how they felt about themselves and the relationship with the professional.

she spoke to me like I was a person, and that.. everything that I felt wasn't in my head --- she, if I said to her, I don't understand it, can you explain it, she did (IM5)

he was really good, and supportive and sort of talked to me about things, and then sort of, my little boy had sort of questions, and he --- he asked them, and the doctor answered him in a childish way --- which I thought was fantastic (IM3)

Unfortunately, there were also accounts given of communications with professionals that felt insensitive and harmful in the way that opinions were expressed at times of distress.

she turned around and she said, 'um, you've got to go to the hospital, obviously don't drive yourself, I wouldn't expect there to be a baby alive when you get there for a scan', and that was in front of my little boy, and I was like, 'you insensitive person' (IM3)

Clearly the style and content of communication with professionals was significant in its impact on women's emotional experience of services. From earlier data relating to the importance of knowledge in women's feelings of empowerment, this lack of access to information and sensitivity in communication about their own pregnancies can place women in a position that exacerbates feelings of vulnerability and anxiety.

6.7.2. Caring

Beyond direct expressions through communication with professionals about their own care, many participants described interactions with professionals that gave an impression of whether a person was caring. This was described as an important element of the experience and trust in the service delivery to participants. Women

described this as resulting in feeling that they were not important as a person, but were just seen as a job to do.

it was like, 'I'm here to do a job, and I'll just do this, and that's it' (IM5)
when they look at your notes, they don't.. see what it says, they just, you're just a name, aren't you, and a.. well, probably not even a name, just a number of weeks. (IM6)

Other participants described instances of professionals demonstrating that they cared by working beyond their paid hours or acted beyond the remit of their roles in ways that were helpful for women.

we'd say, 'oh, when d'you finish tonight', and they're like, 'oh, I should have finished four hours ago', and it's because they care (CM2)

It is worth noting that mothers most often spoke about individual professionals that they encountered in their experience of services, rather than offering reflections on the systems in which people met each other as professionals and pregnant women.

6.7.3. Confidence in professionals' knowledge

In addition to their appraisals of professionals' personal qualities in communication and caring, participants also expressed concerns about professionals' knowledge and ability to advise women on issues relating to their pregnancies.

you get told one thing by one health professional, then another one by another, and it doesn't help (GM1a)

I want somebody who knows what they're doing, I don't want some idiot (GM2c)

As outlined in an earlier section, some women felt that personal experiential knowledge was more valued than knowledge gained from training and professional

experience. Questions about whether professionals had personal experience of pregnancy potentially undermined some women's confidence in the professionals.

I find it easier, perhaps to look on the internet, or talk to other people, than I would to this person, because there's also the thing that perhaps they've not even had children.. so it's very difficult for me to say, is this feeling normal, or what is this, when actually, they don't, they can only read from a text book (IM6)

6.7.4. Focus on both mother and baby or focus just on the baby

Within the data, a distinction arose between women's experiences of feeling cared for in their own right, versus feeling that the role of maternity professionals was narrowly focused on the health of the baby. Although many other elements of women's experience related to primary care, maternity and mental health services, the issue of the priority for care was focused only on the experience of maternity services. Some participants said that the focus on the care for the baby detracts from the experience of the mother.

she had a job to do, she had to check my blood pressure, check my sample.. and then.. check the heart beat, and that was her three things ticked off, really.. um but there wasn't necessarily.. much concern for me as there was.. perhaps for.. the baby (IM6)

I think midwives aren't um.. that's sort of, that's not their area that they cover, they sort of cover the baby's wellbeing --- and health side of things but that's not sort of something they say, it takes a couple of minutes to say 'how are you actually feeling' (GM1e)

In response to the above comment in a group discussion, one young woman described a different experience of consultations with her midwife, which were equally focused on her wellbeing.

she wouldn't even ask about the pregnancy, to start with, that would be, 'how are you feeling' --- how are you coping, and things like that, she always was, obviously concerned about the baby, and whatever, but she was always concerned about me (GM1e)

This data reflects a further way that participants appraised the nature of the care they received from professionals in the interpersonal relationship.

6.7.5. Degree of continuity of services and professional relationships

Considering how participants talked about the importance of feeling cared for in relationships with professionals, it is unsurprising that women expressed strong views about the continuity of care within those relationships. For a few women, there was at least one professional with whom they had a positive and trusting relationship.

my doctor's known me since the year 2000.. I've never left her, and that is, is one of the things that actually stops me from moving away (IM7)

my midwife was good... I was seeing her all the time, my community midwife --- and she was just there at, you know, all the time, whenever I needed her, really... which I thought was quite good (GM1f)

This continuity and availability was described as important for participants for a range of positive effects on their wellbeing. Some women valued feeling known by a particular professional with whom they have a positive relationship and trusting that they would not be judged or with whom they could reflect on their own progress.

seeing my psychiatrist again helps as well, cause just being able to see him, and him point out how much of a difference there is, because obviously, sometimes you don't notice it (IM1)

talking.. really, being able to talk to her and, um.. tell her things that I wouldn't tell anybody else, because I think they sound silly (IM6)

For other women, there were experiences of difficulty in maintaining contact with trusted professionals, or lacking the opportunity to build a positive relationship with a professional due to frequent changes.

I haven't seen him since about a week be.. week after I fell pregnant, he never has any spaces.. so I never had anybody there to.. help me through it (IM2)
I had, um, about six different midwives throughout my pregnancy, every time I phoned up with, um, a problem, they never replied, they never answered their phone, so I ended up seeing my doctor most of the time (GM1b)

Some women struggled to access an appropriate professional with relevant knowledge and skills, therefore the process of referral and established care pathways between services are essential.

6.7.6. Being referred on to other services when necessary

Although the importance of establishing care pathways has been recognised within services, this does not always result in smooth transitions for care provision, which can result in loss of confidence in services and professionals.

I was told by a midwife she'd get me.. mental health help, basically, someone to talk to, but never did, it's like they.. they listen to you, but they don't --- it's like, no that, everyone listens, but no one actually does anything (IM5)

In addition to the value of access to specialist professionals for help with non-pregnancy related conditions, it was also important for participants to have continued

contact with other relevant specialists, rather than accessing only one single professional who has knowledge of one aspect of their care needs.

I think, just having somebody to talk to about the pregnancy, about, just how exhausted I was feeling, and it, it wasn't just simply tired, I was.. really bad, um, I did feel depressed, um, I just think maybe having her around more.. but because I was being seen by the diabetic, the very medical side of it (CM2)

Because this woman's complex health needs triggered a referral to the specialist nurse for diabetes, she had not been followed up by midwifery through her pregnancy and did not access any further services in relation to her mental health. Although she expressed the hope that she would have more time from other relevant professionals, data from other participants suggests that this may not have been a realistic hope given the level of demand and limitations within existing services. Some women described positive experiences of access and continuity of care that suggest a patchy picture of service provision for women who experience mental health problems during pregnancy.

then I went to see a lady GP who had all the time in the world for me, um, and she was really good, and she actually referred me to the Linkworker (IM6)

I have had a CAF¹ in place --- because I have Bipolar --- and I've had, I've been referred to so many very helpful services (IM4)

Some data reflects women's experiences of services working well where referral routes and processes are supportive for their mental health, although this did not reflect the majority of the data.

¹ Common Assessment Framework is a process initiated by professionals where a child's needs are considered to be likely to exceed routine service provision, and is used to identify roles and responsibilities of different agencies and professionals (Department for Education, 2012)

6.7.7. Adequacy of medical care

Beyond supportive relationships with trusted professionals and reliable service processes, are underlying essentials of care for pregnant women. For one woman, there was a perceived failing in the care she received from one obstetric consultant, resulting in the loss of her baby without further care, which was not offered for a second baby born at twenty two weeks, although her baby was breathing when he was born and subsequently died while she held him after delivery.

*there was something that could have been done, yeah, and it wasn't (IM5)
he knew I'd lost one at twenty two, yeah, um.. and I was in floods of tears,
talking to him, trying to tell him that there was something not right, 'can you
please do something' --- and he didn't, and he didn't ever like, so at twenty
two weeks, I went into labour (IM5)*

In a subsequent pregnancy she changed to a different consultant who offered intervention that enabled her to carry the pregnancy to term and provided follow up care to the baby at thirty five weeks gestation.

*they took the stitch out at thirty five weeks to allow her to come out --- and
they had, um SCBU ready for her and everything (IM5)*

6.7.8. Whether mothers felt that their concerns were taken seriously

Women described feeling that their concerns were not taken seriously. In many cases, this related specifically to professional responses to their mental health problems. Women described concerns about not being offered a thorough assessment of their needs and not being believed about the presenting problem because of questions about their mental health.

*I felt quite disgruntled that it took me about four attempts to go to the doctor,
and on the fourth time, I had to tell him I had anxiety, and he just had this*

very knowing kind of.. 'aaw, you've just got married, haven't you' sort of look on his face that really put me off with going back (IM6)

they just seem to think, that you're, you're making everything up, or you're.. you're just too... too much of an emotional wreck, basically, they just can't bothered with you (IM5)

Several women described feeling patronised, dismissed and brushed off by busy professionals who seemed not to have time for them, while other women gave a very different picture of the services they received.

she was always concerned about me, and any issue I had, she was always.. you could feel like you could ring her and you weren't wasting her time... and she was just, I think generally good, I found her brilliant (GM1a)

Following an experience with a consultant during which one woman felt her concerns were 'brushed under the carpet', she raised this with a hospital midwife and was reassured that her problem was being taken seriously.

that midwife did make a point of saying, 'make sure.. you show.. your midwife the paperwork', so obviously she felt that it was quite a serious thing as well (IM3)

For some women there were feelings of uncertainty about whether they could trust their own perceptions, and their self confidence was dependent on views offered by professionals.

6.7.9. Involvement in decisions

The extent to which professionals took women's concerns seriously may also have had an effect on the degree to which women were involved in making decisions about their care.

you just get told, 'well, take these tablets, take those tablets, everything's fine, ok, we'll leave you now' --- and you just get left to get on with it.. there's no.. trying to work out what the underlying thing is, they don't.. wanna know (IM5)

In some cases medical risk appears to have over-ridden shared decision making, and women did not feel that they were informed and included within the process.

half past nine, doctor came round and said, 'we're prepping you for an epidural, you're having him now', and I kind of went 'um, ok, ok' (IM2)

For other participants, there were examples of collaboration between patient and professional, resulting in the woman being able to make choices about how to manage her mental health needs, and developing a trusting relationship with the professional.

I was seeing a psychiatrist, who.. worked with me for, probably about a year, I'd say, and during that year we figured out a support system --- cause my medicines were making me gain weight, like, madly --- and I wanted to come off them anyway, and um, he and I decided together that we would work out a way that I could cope without being on them (IM4)

6.7.10. Additional experiences of services

Some data about experiences of services did not fall into the above themes, within which there were a variety of both positive and negative experiences within each theme. There were two predominant themes that did not contain this range of data, one reflecting positive, and one reflecting negative perspectives on experience of services.

6.7.10.1. Practical help and advice

Some participants said that they had received practical help and advice from professionals, beyond the immediate role of that professional in offering a service to the woman.

he's actually in the process of writing me a letter about my Bipolar, and having children, so that I can give to the council, so that they can pay my rent to my landlord --- cause I'm, if I'm manic, my money management is terrible (IM4)

he doesn't know much about baby claims or anything, but he looked into all that for me, he even went up on the internet and suggested a couple of websites, to maybe get some cheap baby things (GM2c)

6.7.10.2. Waiting times

Although some women described positive experiences with services, there were still obstacles and delays for access, especially of relevance in time limited period of the pregnancy. One woman who delivered early had not been able to complete any antenatal preparation, due to the late scheduling of the antenatal class, and felt that this had not only left her feeling unprepared for the birth, but also did not provide an opportunity to meet other pregnant women. Other women had a long waiting time for a mental health service or did not receive timely information about available services.

I was already seven months gone, by the time I found out that there was actually a [perinatal mental health service], and um, by the time they, they came round to see me, I'd already had her (IM4)

For another woman, the medical referral became unnecessary after delivery because the end of the pregnancy resolved the problem.

she goes, we'll get you referred to a dermatologist, but this is seven and a half.. you know, she would have seen me maybe a couple of months before, it would have made a massive impact, cause that really did, did.. drive me crazy, um, the dermatologist appointment came through two months after I had [child], so obviously, it was, it, you know, it was not needed (CM2)

6.7.11. Summary

Much of the data on women's experiences of services reflects the importance of women's perceptions of care in their relationships with professionals. This is particularly relevant in the broader context of many women feeling unsupported in other relationships in their lives. For some participants there appeared to be a striking resonance with historical experiences of feeling uncared for, neglected or disbelieved in their early lives.

6.8. What is Needed from Services

All participants had ideas about what they felt was needed from services. For many, these ideas reflected what they found wanting in their personal experience, and for some, this was informed by positive experiences of services during their pregnancies. The data reflects what women would want from services regardless of who was delivering these. It also reflects the particular qualities of professionals with whom they could build trusting relationships.

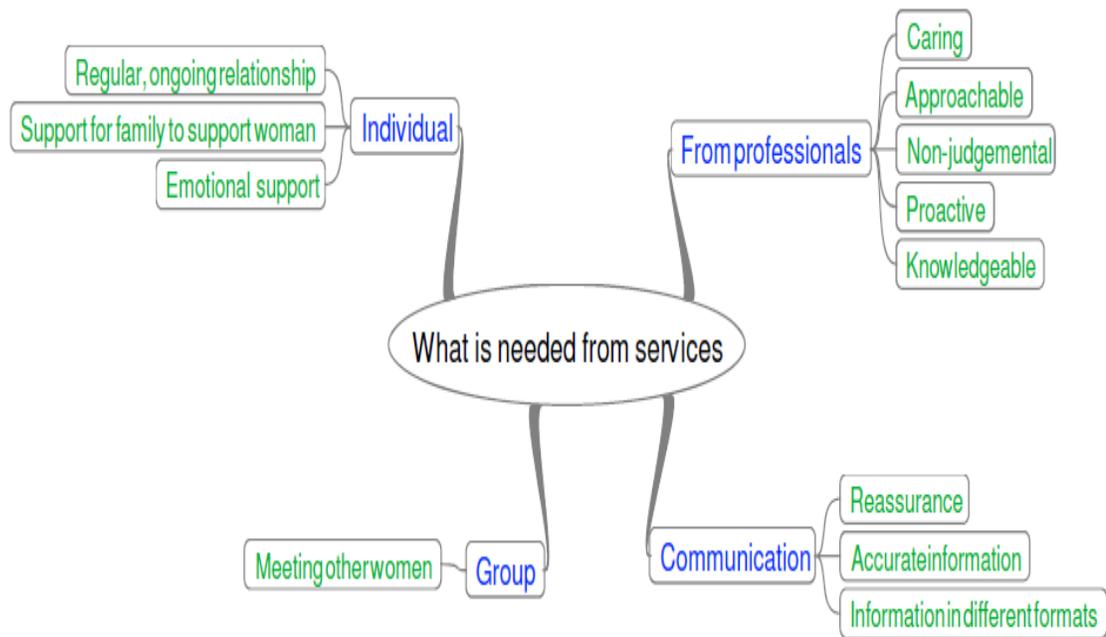


FIGURE 6.8 - WHAT IS NEEDED FROM SERVICES

6.8.1. From professional relationships

Women described the qualities of professionals that they thought were needed to deliver good services for women who are pregnant. Participants said that they would value contact with professionals who are caring, approachable, non-judgemental, proactive and knowledgeable. Much of this emphasis has been reflected in women's descriptions of positive experiences of services. When asked directly about what would be needed from services, some were very clear about these qualities.

6.8.1.1. Caring

Participants described the importance of professional behaviour that showed they care about the person.

supportive one that gives a damn [laughs] --- not there for their wage packet or sort of, not there because, well yeah basically because they're getting a

wage packet but there because they actually care, and they actually give a damn (IM3)

In relation to services they received, some women were able to give concrete examples of what professional behaviour seemed to show that they cared. However, in data where women expressed wishes that professionals would be more caring in their interactions, this was less concrete in relation to how participants could tell that the professional was caring.

just more help from someone who can actually listen to you, rather than, you sit there, and you're thinking, 'well, I know you, you're listening in a way, but you're not, sort of really listening' so you, you leave there, and you just think, well what was the point of that (IM5)

6.8.1.2. Approachable

Some women said that they felt able to assert themselves in relation to their own needs, but other women said that this was dependent on the professional and the relationship with the professional.

if I had somebody who was very approachable, at times when there's been particular symptoms you think, '[intake of breath] is that something to worry about', I perhaps would either phone, or.. think that's not too much trouble if I pop in, but with him, it's kind of like --- 'oh, I'll see what it's like next week' and.. you know, I could, I felt I could have been putting myself at risk (IM6)

6.8.1.3. Non-judgemental

Issues were raised by women about perceived professional judgements relating to stigma about mental health and teenage pregnancy.

*not to look down their nose at young.. parents, it just, it winds.. me up
(GM2a)*

Some women discussed how perceived judgements by professionals could have a negative impact on women's help-seeking.

*not to be so scared, there's got to be someone there that --- can help you
through it, and not judge you totally (IM5)*

women need to be.. really made to feel there's no shame needing help (IM7)

Participants said that it was important for there to be opportunities for open discussion about mental health, where the fear of stigma could be overcome.

6.8.1.4. Proactive

Women talked about the potential value of having a telephone number to access services as needed, but also wished for proactive contact from professionals to follow up initial appointments in the event of additional difficulties arising and women not feeling able to make contact themselves.

*I mean afterwards you turn around and say [inaudible], 'I'm ok', but a few
days later, it'd be nice to, if they could say, 'well, ok, we'll contact you again,
in a few days, about a week, and just see if you want the help then' (IM5)
the services are amazing, but I think maybe.. people need to be made more
aware, um.. but then I suppose it depends on the individual, if you're not
forthcoming in letting people know, I mean it's very difficult as a mum to let
people know that you might be struggling (IM7)*

These concerns also relate to the earlier section about the importance of approachable and non-judgemental professionals.

6.8.1.5. Knowledgeable

Participants expressed wishes that they could have greater confidence in professional knowledge about medication safety and greater consistency in advice from professionals. One woman expressed anxieties about her own knowledge about caring for her baby before he was born, and felt she was not able to access the information that she felt she would need.

nobody told me anything.. nobody gave me advice that I thought I could use, it was all, kind of, 'oh well, all babies are different (IM2)

Another woman wished that there had been greater knowledge available about her mental health. She thought that if it had been better explained to her, she would have been able to deal with the difficulties she was experiencing.

6.8.2. Communication

Similarly to the broader experiences of communication within services, participants described important ways that professional communication would improve their emotional wellbeing during the pregnancy. Women talked about the value of reassurance, availability of accurate and timely information, in usable formats.

6.8.2.1. Reassurance

Women who had difficulty with anxiety focused on the importance of reassurance.

it's just having that extra reassurance and somebody to.. tell you that you might think it's a silly question, but.. it means a lot to you to know the answer (IM6)

if I'd had someone say, 'ok, we'll come and see you once a week' or something, it was that little bit of reassurance that I wanted, from someone medical (IM5)

Both women described anxieties about their health and the wellbeing of the baby. They both said that they would have felt their anxiety was reduced by regular reassurance from professionals in whose knowledge they felt confident.

6.8.2.2. Accurate information

Connected with participants wishes for knowledgeable and reassuring communications from professionals, were the importance of access to accurate information from trusted sources.

I would love.. that, um... if I fell pregnant again, I'd love to be able to have a service, like NHS Direct, for example, that.. if I had a concern, I could phone up and get a question answered (IM2)

Women wished for timely advice and signposting, available when they needed it to enable access to services.

I had a couple of ladies come round not too long ago and say, 'well, we think that you would benefit from seeing this counsellor, and from going to this group' doing that --- and if they'd done that to begin with, while I was still pregnant --- I would have got a lot more out of it (IM4)

Although this woman thought such information would have been helpful while she was pregnant, the reality was that during the period of the research, there were very few groups available to antenatal women, compared with services available to postnatal women with babies. This difference reflects the focus on the baby in many services that are not available to women who have not had live births or who are not continuing to care for their babies due to local authority interventions.

6.8.2.3. Information in different formats

Some women described difficulty in accessing information in a written, pamphlet form, and on the internet, some women had access to these, but would have preferred something different.

there's never any information given to you, um, you don't see leaflets about things, there's not like leaflets saying, if you have this problem, or that problem, you can contact so and so to get, try and help you through it (IM5)
if somebody's gonna come round to the house and give you a pack of pamphlets, instead they could find out what your needs are, and then rather, instead of saying, 'yeah, pick one', point you to the ones that they think you should go to (IM4)

Participants clearly had different experiences about what information was made available to them. While some participants would have wanted books about what to expect during the pregnancy and birth, some preferred peer-based internet chat resource, and some expressed a wish to have professionals to explain to them about pregnancy, birth and parenting. Clearly there are issues with access to written information, where there might be limitations for women with poor literacy or English language.

6.8.3. Service provision

Many women had clear ideas about what kinds of services they wanted for pregnant women. These ideas included groups and one to one contact with professionals.

6.8.3.1. Groups

Employed and unemployed, young and old, many participants expressed a wish for more opportunities for facilitated and informal contact with other pregnant women.

Women expressed concerns that there were insufficient opportunities to develop supportive peer relationships within their communities.

a community based thing where anyone.. can just walk in if they need to --- like a drop in clinic, sort of thing --- I think that'd be quite a good thing --- that could help.. I know I would have used it, if there was something here like that (IM1)

something could be set up through the health visitor.. to perhaps join a group with other people... who are pregnant, and just, you know, for a chat and whatever --- and then do activities together, possibly (CMI)

Loneliness and isolation were identified in section two of this chapter as contributing to women's emotional distress during pregnancy. Wishing to form friendships with other women who had similar experiences was a theme that emerged many times in the data.

once a week, for a couple of hours, where.. we can get together, and .. sit and have a cup of tea, and you can air your thoughts, and .. the feeling like you're not alone in what you're thinking (IM2)

so once you get out and sort of --- start making friends, I think that'd be a lot more, sort of, help and supportive (IM3)

Working women also raised issues with availability of regular groups that were restricted to hours when they were at work, rather than evenings or weekends.

6.8.3.2. Individual

In addition to wishes about the qualities of professionals, women expressed wishes for the types of roles that professionals could offer during their pregnancies, and sometimes beyond.

6.8.3.2.1. *Regular contact, ongoing relationship*

Reflecting women's data about the importance of relationships with trusted professionals, women said that the disruptions in relationships with professionals due to service changes and limitations reduced the usefulness of the service provided.

a lot of people it takes a while to get comfortable --- and by the time they've actually got comfortable by, to the point that they can talk, it's finished, and you think well --- that was a load of good, so --- it would just be nice to have something that runs.. constant (IM3)

One woman wished she could have had regular support from a trained support worker like she had been able to access from Home Start after her baby was born. This situation reflects the differences in availability for antenatal and postnatal services during the period that this research was undertaken.

oh yeah, it really really helps, and I wish that I'd had someone like that --- during my pregnancy (IM2)

6.8.3.2.2. *Support for families to support women*

Where there were supportive family members present, women wished that professionals could help their relatives to understand their difficulties and know how to offer support.

[husband] will need a lot of help with me.. because.. um.. sometimes he can just go a bit.. you know a bit quiet, cause he doesn't know what to say, so he doesn't say anything (IM6)

However, in many cases, women did not describe existing supportive relationships that could be improved by professional input.

6.8.3.2.3. *Understanding and emotional support*

This sub- theme connects again to women's wishes for available and knowledgeable professionals to help them with making sense of, and managing their own emotions.

I just.. just wish there was more, more understanding out there --- of the situation, and more help in a way, it doesn't have to be like, um, like pills and stuff like that, it can just be someone that can talk to you, and help, help you understand things (IM5)

Some women expressed more general feelings that they were in need of more support, without such a clear focus for what that support might offer. Over the course of several pages of transcript this teenaged participant repeated several times that she wished for more support.

*there needs to be a lot more help.. --- mentally and socially, anything ---
--- just need a lot more help and support, and you know --- nice people---
--- just need a lot more help (GM2c)*

6.8.4. *Summary*

A significant issue that stands out from the data relates to women's wishes for facilitated peer support. Many women talked about what they would wish for from services and particularly their relationships with professionals. Some aspects of these descriptions would require additional resources, such as availability of group and individual therapies, and longer-term supportive relationships with professionals. Many issues that women raised were related to development of professionals' skills and knowledge, with other, more hidden resource implications such as professionals' time and training. Wishes relating to participants views of professional attitudes, such as being caring, approachable and non-judgemental may also reflect systemic

factors associated with excessive demands on services. These issues will be considered in relation to data from professionals in the following chapter.

CHAPTER SEVEN

FINDINGS FROM PROFESSIONALS' DATA

7.1. Introduction

Following the previous chapter, which presents analysis of data exploring women's perspectives on mental health during pregnancy, this chapter focuses on data from professionals, addressing the same issues, with the addition of further data to examine professionals' own needs to facilitate their ability to support pregnant women's mental health.

Data from discussions with professionals are presented in six primary categories.

These are:

- Professionals' descriptions of women's mental health problems
- What undermines women's mental health during pregnancy
- What promotes women's mental health during pregnancy
- Professionals' views of services for pregnant women
- What is needed to support women's mental health during pregnancy
- Professionals' development and support needs

The following diagram (Figure 7.1) shows the connections drawn between the different main categories of data as listed above. This diagram differs from the similar diagram in the previous chapter, in that it does not include professionals' views on the effects of women's mental health problems, or women's own resources for coping with their poor mental health. These issues were not represented within the professionals' data. Although other issues were present in the data and were explored during the analysis, these were not the focus of the research questions

within this study, and have therefore not been included in this report. A range of themes not reported in this thesis included issues raised by professionals about their wider organisational roles and responsibilities; relationships within their own and connected organisations; general discussions about pregnancy; the influence of their own life experiences on their work and vice versa.

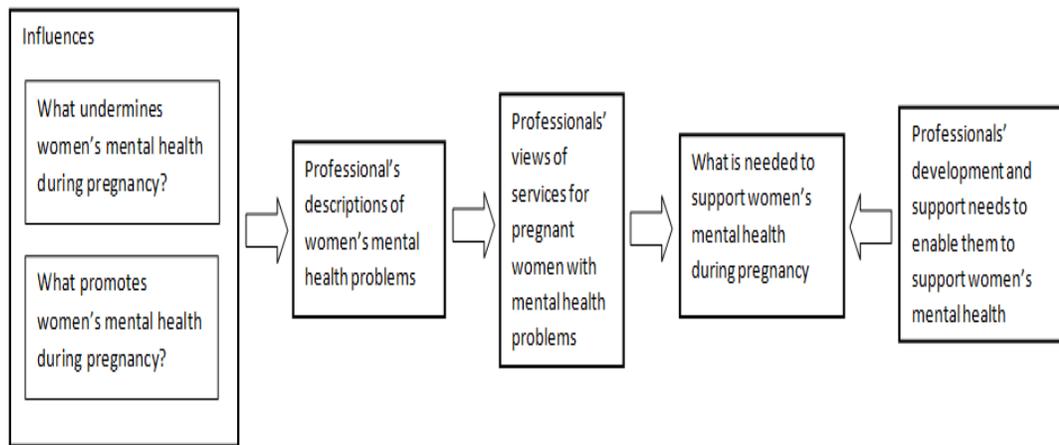


FIGURE 7.1 - OVERVIEW OF ANALYSIS OF PROFESSIONALS' DATA

At the beginning of each section, a mind map is shown to summarise the data within that section. Data is presented as it was transcribed verbatim, using the same symbols to indicate pauses, omitted data and insertions as summarised in the previous chapter (page 167).

At the end of each quote, the anonymous unique identifier for each participant is given in brackets (). At the time of transcription and analysis all professional data were given unique identifiers of either IP (Individual, Professional) and a number, or GP (Group, Professional) and a number to identify which group they took part in, followed by a letter to identify which member of that group was speaking. The original unique identifiers given at the time of transcription and analysis have been

changed for presentation in this chapter to enable the reader to more easily identify the service context of the person speaking. The details are given in the following table. The numbers and letters have been retained from the original identifier.

GMat	Data generated in a group of maternity professionals, followed by the number of the group and letter to represent the speaker within that group
IMat	Data generated in an individual discussion with a maternity professional, followed by the number of the individual
GMH	Data generated in a group of mental health professionals, followed by the number of the group and letter to represent the speaker within that group
IMH	Data generated in an individual discussion with a professional working in a primarily mental health role
ICom	Data generated in an individual discussion with a professional working in a community-based role outside of mainstream maternity and mental health services. This group includes health visitors, voluntary sector youth workers.

TABLE 7.1 - LABELS REPRESENTING DIFFERENT PROFESSIONAL/ROLE IDENTITIES OF PARTICIPANTS

7.2. Descriptions of Women’s Mental Health Problems

Professionals’ data showed widely differing understandings and perspectives of women’s mental health during pregnancy. The range of professionals included in this research reflected the broad range of people who would have contact with women with mental health problems during pregnancy, with differing levels of mental health specialism within their roles. In common with descriptions of mental health problems given by mothers in this research, professionals described problems ranging from mild to moderate distress to more severe and enduring mental health problems.

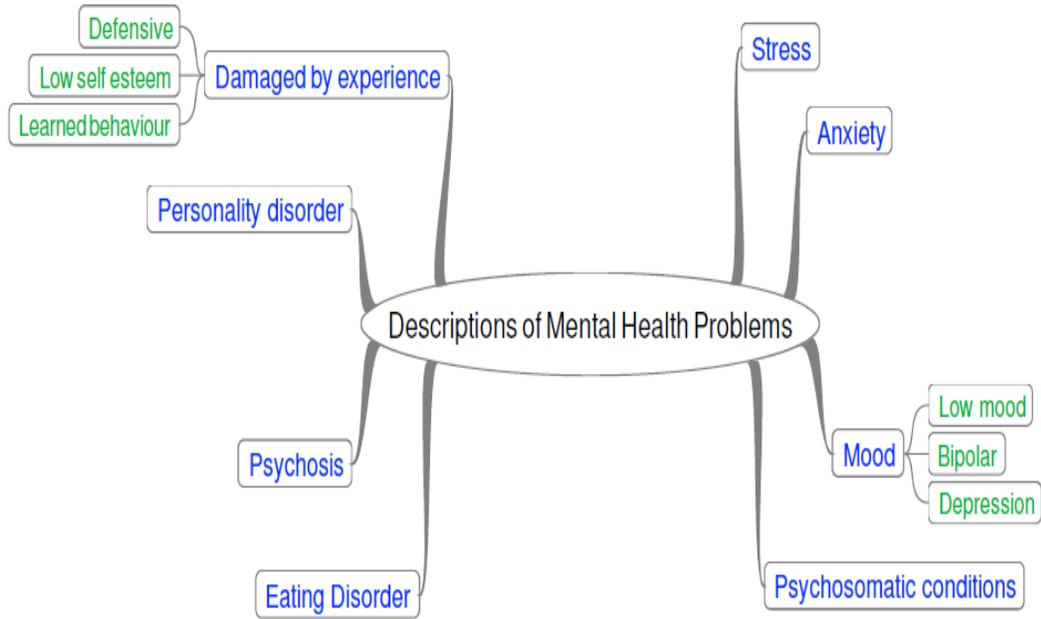


FIGURE 7.2 - PROFESSIONALS' DESCRIPTIONS OF WOMEN'S MENTAL HEALTH PROBLEMS

7.2.1. Stress

Professionals gave examples of mothers' feelings of stress and distress arising from difficulties in everyday life.

half of the referrals are worded in terms of mums who are just generally feeling, um, anxious and overwhelmed by their difficult, you know, by their feelings and because of circumstances in terms of poor housing, or difficulties in relationships (ICom2)

Some professionals described concerns about the impact of stress related hormonal changes and 'corrosive cortisol' (IMH1) on the foetus in utero.

7.2.2. Anxiety

Participants described working with women who experienced normal anxieties in pregnancy, and particularly anxieties driven by information from the internet.

I don't think we'll ever completely alleviate that, they're, they're natural, natural concerns, I think --- it probably would be, wouldn't be right if you didn't have those concerns (GMat1c)

Some professionals expressed frustration that information from poor online sources is taken seriously by women and its widespread availability. As described in the earlier chapter on women's own experiences of accessing knowledge, it can be seen that women have variable degrees of access and trust in different information sources.

Beyond normal anxieties encountered in their practices, some professionals described more significant anxieties arising from traumatic life experiences, disrupted relationships and uncertainty in access to care and support during their pregnancies.

the ones that I know of when you actually sit and get to know them, they're just, they're just scared young women (ICom4)

7.2.3. Mood

Professional participants described a range of problems with mood including low mood, bipolar affective disorder and different types of depression. When asked about women's 'mental health', depression was the frequently the first issue that participants talked about. For many professionals there were concerns about the chronic nature of depression within the local population.

the mental health issue is like a norm, they're used to being depressed and low --- and, and that's something that I think that they just accept as that, perhaps that's just them (ICom4)

In many cases there were clear associations drawn with the lives that women led and their emotional health. One professional used a clear diagnostic description of

'reactive depression' (IMat6), whereas other professionals talked about the conditions of living and relationships that had an impact on women's mood and mental health.

a lot of the young people I work with, you, discussing mental health with them and they're coming into pregnancy with low mood, low self esteem, depression, it's not particularly antenatal depression, it is --- depression, they have really hard lives --- it's not, you know, it's not suddenly come on cause they're pregnant (IMat8)

7.2.4. Psychosomatic conditions

A small number of professionals talked about psychosomatic conditions, however these were not widely reported as problems encountered by participants, and when mentioned, they were acknowledged to be an unusual presentation in participants' everyday practices.

we get funny, um psychosomatic conditions in pregnancy, um, we can get almost [exhalation of breath] Munchausen type things where people are.. experiencing somatic.. um, symptoms without any organic basis to it (IMat6)

7.2.5. Eating disorders

More commonly, professionals described physical effects on women's health in relation to the behavioural impacts of mental health problems.

I measured her, and she was thirty weeks, and she laid on the couch, and her hip bones stuck up above her bump, well, there wasn't really a bump there --- so I weighed her, and she hadn't put on anything (GMat1b)

For some professionals, there were notable connections between the physical changes arising from pregnancy, and the emotional distress arising from pre-existing mental health problems.

somebody who.. I worked with a while ago, and.. who has anorexia, or had anorexia, and actually getting pregnant was about being more visible and how she.. the changes in body shape and.. were the most distressing things, the baby was almost secondary to the whole process that was going on at the time (GMH2c)

Clearly, as an embodied process, the physical and emotional experiences of pregnancy may be more entangled in a complex interaction than some other experiences of mental health.

7.2.6. *Psychosis*

Within the data there was a distinction between emotional distress that seemed understandable to professionals in the light of women's life circumstances, and problems that seemed frightening, unfamiliar and difficult to manage.

we're getting much better at dealing with antenatal depression, recognising postnatal depression, it is when it's a crisis, when it's not just a few tears, but it is, you know.. psychosis or a real crisis (IMat8)

Maternity and community professionals in particular described feeling ill equipped and fearful when encountering women with more severe mental health problems. For some professionals, dealing with women experiencing mild to moderate mental health problems could be seen as an extension or extreme version of their own experiences. Less commonly encountered mental health problems such as psychosis generated more anxiety in the professional.

7.2.7. *Personality disorder*

Similarly to other forms of more severe and enduring mental health problems, some professionals described personality disorder as a qualitatively different category of mental health problem.

it covers a whole range of different difficulties --- um, from you know, those who are depressed and down, those who are depressed and anxious, those mums who've always been depressed, and who happen to have a baby as well, those mums who you wonder whether they, you know, there is some sort of ... personality disorder going on (IM2)

In mentioning the label of personality disorder, this professional uses the expression 'you know' and pauses before using the words, which may suggest some degree of discomfort in the use of the term (Wennerstrom, 2001).

7.2.8. *Damaged by experience*

Some professionals used explanations relating to women's experiences without using psychiatric diagnostic labels to describe mental health problems. Participants described behaviours including self harm, ways of interacting including defensiveness, observations that women may experience low self-esteem and suggestions that their behaviour may have been learned from difficult experiences in their lives.

a lot of young women self harm, you know, and I think that is across the board and of course then in pregnancy that shows up even more --- when you're working with young women, it's quite depressing, seeing the state of the youth really, and that they are.. very damaged --- a lot of our young girls are very damaged (IMat8) possibly they've learned some behaviour --- and I

think that can be --- that can happen, that they learned to react, to react, to, um some certain actions (IMH5)

7.2.9. Summary

Data shows that professionals are working with a range of different problems, and within a range of different theoretical models and levels of understanding about mental health during pregnancy. These ranged from primarily medical models to developmental and social models that informed the understanding of the difficulties that participants encountered in their routine practices.

Many professionals went on to give detailed accounts of the relational, social and material conditions that they considered had harmed women and had a negative impact on their mental health during pregnancy.

7.3. What Undermines Women's Mental Health during Pregnancy

Comparing professionals' and mothers' data relating to factors that undermine women's mental health during pregnancy shows a range of very similar features. Interestingly, the major difference between mothers' and professionals' data can be seen in the lower left hand sections of the two diagrams (the mothers' data diagram Figure 6.3 can be found on page 174), in which mothers identified internal processes of negative thoughts and feelings, where professionals identify service related factors that can be seen to undermine women's mental health. Both aspects appear to reflect an inward gaze to examine the participant's own role, or fellow professionals' roles in affecting women's mental health. Other factors identified by both mothers and professionals were issues arising from the women's childhood experiences, health conditions, relationships, the pregnancy itself, and the social and material conditions of life.

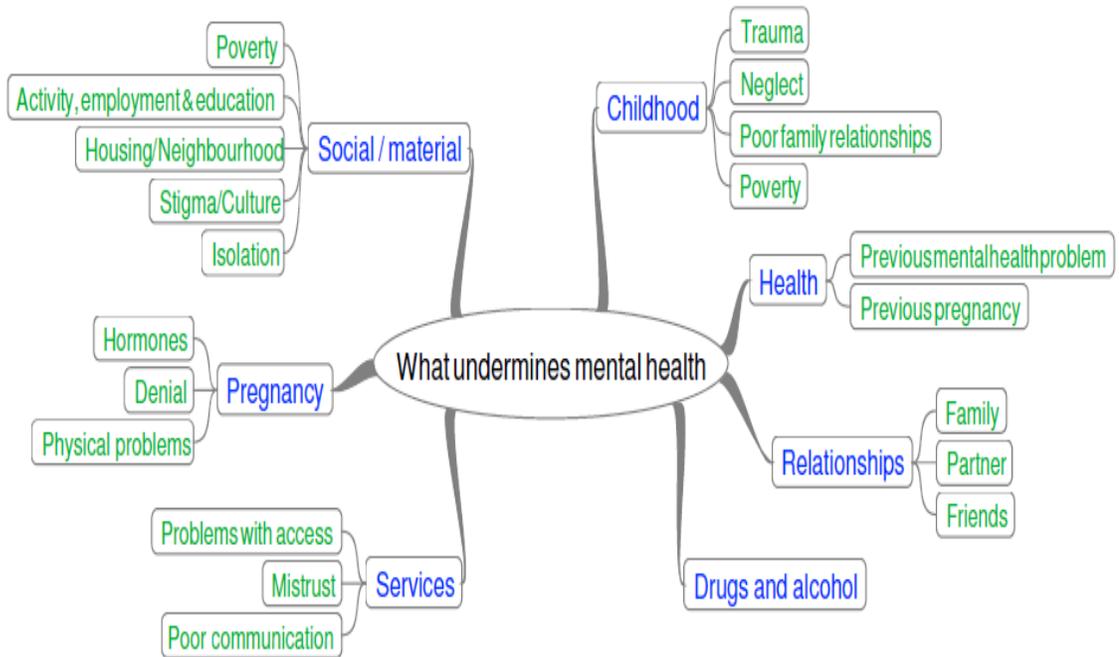


FIGURE 7.3 - DIAGRAM SUMMARISING PROFESSIONALS' DATA ON WHAT UNDERMINES WOMEN'S MENTAL HEALTH DURING PREGNANCY

7.3.1. *Childhood*

Many professionals identified women's childhood experiences as having a detrimental effect on their mental health in adulthood, and especially during their pregnancies. Professionals described their knowledge of women's early lives involving trauma, neglect, poor family relationships and poverty.

when you start digging around, it's amazing what you can find --- domestic violence, um, childhood abuse, witnessing.. domestic violence when, when the mother's a child, um... constantly being put down by, say your own mother, so you then start to doubt your own capabilities as a mum, um... when you start, you start asking the right questions (IMH5)

Participants described some women having significant fears and suspicion about openness with professionals due to the woman being taken into care in childhood due her own mother's mental health problems,.

she thinks you've already labelled her as a.. fruit loop like her mum, and 'you took me from my mum, which means you're gonna take my child from me'
(ICom4)

Professionals described the inter-generational and chronic long term conditions of women's lives in the local area.

quite often what we're seeing as adults is those children that were living in abuse and neglect, obviously ten, fifteen years ago, and the rates of poverty haven't improved --- in terms of, you know, some of the most deprived areas
(ICom2)

Pregnancy was described as a time when some women reflect on their own early experiences, and re-evaluate their lives and potential new role as a mother.

then looking back at her own childhood, can see that she wasn't, she wasn't protected, um... by her own mum, and, um, maybe mum's been in and out of different relationships (IMH5)

Professionals described observing parallels between women's current lives, and the lives of their own mothers, some of whom had been known to professionals when their currently pregnant service users were born.

7.3.2. Health

Professionals described both physical and previous mental health as factors contributing to the complexity of women's emotional experience during pregnancy. In common with mothers' data, professionals identified non-pregnancy related

illnesses, pregnancy complications and previous pregnancy loss as having a negative impact on emotional wellbeing.

the medical terminations, it's, they feel guilty --- because they've had to have the medical termination, on the one hand they understand the rationale behind it, but they still feel guilty, they feel it's something that they've done wrong (IMH5)

women who have had.. multiple miscarriages, and then become pregnant --- and that produces this, massive experiences of anxiety (GMH2c)

Professionals cited research and their own clinical experience in relation to the risk to women's emotional wellbeing during pregnancy that arises from previous experience of mental health problems.

I think any, potentially anybody can --- suffer from any kind of mental health problem, but, there is research to show that if you've previously suffered, from a mental health problem, you're more likely (IMH3)

In addition to a unidirectional influence, some professionals described an interaction between pre-existing mental health problems and wellbeing during pregnancy.

I think, if, if people have had mental health problems.. previously --- I think pregnancy tends to exacerbate them (GMat1c)

Participants suggested previous depression, and family history of depression, especially in mothers and grandmothers seemed likely to increase problems during pregnancy. For some professional this reflected a primarily medical/genetic understanding of causation, and for other professionals, this related to early experience resulting from growing up with a depressed parent.

for a lot of women I see, it's chemical changes... um, which, you know, you can't really do anything about (IMH3)

I think sometimes they think it's because they, they've grown up with it, they've seen it --- possibly they've learned some behaviour (IMH5)

7.3.3. Relationships

Professionals expressed concerns about the negative impact of poor relationships and lack of supportive relationships on women's mental health.

Professionals either directly observed, or heard from women about the difficulties in family life, primarily relating to relationships with extended family, who in many women's lives are a source of support.

family members often are the worst --- that's what I've found anyway, family members are often the worst, yeah, especially grandma, or somebody like that, you know --- if everything's always been plain sailing for them (IMH5)

Professionals described problems arising for women from earlier difficulties in the relationship with their own mothers or the development of role-based rivalry when the daughter becomes pregnant.

I think there's something about them that, kind of threat about them becoming a mum, which then creates difficulties and friction with their mothers, um... again, you would hope at a time, that that would bring, you know, a mother and daughter closer (ICom2)

As opposed to this conflict, participants also described some young women's acceptance of the pregnancy because they had been like a parent in their household, caring for a vulnerable mother, or accustomed to responsibility for care of younger siblings.

I think, to be honest with you, that haven't had anyone to listen to them, and .. have had to grow, had to live grown up lives (ICom4)

Some professionals described conflict arising from the pregnancy and lack of practical and emotional support for the woman, including being thrown out of the family home. In other cases, participants described family breakdown not directly related to the pregnancy.

some of them we have that have moved here, um, some that have um, you know, some they come here with their family, but then, uh, then in a short while their family then move on, and then, you know, they sort of tend to be left here (ICom4)

In addition to conflict and lack of support within their families of origin, professionals described observations of lack of emotional and practical support from partners beyond a financial role.

the fathers, they, that's their economic, you know, function is fulfilled so that's it, you know, I go out to work, and that's what I do, that's what I contribute to the family (ICom2)

Additional difficulties can develop for women who had previously been in a caring role for a partner has mental health problems, in relation to the expectation of the partner for the woman to continue to offer emotional and financial support.

if he's always used to the wife doing this, and maybe the one that's gone out to work, because he was unable to work because of his mental health problems --- so you've got your impact on your finances (IMH5)

Although social relationships within the community can be an important resource for women during pregnancy, this was often described by professionals to be especially complex for young women.

[town] is a small town, they often know of each other, by reputation, often slept with each other's boyfriends, you know, hit her sister, done, you know,

*it is a small town, and there is a lot of barriers you've got to break down
(IMat8)*

Professionals described a vicious cycle between poor mental health, poor communication skills and poor social connections to offer support to women during pregnancy.

7.3.4. Drugs and alcohol

Whereas mothers described drug and alcohol use as a coping strategy or a result of their mental health problems, some health professionals also identified substance use as a factor that undermines women's mental health and exacerbates problems, including financial, physical and mental health.

if it's consumed on a regular, too much basis, it actually can change the personality, but uh, when you're already feeling low, it can push you even lower (IMH5)

with the drug use, you know, if they, if they're dabbling in cannabis, then that, you know is a, is a risk, cause it, where are they getting the money from, and you know, often, that puts them in a high risk category for me, for the unborn and for their own mental health (IMat8)

One professional in the voluntary sector described substance use as both a coping strategy for difficulties in life, and a factor that contributes to difficulties.

turmoil going on at home, and, and that was her coping strategy was to just sort of, like, you know, you, they get drunk and take drugs and they don't sort of, they forget about what's going on in their lives (ICom4)

7.3.5. Services

Some participants identified the role of services in undermining women's mental health. For some professionals working within mental health services, a lack of mental health knowledge within other services, and problematic and inconsistent communications with pregnant women were considered to undermine emotional wellbeing.

having mixed messages, different information from different people can be, um.. well confusing for anyone (IMH3)

I over the years have worked with two people who, who were traumatised as children, but then re-traumatised by disclosure during pregnancy, and judgement by... um.. uh... hospital staff.. with simple misconceptions around abuse (GMH2c)

For many professional groups, concerns about women not taking up primary care services were seen as both reflecting and contributing to problems with emotional wellbeing. A woman's denial about the pregnancy could lead to problems of accessing services and for some groups, such as Travellers and migrant workers, a culture of mistrust of professionals also led to not accessing services.

they've always refused to see the GP about it, felt that it was something that would be dealt with by themselves, wouldn't accept listening visits --- so very closed to any form of intervention (ICom7)

Where a mental health problem was identified in primary care settings, some professionals expressed concerns that the lack of access to appropriate specialist support and information could further undermine women's mental health.

7.3.6. Pregnancy

Many professionals identified the pregnancy itself as undermining women's mental health, or exacerbating existing problems. Different descriptions were given of the mechanism for this influence. For some professionals, this was a relatively straightforward biological influence.

for a lot of women I see, it's chemical changes... um, which, you know, you can't really do anything about (IMH3)

Other professionals talked about more complex issues relating to feelings about the pregnancy and the wider context in the woman's life.

whether they wanted to be pregnant, whether they were in a relationship that they want, all those kind of things about how an individual woman, um, is feeling about the, uh, the pregnancy, where, and where that happens in her life --- will affect how, how she feels about.. the pregnancy, and, and herself (IMH1)

Unintended pregnancy may have occurred at a time that created difficulties for women within their lives and relationships, including resulting in relationship breakdown with parents or partners. Professionals described women being unable to accept, or being unprepared for the reality of the pregnancy.

I don't know whether that's uh, again that's a conscious.. psychological barrier that they've put up themselves --- that if this isn't happening, this isn't happening (ICom4)

Participants described physically difficult pregnancies also undermining emotional wellbeing through exhaustion and sickness.

if you, you know, you have.. have a diabolical kind of pregnancy and you're sick the first eight and a half months or something, that's gonna wear you out a bit (IMH1)

7.3.7. Social and material conditions

Like many women who took part in this research, professionals identified a wide range of social and material conditions that they thought had a negative impact on women's mental health during pregnancy. These included poverty, education and employment, housing, stigma and isolation.

7.3.7.1. Poverty

For many professionals, poverty and the level of deprivation in the area were connected to other social and material problems, and to women's experiences of poor mental health.

[town] is quite a deprived area, so .. and you know, if a lady is, especially if she, her partner has left her, say, during pregnancy, or whatever, and she's, she's living in a, a bedsit, and you know, very little coming in, I mean, that's really not going to be.. good for her, good mental health (IMH5)

there'll be lots of stuff that's the same for everybody, like the, you know [sigh] social kind of issues and money and housing and work or not work and... those, debt, and all those kind of, um, struggles and trials that, that can be bad for anybody's mental health (IMH1)

Participants talked about the relationship between deprivation and risk for other adverse social conditions such as domestic abuse and child neglect in relation to women's emotional wellbeing. Some participants acknowledged the differences

between themselves as professionals and women without the same material and social resources.

cause we don't struggle.. at home.. you know, I have.. no struggles, uh.. that I don't think of, so, but people do, and that just, it automatically affects the mind (IMat6)

7.3.7.2. Education and employment opportunities

Professionals described circumstances where women, particularly young women, had few opportunities, and lack of aspirations and activities in life.

the local [town] girls whose families have been here two or three generations who have never worked, and, they have no ambition, no aspiration --- I think they're just low, they just all seem very low (IMat8)

that's everything, isn't it, that's their environment, that's their society, that's their housing --- that's their lack of education, that's their lack of positive role models --- you know, and, just one of them can have an impact on someone (ICom4)

Different participants working with young women described a significant issue with boredom and lack of meaningful activity.

they're almost like retired at sixteen, because they leave school.. and um.. sign on.. and they're retired at sixteen, and that's really boring isn't it, you know, you just feel that.. when you say to them, 'what d'you do with your day?', they fill their days with absolutely nothing --- to actually have endless weeks and weeks with nothing going on.. is depressing (IMat8)

One professional was working in a third sector service that had previously provided basic educational opportunities for young women, and explained that the funding for this had been cut, leaving women with fewer opportunities.

7.3.7.3. Housing

The impact of housing problems was acknowledged by many professionals. Housing problems in the area reflect the high levels of socio-economic deprivation experienced within the community.

they're constantly stressed about it --- they're constantly, you know, they get put in temporary accommodation (ICom4)

The council sometimes house women and families in temporary accommodation in bed and breakfasts, without any clear indication of when a permanent placement will be available. One professional described particular issues for migrant workers in the community, with overcrowding and unsuitable housing.

a lot aren't entitled to certain benefits, things like that --- can also impact, I think, particularly if they haven't got a very good income, or a lot of them work for agencies, um... so the pay's quite poor, um.. and they tend to live in, um, kind of sublet houses, so there'll be like a three bedroomed house, and four, five, six families within that house (ICom7)

In addition to stress arising from housing problems, professionals also described health impacts on mothers and babies arising from problems with housing stock, including dampness and poor heating.

7.3.7.4. Stigma and culture

Professionals within and outside of mental health services recognised that there is still widespread stigma attached to mental health problems. During data collection, some participants expressed ideas that it would be better to use different terminology, such as 'emotional wellbeing' instead of talking about 'mental health'. One participant described difficulty with recruitment of staff to a community organisation, which she speculated was due to the use of terminology ('postnatal')

that had become associated with mental health problems. An initial advert describing the post as focused on working with postnatal women generated few applicants, whereas a subsequent advert describing the post as relating to work with new mothers was more successful.

got hundreds of people apply for it, cause you've changed the title, so that to me was like, 'ah, right, so from a professionals point of view, they're looking at that in a different light' (ICom4)

Professionals working with Travellers and migrant workers said that they observed greater levels of stigma within those communities.

I think there was a huge, within this community, a huge stigma, um about depression, um, it's not a nice thing to admit to, you know, it kind of tinges the whole family --- so it's very much dealt with in house (ICom7)

Professionals working with teenage mothers described judgement about becoming pregnant at a young age.

society frowning upon them, because they're young mums (ICom4)

Young mothers and migrant workers were both described by professionals as experiencing stigma in relation to their identities within the wider community. For both groups, professionals described finding it harder to engage in delivery of mainstream health services and mental health services. The presence of a stigmatised identity may increase women's reluctance to acknowledge their additional struggles due to further stigma associated with mental health problems.

7.3.7.5. Isolation

Participants identified isolation amongst pregnant woman as reducing the availability of support and impairing emotional wellbeing at a time when women are potentially more vulnerable to distress, and in greater need of day to day support.

her and her boyfriend weren't happy, her mother had.. thrown her out, [inaudible] all the indicators for, you know, she was living in really poor housing, all the indications of somebody who would eventually have poor mental health were there antenatally (IMat8)

Although the data from mothers identified difficulties with isolation across a range of ages and circumstances, professional participants more frequently identified isolation as a problem amongst young and migrant women.

moving away from their home country, losing links with extended family, being quite isolated, um.. and in those kind of, um, situations, it's quite difficult, because often, there isn't a kind of community resource which you can refer them to (ICom7)

Professionals described fragmentation of family life and changes within communities as further reducing availability of support networks.

we're more nomadic I suppose, because we move for work and --- you know, we may not have mum round the corner (IMH5)

Participants saw these practical and lifestyle changes as adding to the difficulties for women with poor mental health in forming and maintaining close and supportive relationships.

7.3.8. Summary

Many of the issues raised by professionals in relation to undermining women's mental health were the same as those identified within data from mothers in this research. The main focus of the professionals' data related to the impact of early life experiences and social/material conditions of living in undermining women's mental health. There was one negative case, in which a mental health professional (IMH3) identified biological and hormonal factors to be primary in causing women's mental

health problems. One maternity consultant acknowledged the role of social and material factors in undermining women's mental health and suggested that it was necessary to distinguish between 'mental illness' and distress caused by social factors. This difference reflects ongoing lack of consensus and divergent opinion amongst professionals regarding the origin and management of poor mental health during pregnancy.

7.4. What Promotes Women's Mental Health during Pregnancy

There was little data focused on what supports women's mental health compared with data about the many circumstances and conditions that were thought to undermine a pregnant woman's mental health. Professionals were able to give extensive examples of problems that would undermine a woman's mental health, but in many cases, when asked, participants frequently identified the absence of a problem as promoting women's mental health. Examples given below also contain caveats relating to the potential for positive effects for women, including how attempts to support the building of peer relationships do not always work, how partner relationships are not always supportive, how extended families are not always nearby, or how not everybody is willing to attend peer support groups. Most of professionals' data in this area focused on supportive relationships either in the community or with professionals.

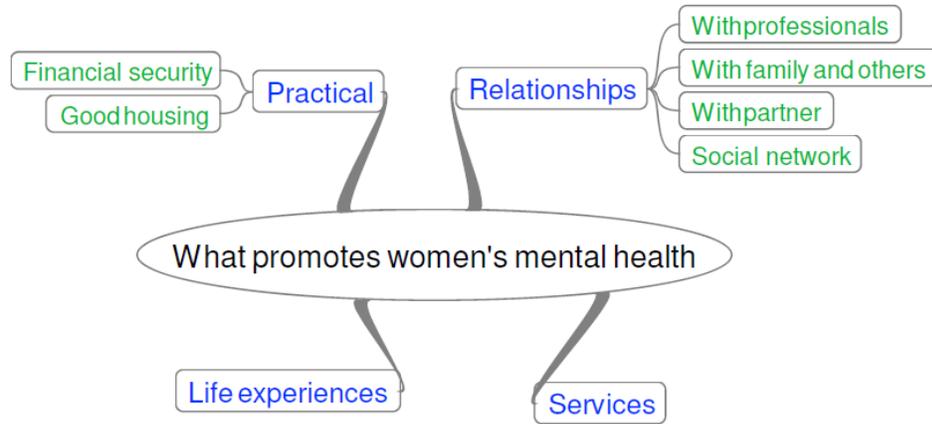


FIGURE 7.4 - WHAT PROMOTES WOMEN'S MENTAL HEALTH DURING PREGNANCY

7.4.1. Relationships

Professionals talked about the importance of a wide range of positive and supportive relationships in supporting women's mental health during pregnancy.

speaking to other pregnant ladies --- sharing common concerns --- support from their partners --- and families --- and support from us hopefully (GMat1c)

7.4.1.1. Relationships with professionals

Some professionals outside of specialist roles in maternity services recognised that there were limitations to the time available to offer support to women beyond routine care. For professionals within mental health roles and other specialist community roles, there were greater opportunities to offer support in various ways.

we wouldn't necessarily be there to offer a lot of advice, just that supportive listening --- hoping that some of that can help the mums feel a little bit, you know, listened and heard and contained --- in order that they can, they can fulfil that function with their babies when they arrive (ICom2)

The ability to spend time and build trust was seen as one of the prerequisites to developing supportive relationships with women and enabling disclosure of distress.

and it's amazing what can come --- to the front, when the lady trusts you, or starts to trust you (IMH5)

Professionals described the importance of providing space for women to talk about their experiences, in addition to other forms of practical support, advocacy, activity and encouragement to access other services.

mums will always need help with the practical side of things, cause um, you know, it does help to know that you're getting support with housing or money issues (ICom2)

7.4.1.2. Relationships with family and friends

Although professionals recognised how difficulties within family relationships can undermine women's mental health, they also talked about the importance of positive relationships with family and friends.

the extended family, if you like, being supportive, and being there for each other... I know many, many years ago we used to live back to back, aunty would be up the road, and grandma would be round the corner, and you know the support network would be there (IMH5)

7.4.1.3. Relationship with partner

Professionals mostly described difficulties in relationships with partners in relation to women's mental health. However, they described the importance of positive partner relationships, security and stability in promoting good mental health.

I think if they're in a good stable relationship it can help to promote, um healthy [inaudible] --- it doesn't always, as we know (IMH5)

7.4.1.4. Social network

Professional participants talked about the importance of peer groups in sharing supportive relationships for pregnant women.

I suppose, like anyone else, um, a social network, and... people who've been through similar experiences, I know there are groups locally --- for women, um... not everyone wants to attend (IMH3)

Although it was widely acknowledged to be important, it was also recognised that for many women, it would be difficult to engage in groups. One professional had been successful in bringing young women together, based on the knowledge of individual women's circumstances and community relationships so that interpersonal conflicts could be minimised and development of supportive relationships increased.

if you can engineer it to get them in the room together that they can.. uh, they can look after each other with a lot of support, they can offer far more support than any of the professionals can --- if you could only break down the barriers --- sometimes it works, and sometimes it doesn't (IMat8)

This professional recognised that it was not always possible to overcome long-standing conflicts amongst young women in a small community.

7.4.2. Services

Although many professionals talked about resource limitations within specialist services, some focused on the importance of access to mental health services in the cases where a woman who has a pre-existing mental health problem becomes pregnant. From within mental health services, the issue of timely referral was the focus of ensuring important links with primary care.

a referral in, in you know, good time [laughs], um... and then, you know, appropriate monitoring of their mental health (IMH3)

Professionals in maternity services identified the value of working together with colleagues in mental health services, but found that there were frequent barriers to access for women who were not already known to the services.

women with, um, known mental health problems, already, um, bipolar disorder springs to mind, if they've got a consultant psychiatrist, then.. you know.. the, the jobs done, you're already working --- within a network, that's, that's almost easier than a woman who has been undiagnosed, and then you're fighting to get her into the system (GMat1a)

7.4.3. Life experiences

Professionals identified positive early life experiences as protective of women's mental health during pregnancy. Feelings of financial security, opportunity, education and positive social role models were considered to be important, in addition to secure and nurturing early relationships.

if your earliest relationships were good enough, then you're likely to, to be able to, to, to form good enough relationships later on --- which can support you both in terms of your own wellbeing and that of your developing role as a, as a, a mother to be, parent (IMH1)

7.4.4. Practical issues

Women's positive financial and material conditions were described as contributing to good mental health.

if they're sort of, maybe.. financially more secure, it can obviously help (IMH5)

The presence of security and the absence of direct experiences of deprivation were connected to a young woman's ability to be a positive influence on other women who did not have the same advantages.

the ones that we have come here that are just fantastic and have... no issues like that, have a good home life, have, you know, they haven't gotta worry about housing, they haven't gotta worry about this that and the other, we want them in as well, because we want them to have a good influence --- on the young women (ICom4)

7.4.5. Summary

Unsurprisingly, much of the data reflecting professionals' views on what supports women's mental health during pregnancy is directly opposite to the features of women's lives that participants considered as undermining their mental health. The extensive social and economic disadvantages of the area were frequently reflected in professionals' descriptions of factors that promote women's mental health.

7.5. Professionals' Views of Services for Pregnant Women

The detailed information about what is available to women with mental health needs were mainly outlined by a small number of specialist professionals, mostly working within mental health services or having a specialist role in community-based services. Many participants gave perspectives on difficulties and problems within existing services. Significant problems were identified from outside specialist / mental health services, primarily by professionals working within mainstream maternity services.

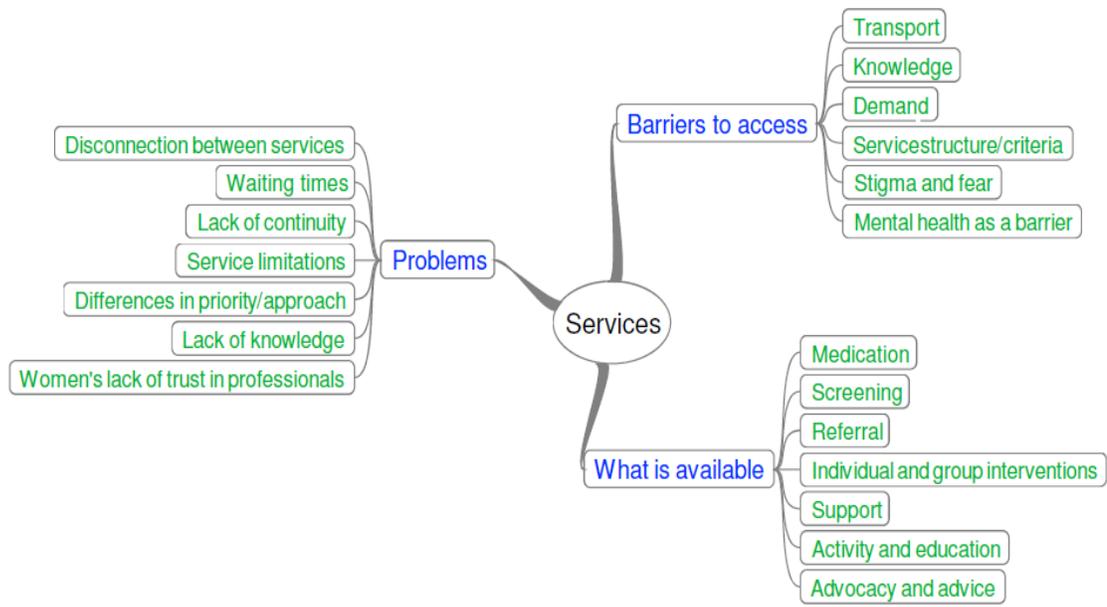


FIGURE 7.5 - PROFESSIONALS' VIEWS OF SERVICES FOR PREGNANT WOMEN

7.5.1. Barriers to access

Professionals talking about pregnant women’s mental health needs often described difficulties experienced by women in accessing services. In some cases these were simple, practical obstacles such as transport, but the primary issues that professionals discussed were service related barriers, such as lack of professional knowledge; lack of resources to meet the level of demand; and service structures, including referral pathways. Other significant barriers related to women’s reluctance to access services due to stigma and fear, and the nature of the mental health problem itself presenting an obstacle to access.

7.5.1.1. Transport

Participants discussed practical difficulties associated with transport related to issues of poverty and the large rural area covered by many professionals within their roles.

I don't know of any groups outside of the town ---which can be difficult, obviously the, you know the buses are fairly few and far between --- out in the villages... and that can be difficult (IMH3)

Participants also identified difficulties in managing public transport for pregnant women who already have young children.

7.5.1.2. Knowledge of how to access specialist mental health services

Midwifery professionals in both community and delivery suite roles described their difficulties relating to knowledge of how to access the relevant services.

we just didn't know who to ring and, everybody kept passing the buck, of who was gonna come and assess her, and it was just an absolute nightmare (GMat1b)

Beyond lacking knowledge of referral pathways, participants talked about confusion regarding which professionals in mental health services were adequately qualified and knowledgeable.

we don't understand the, the workings of the mental health team enough, or -- knowing who has the specific, correct knowledge, I mean some people may come up, and say, 'oh, I've got the knowledge..' do they? --- I would have absolutely no idea (IP6)

Where a maternity professional was able to access a service on behalf of a mother, they sometimes felt that they were asked to make assessments of women's needs that were outside of their own level of knowledge and experience.

when I've made a referral to single point of access, the crisis line that we have access to, that they're asking me to make a judgement that I don't feel qualified to make (GMat1a)

7.5.1.3. Demand

Both mental health and maternity professionals reflected on the difficulty in meeting service demands within available resources. Professionals in maternity services described difficulty in accessing primary care mental health services, which is a first step before further specialist mental health services can be available to women.

there are mental um, health link workers --- at most of the surgeries, but they do get very, very booked up, don't they --- so again, sometimes you've got --- weeks waiting, three, four weeks, and if they're having a .. a crisis time, that's, you know, you need to be able to access that within that week, really -- - it is, far too long (GMat1b)

Some maternity professionals talked about their awareness that women with complex needs require time consuming input from mental health services, and that services may be overwhelmed with demand.

I guess the people that are out there are overwhelmed, I mean I don't know, I'm not out there, but I would imagine they're overwhelmed, and, you know, it's just an expensive business, you can't.. go and see someone.. X times, you know a week, because they've got mental illness, because there's so many other people, also with a mental illness (IMat6)

From the perspective of professionals within specialist roles, concerns were expressed about the level of demand, not just related to the number of people who can be seen, but what professionals are able to offer to women.

the more I understand about it, the more kind of problems you see and the more, you know --- the more you want to help, really --- and believe that you should help --- but that doesn't equate to having the time to do it in a, in your caseload (ICom2)

This professional also talked about the difficulty that non-specialist professionals like midwives may experience in consultations where they may be aware of a difficulty, but are reluctant to open up a discussion with the woman because of lack of time or perceived lack of skills and support from other services.

a lot of people get very worried about mental health and they have a huge amount of anxiety about it --- I think probably midwives don't feel that they have time to listen to mums --- and so I think that that pressure equates to not asking for fear of the answer that you'll get really (ICom2)

7.5.1.4. Service structure

The way services are structured was frequently discussed by mental health professionals as presenting obstacles to flexible and responsive services for women. This particularly related to the limited timescale of the pregnancy, and the slow movement of referral pathways and service waiting times.

if you want to see somebody before their baby's born, you've got to, you know, you've got this amount of time, you've got to get a move on, and sometimes that doesn't fit with the, the kind of.. the structures that exist (IMH1)

Some issues were described as relating to promptness of referral, which could hold up a services ability to respond in good time to a woman's needs. Some services were only available in certain conditions.

if they've previously been known to acute services, which is the ward and the home treatment team, um, they can phone them, but they'd have, the team would have to have a knowledge of the person in the first place (IMH3)

For maternity professionals, this was a source of frustration.

I've worked with, with the crisis in the mental health has just been.. awful to try and get some help for them (IMat8)

Professionals also talked about the structure of mental health services as enabling access only within traditional office hours. This was clarified by a co-researcher during an interview with a mental health professional and confirmed as a source of difficulty by a maternity professional.

[is there someone on call twenty four hours a day?] no we work um, nine to five, Monday to Friday, and out of those hours, um, if the woman goes into crisis they can phone their on-call GP (IMH3)

if you want mental health referral after five o'clock, forget it (IMat8)

Professionals in community and maternity services described their own stresses arising from difficulties in accessing mental health support for patients. Participants talked about lack of direct access to services and feeling responsible for the impact on women of opening up distressing conversations when other services will not accept referrals.

I don't think if I phoned [CAMHS] and asked to speak to someone there to say, 'well, I've got this young woman, and I think she might benefit from this that and the other' --- that they would even entertain that (ICom4)

you open a can of worms at thirty eight weeks, you're then discharging at ten days, you're leaving them high and dry (IMat 8)

Professionals talked about the difficulties caused by GP gatekeeping for mental health services, and the expectation that a service user would be able and prepared to repeat her story to different professionals when being passed from person to person in a complex referral pathway.

so by the end of it, she's thinking, 'right, well actually, why bother, cause I think I feel worse than I did originally' --- and I actually only came to speak to you, and now I feel let down by you, and I feel let down by them (ICom4)

However, it is also clear that professionals described problems with levels of resources and demand that create additional obstacles to access, which might be exacerbated by more flexible access into services.

7.5.1.5. Stigma and fear

Professionals described additional barriers to access arising from women's reluctance to disclose information about their mental health due to feelings of fear of social and other consequences.

I've just tried to encourage them to, to do it, because again it's that stigma it's [name of hospital], you know --- that's where the nutty people go, that's where the, you know, there is all that stigma attached to it --- you know, 'go and see a shrink', and 'I'm not mad' (ICom4)

I think most of it goes back to when we had the old institutions, and you know, um, the fear of going into the institution, you know, the first thing that's going to happen is, you know, they're going to lock me away and throw the key away and they're gonna get social services involved and this baby's going to be taken away (IMH5)

Professionals working with all age ranges and across different cultural groups raised concerns about how the stigma associated with mental health problems and the label 'mental health' created an obstacle for women in accessing services.

7.5.1.6. Mental health itself as a barrier

Professionals talked about women's mental health problems as barriers to accessing services. This related to shame, low self esteem and avoidance of acknowledging there is a problem. Lack of insight and recognition of the need for help was seen by some professionals as part of some mental health problems, and a barrier to access.

if you were in the depths of depression, you cannot say, 'oh God, I'm in the depths of depression, I need to go and contact so-and-so and let them know', I mean, that's the whole thing.. you can't... cause you're.. unable to do so (IMat6)

Some mental health problems were described as producing self-destructive behaviours amongst young women, and undermining their help-seeking.

they don't care what happens to them, so why are they gonna care that their health is ok, during, through, during their pregnancy (ICom4)

7.5.1.7. Summary

Participants' views of barriers to accessing appropriate services related to a range of factors from practical obstacles such as rural locations and transport, to service related problems and barriers arising from social stigma and women's mental health problems. Existing service structures and referral pathways may serve to limit access to services and reduce pressures to meet levels of demand that could not be met due to limited resources.

7.5.2. What is available

Participants described some resources that were available to women who had been able to access specialist services, including medication, and individual or group interventions. Within mainstream services, professionals described the availability of

screening and referral, but recognised that referral did not always result in access to a service. Outside of specialist services, professionals described offering different types of support, activities and education, and advocacy and information.

7.5.2.1. Medication

Although medication for common mental health problems is widely available in primary care, professionals described ongoing uncertainty about safety of drugs for prescription to pregnant women. Participants described general practitioners' reluctance to prescribe.

Two professionals with backgrounds in mental health nursing identified the need for monitoring the use of medication to ensure safety and the impact of medication reduction during pregnancy.

when certainly I worked in secondary care, you may have a lady with bipolar ...who is pregnant --- and obviously need very close monitoring --- because medications have to be reduced right down, so to keep an eye --- very much on the moods, make sure .. that things don't go wrong for them (IMH5)

Another mental health nurse talked about the role of informed professionals in enabling women to make choices about taking medication and protecting their babies from medicine-related harm.

I suppose a lot of women think that they would prefer to breastfeed if they can, but know that they, or, because they would probably stop if they needed to go on medication --- so we'd have discussions around that (IMH3)

Many professionals without specialist knowledge and experience in mental health acknowledged that they did not know about the safety of medication use in pregnancy.

drugs can make moderate to severe illness better, but there's .. growing anxieties I think over antidepressants in, in pregnancy, and again, it's not a lot of real actual knowledge about that (IMat6)

7.5.2.2. Screening

Many professionals talked about the importance of screening to identify women's mental health problems within their routine practice. Participants working in community midwifery described prompts in booking notes that are used when making an initial contact with a pregnant woman, and considered these to offer a helpful opportunity to raise discussion of the issue of mental health and inform women of professionals' role to offer help when needed.

I would ask the Whooley questions, obviously, as we do that as a routine screening --- but I might do it again if it, I'll ask them again if I've noticed scars and I hadn't previously, that sort of thing... but um, a lot of the time, you know, if somebody says 'no, I don't do it now' or 'no, I don't want any help now' --- what can you do? (GMat1a)

Beyond the prompts in booking notes and the 'Whooley' (questions recommended in NICE 2007 guidelines), professionals also described the use of the Edinburgh Postnatal Depression Scale (EPDS) in screening and identification of mental health problems (Cox *et al*, 1987).

midwives pick up things a lot quicker than they used to, and health visitors as well --- and they're more likely to pick it up even before the GP --- obviously now they do the EPDS screening and things like that, so, um, you know, it is .. they flag it up quicker (IMH5)

7.5.2.3. Referral

Although primary care professionals described difficulty in accessing specialist services when a mental health problem has been identified, there were fewer concerns expressed about referring within services.

eating disorders is another fairly big issue in pregnancy --- usually at booking, um, if somebody has a low BMI, body mass index --- we um, would refer to consultant led care (GMat1c)

Within mental health services, a mental health nurse explained that because of her previous experience, she had been identified as the member of the team who would take on the majority of work with women who were referred when they are pregnant.

I think that's probably mostly because obviously I've got this.. past history of working with women, um, but also I, I'm aware of where to refer women, should they become very unwell, mother and baby unit (IMH3)

This participant, when asked by the co-researcher during the interview about team resources and capacity, said that she thought there was adequate staffing.

we don't carry a waiting list, um, at the moment, um... so therefore I suppose there are enough people (IMH3)

This participant's perspective appears to be at odds with other primary care professionals who described difficulties in accessing services on behalf of women. Other issues that arose in the professionals' data related to making safeguarding referrals. Most professionals who talked about making safeguarding referrals described resulting difficulties in relationships with mothers following this act which may have appeared to the woman as a breach of trust. However one professional described her experience as working together within a positive relationship with the woman and enabling the process to become more supportive and positive.

on the couple of occasions I have managed it, it was a bit shaky at times, but --- I have managed to, to maintain it because we got the correct help put in -- - so the support was given, and extra support was given, and uh, um.. the individuals learned a lot from it (IMH5)

In many cases, the process of referral to specialist mental health services was described as frustrating for professionals in maternity services.

the waiting list to be seen is immense --- and they are just completely overwhelmed.. and therefore we, whilst we have a service, we don't feel that the service is adequate enough for our needs (IMat6)

I find that working within the mental health service --- incredibly frustrating, there is no mental health service to work with, with any efficiency at all (IMat8)

7.5.2.4. Individual and group interventions

Within specialist mental health services, and community services run by professionals with specialist roles, participants described offering individual sessions for women to feel heard, believed and supported. For some professionals this focused on the ability for women to reflect on their circumstances, and develop a better understanding of their difficulties.

when you talk them through it, um, and they sort of stop and reflect, they can see, that there possibly is a pattern [family history of mental health problems] (IMH5)

Professionals described valuing counselling services, and feeling frustrated at the limitation in this resource.

I think, because it's successful, the service, and it's good, it's full --- and that's a shame, because it's so good we can't use it --- it's a victim of its own success really (IMat8)

Beyond one to one counselling services, some specialist practitioners also described offering groups, although availability of places within these is also limited.

Participants across mental health, community and maternity services described the value of early intervention during pregnancy.

we've started an antenatal support group for mums, um, and we, we obviously believe that that will help in that if there's, rather than waiting for mums to deliver (ICom2)

These services were seen by participants as an improvement in care for women with mental health problems during pregnancy.

[Children's centre] certainly has improved access to counsellors and --- groups that involve, you know, ladies getting together and having a chat, so um, prior to that there was.. we referred on to GPs which I didn't always feel was particularly appropriate (GMat1c)

7.5.2.5. Support

Many professionals described the use of listening sessions for women who have emotional difficulties during their pregnancies. This activity was primarily described by professionals working in specialist roles within the community.

it may well be helpful, you know, to do that, um to help relieve some of that stress and anxiety through listening sessions really --- we wouldn't necessarily be there to offer a lot of advice, just that supportive listening (ICom2)

try and give them quite a lot of support, listen, not to talk, listening therapy for them --- allowing them to express.. how they're feeling (IMH5)

Many primary care and community professionals emphasised the role of listening, rather than offering practical advice or assistance. In the local area this approach appears to have been enthusiastically embraced as a way of offering support to women who are not accessing mental health services.

7.5.2.6. Activities and education

Some specialist, community-based professionals discussed the role of psychoeducational approaches for pregnant women and their partners. The role of education was in part focused on women's understanding of mental health, and in part focused on empowerment and increasing choice and self esteem.

part of our antenatal contact is to discuss post natal depression, and the misconceptions around depression and the services that we're able to offer to mums (ICom2)

it's a way of just.. drip feeding them slowly, you know, just by, you know, not bombarding with it, but, hopefully so that they go home and think, 'right, well perhaps this isn't normal --- and perhaps it isn't right, and if I haven't got enough.. courage to, to do something about it for me, then perhaps..'

(ICom4)

In addition to supporting women to consider their own emotional needs in relationships, several professionals across mental health services talked about the value of supporting others, including partners and families, to enable them to offer support to women during pregnancy.

sometimes it's just, 'please tell me what to do, how can I support my partner, what help can I give her' you know --- so I tend to use a lot of, um, self help material (IMH5)

In addition to addressing relationship issues through education, participants described some limited services providing activities for young women in the third sector.

the antenatal groups here are always, very sort of low key, nothing heavy, you know, it's just nice, somewhere that's nice for them to come (ICom4)

Professionals talked about using craft and group activities for young women to raise self-esteem, feelings of achievement and positive experiences of the pregnancy, through activities such as making abdominal casts of the 'bump' & decorated boxes for keepsakes such as scan photographs.

they made nappy holder stuff, uh.. memory boxes, and lots of different arts and crafts, and the idea about that is raising self esteem, again getting them talking (ICom8)

These services were only described by professionals working with very young women, and other groups considered to be at greater risk of poor mental health and non-engagement with services, such as migrant workers and Travellers.

7.5.2.7. Advocacy and advice

A small number of community-based professionals mentioned roles that involved giving practical advice and support, instead of listening visits. These roles focused on helping to address the social and material problems confronting young women.

they need people like us to be able to go to meetings and say, 'right, well we understand the pressures you're in, but, you actually do have an obligation to help these people --- so, you know, I can, I can, sort of not encourage them

to come down there and shout and swear over your counter about being in inadequate housing, but, you know, you need to do something about it'
(ICom4)

For some professionals this practical assistance involved allocation of support workers to young mothers to offer guidance on practical and health related needs.

7.5.2.8. Summary

Professionals across a wide spectrum of roles described ways that they and their services were able to offer help and support to women experiencing mental health problems during pregnancy. Because this research sampled participants with different professional backgrounds and service contexts, we were able to examine the range of available services and relationships between services. The most frequently discussed difficulties between services related to service limitations. The range of services and service activities could represent a 'stepped-care model', with more intensive services (such as individual and group therapy) being available to only a fairly limited number of the population, and lower intensity services (such as routine practice and listening visits) being more widely available. However, this model places pressure on the providers of low intensity services which have high volume related demands when there are more service users with complex presentations than there is availability of high intensity services.

7.5.3. *Problems within and between services*

Many professionals from maternity, community and mental health services talked about problems that exist within and between services for women during pregnancy. Some problems related specifically to service structure and demands, including the disconnection between maternity and mental health services, and service limitations.

Other problems related to capacity issues within services, such as waiting times, lack of continuity and service limitations. Other issues that could be seen are focused more on the professionals within services, including differences in perspectives and lack of specialist knowledge. Some professionals raised issues about women's lack of trust in professionals, and the impact of lack of trust on professionals' ability to provide a helpful service.

7.5.3.1. Disconnection between services

Although many professionals from maternity and mental health services recognised the importance of working collaboratively, many also expressed that there were difficulties in developing and maintaining these connections.

you can't have all the knowledge, so, what do we do, we network --- it's not what you know, but it's who you know --- so you go and get your friends in each subject to help you when you have a problem --- and you get on the phone --- and you meet them face to face, um, and that's what it's all about --
- [Co-researcher: is that available with mental health services?] --- no, no, absolutely not (IMat6)

sometimes it's really difficult to create those points of contact, how..however much, however much, um, will there is to do that (IMH1)

The importance of connection between services did not only relate to sharing of information and expertise, but offering practical assistance when needed.

we need to be able to rely on our colleagues, and that, for whatever reason, they've probably got their own crisis in their own service, that doesn't seem to be happening (IMat8)

The exception described by some participants was a specialist primary care link worker (IMH5), who had retired after the end of data collection. The Linkworker

service in which she worked was being reduced due to budget cuts to mental health provision.

midwives refer through to me --- as well as health visitors, and um.. my colleagues --- in the [primary care] team, they refer to me as well (IMH5) outside of [perinatal mental health service] is almost non-existent, I mean, I've used the.. occasion, occasionally when I've really needed it, I've then got hold of [IMH5], is the only one I get any sense out of (IMat8)

Although the perspective from professionals in maternity services described frustration and inadequacy of mental health service response, the reality is that these services are being further reduced at the time of writing.

Although professionals in maternity services expressed frustration about waiting times service responsiveness and other limitations in mental health services, they recognised that this was related to lack of available resource within those services.

we've got phone numbers and we've got helplines, and we've got acute referrals, we've got chronic referrals, we've got, um.. that barrage, but the waiting list to be seen is immense, I mean they have the non-pregnant population in the mental health services to deal with as well (IMat6)

There was recognition by some professionals within mental health services that waiting times were a problem when considering the needs of pregnant women.

one of the things about pregnancy, it's a very time limited thing, you know, it is forty weeks --- give or take, you know, and um and so it, it provides a very definite kind of structure.. um.. an external kind of structure which possibly we wrestle with as mental health services (IMH1)

7.5.3.2. Lack of continuity of care

Participants talked about the difficulties arising from the large number of GP locums in some surgeries, and women's inability to access a health professional with whom they can develop on-going, trusting relationships.

they haven't picked up on it, even though they've looked, say, well this lady's been, as you say, to the doctors ten times in, in six weeks --- what else is going on --- rather than just looking at the, the sore finger, or you know --- what else is going on? (IMH5)

Professionals related problems to lack of continuity available in out of hours GP care, but did not describe problems with their own inability to provide continuity of care due to working patterns within midwifery or mental health services.

One professional described the importance of pregnant women taking up a proactive role in accessing appropriate referral to specialist services.

I guess we don't, really don't see those women, I don't know if maybe they'd ask to see a different GP, that's what I would advise, to change your GP --- or ask to the speak to the, um, Linkworker at the surgery, um, who would then refer (IMH3)

7.5.3.3. Service limitations

Participants talked about their experiences of service limitations, in relation to services in which they did not work, including some services being limited to working with young women under age 25 and other services only accepting referrals from NHS primary care or being limited to a geographical area.

people will say, 'oh no, I can't see her, she's not in my region' --- and you think well.. [laugh] --- you know, we don't say that in here [maternity

services]! And it's the way they're set up --- and it's the way they have to be set up, but it doesn't help us (IMat6)

From an insider perspective, professionals expressed concerns that how services function and what they are able to provide has a direct impact on women's experiences of pregnancy.

the more you intervene, the more expensive it becomes, and the more complicated it becomes, so we have some women, absolutely terrified of childbirth, who say, 'I want a section', and we've got p..politicians, government, health authority, everyone, Trust, saying, 'get your section rate down, get your section rate down', so we're, we've got this battle of thinking, 'yeah, actually, she probably would be better with a section' (IMat6)

Service limitations were also described as shaping the way that professionals engage with women who may have mental health problems.

my fear is, if you open the box.. that I know that the other services.. [whispering slightly] aren't up for the job a lot of the time, you can't refer --- so sometimes you open that box and then you've got nothing to offer them, apart from yourself --- and often then at that point, we're at a point of.. almost finished my time with them --- so that's the scary bit (IMat8)

Some professionals recognised that services are not equally appropriate for some cultural groups, and identified a need for flexibility in service provision for diverse groups.

I suppose you're probably limited to what you can offer them, and slightly more so with the kind of client who is English speaking, um.. and have good literacy, I would normally, sort of say, you know, talk about anti-depressants

and then talk about the possibility of, um, listening visits and then also do, sort of like an online CBT (ICom7)

Some participants described services as providing a better fit for some members of the community than others.

7.5.3.4. Difference in priority/approach

Research participants recognised variation between professionals relating to the priority that is placed on the needs of either the woman or the baby. This issue was particularly important for some professionals in relation to mental health due to the potential for psychiatric medicines to harm the foetus.

I know they don't like people to take medication in the first three, the first trimester of pregnancy, um.. so if a lady has major mental health problems becomes pregnant, it's likely that a GP is likely to stop all the medicines, which can cause more problems --- whereas, you know, research has shown that you can take it down to the minimum --- dosage, which.. is less harmful to the baby, um, but, probably is going to keep mum, promote her health (IMH5)

if you then deprive people of the antidepressants, are you going to make them significantly worse.. during the pregnancy, and you've got to weigh up.. risk and balance and balance all of that and... I must admit, our, our first anxiety is for the woman (IMat6)

Many participants focused on the need to find a balance between the needs of the mother and the baby, and acknowledged that for women with mental health problems, the baby may take priority within some services.

because perhaps that relationship was prior to.. to the pregnancy, and actually that provides a space for them to be seen more as, as themselves and

as an individual, whereas other services may be more focused on, on the child, I think it might provide that space to still be seen as, as having their own needs, slightly separate (GMH2e)

In the case of safeguarding concerns and services that are focused on the needs of the baby, professionals identified that although it would be preferable to also consider the needs of the mother, the baby must be the priority.

as much as it is about the mother, you want to make the mum, or the antenatal mum feel contained and heard and looked after, the focus has to be on the child and that relationship (ICom2)

Some professionals described feeling distressed by their own inability and the lack of available services to continue to support women after a baby has been born and removed into local authority care.

7.5.3.5. Lack of knowledge/role limitations

Many professionals in maternity and community services talked about their concerns relating to their own lack of knowledge about mental health.

it's a bit of sort of Chinese whispers, really.. you know, someone who's learned something from a course, and done a bit of work, you know.. and, so no, it's not, it's not a huge amount (IMat6)

In addition to lack of knowledge, professionals described the limitations of their roles in relation to responding to pregnant women's mental health needs.

due to time constraints of our clinics, then I don't feel that we can, and we're not adequately trained to offer that appropriate support, either (GMat1b)

For two participants who were involved in training primary care professionals, there was a greater sense of optimism that GPs and maternity professionals could be

helped to apply their existing knowledge in services provided to pregnant women with mental health problems.

but just, you know, awakening their skills, they have them --- it's just getting them to use it (IMH5)

Although there may be some training available, some midwives expressed concerns about the limited time resource available for midwives, and frustration about the expectations placed upon the role of midwives by other professionals.

actually it's not a midwifery problem --- you wouldn't get a mental health nurse sitting there all night with somebody in labour, cause it's a midwife's problem, so why would you have a midwife, sitting there with somebody who's pulling her fingernails out with depression --- because mental health won't go out, I mean, it's just.. it's shocking, it's very rare.. but it is, when it happens it's very frightening for everybody involved (IMat8)

7.5.4. Lack of trust in professionals

Participants talked about additional difficulties in delivering services within some cultures of mistrust toward professionals. Some participants described how this mistrust related to women's earlier experiences either in family life, or in past relationships with other professionals.

Participants described the importance of striking a balance between a woman's and a child's health needs and honesty to build trust within the professional role, particularly in relation to intimate partner abuse and safeguarding children.

if they've told me a bare-faced lie, I'd have probably said, 'well, I think this', and that hasn't always gone down well, but I think.. at the end of the day, I can't pretend, and if.. I kind of like pretend that [inaudible], then that's collusion, isn't it, and at the end of the day, I have to build a relationship

with them, but then not at the expense of.. their and their children's safety, really (ICom7)

Participants said that they thought women's concerns about ability to trust professionals would stand in the way of the development of open and honest disclosures about mental health, and thereby potentially undermine the service that could be offered.

the mums get the idea from that actually, 'I can't say how I'm feeling, because they, if I say that I'm not feeling too good, then that's gonna look kind of detrimental in terms of my ability to parent' (ICom2)

Lack of openness about self harm, even though scars may be plainly visible to professionals was considered to have a negative impact on the ability to provide an effective service.

[talking to young women about depression] it's trying to say to them, it's quite normal.. and again that's quite difficult --- cause again, when you don't know, what levels, how honest they're being with you (ICom4)
the woman is not willing to give the information, or midwives or GPs haven't helped me extricate that information, or I haven't got it out myself, and you can't help women unless you know what they're worried about, what their concerns are, what their issues are (IMat6)

7.5.5. Summary

Most participants talked about their concerns in accessing and providing appropriate services for women who were having emotional difficulties during pregnancy. There were widespread concerns about the lack of connections between services focused on maternity care and women's mental health. Although there was recognition that many publicly funded services were strained by the imbalance between resources

and demand, many professionals expressed frustration that this had a negative impact on their ability to provide the services that they wished were available for women. Many professionals talked about what they wished would be possible in services for women who struggle with their mental health during pregnancy.

7.6. What is Needed to Support Women’s Mental Health during Pregnancy

Data from professionals showed understandable connections between participants’ concerns about the problems within and between services, and their ideas about what was needed to support women’s mental health during pregnancy. In addition to ideas about the need for services from professionals, participants also talked about the need for informal support for women within their own communities. This data connects up some of the professionals’ discussions about the social factors that undermine women’s mental health, such as poor relationships and isolation with the expressions of need for greater support. Much of this data echoes the data from mothers themselves about their need for appropriate services and informal support within their communities.



FIGURE 7.6 - WHAT IS NEEDED TO SUPPORT WOMEN’S MENTAL HEALTH DURING PREGNANCY

7.6.1. Community services by professionals

7.6.1.1. Accessible and available

Professionals talked about the need for accessible and proactive services. It was acknowledged that accessing some mental health services required a high level of persistence from potential service users, and that the nature of mental health problems was likely to impede the ability to access services for some women. Thus a proactive approach and accessible, less stigmatised locations for service delivery were considered important.

things like having mental, mental health services, more, more accessible and kind of in community sort of settings (IMH1)

you need access.. not that you can seek out, because when you've got a mental illness, you're not up to seeking out.. who you need, so you need people to go in proactively (IMat6)

This was raised as a particular issue for women living in Traveller communities, within which professionals have experienced problems with engagement with services that are provided outside of the Traveller sites.

For professionals across different services, concerns were expressed about the capacity of other services to provide adequate care to meet the needs of pregnant women.

I can't just assume that .. that that, whatever she gets there will be enough... I, I need to be con.. I need to feel confident that, before I sort of.. discharge her (GMH2a)

These concerns were expressed by participants from maternity, mental health and community-based services.

7.6.1.2. Shorter waiting times

Accessibility and availability was also considered in relation to waiting times, and professionals talked about a need for services that are able to respond more quickly to pregnant women's mental health needs.

you've then got to wait two months, then they've got a baby, and they've forgotten that they ever disclosed that, and then.. can't get there, so actually to have a designated antenatal time, for crisis would be really important (IMat8)

Professionals from maternity, community and mental health services all recognised that due to the time limited nature of pregnancy, and the possible delays in seeking services, women's mental health needs required a more rapid response than they observed at the time of the research.

7.6.1.3. Emotional support

Although some professionals emphasised the need for supporting women's health to enable them to develop a good relationship with the baby, several professionals talked about women's needs for emotional support in their own rights, and particularly in relation to some women's histories of poor emotional support in their early lives and need for stable and supportive relationships when experiencing the emotional challenges of pregnancy.

I popped back in with another appointment for her, and [support worker] was standing over her with a glass of water, to make her take her antibiotics --- was boiling the kettle to do eye care for the baby, and was just.. nurturing her and mothering her --- and that's what's missing I think --- is... a good mother figure (IMat8)

some women who perhaps don't have a lot of support in fam, in terms of family and friends and so on, perhaps the professional relationships that they have develop a particular, um, importance (IMH1)

7.6.1.4. Professional relationships with women

Beyond providing emotional support, participants talked about the value of women building trusting relationships with professionals to enable the delivery of appropriate services, particularly with reference to enabling disclosure about intimate partner abuse and other risks to the health of the woman and the baby.

you have to kind of, build up the relationship to a point where they're either, feel safe to tell you --- or you kind of, not confront, that's the right word, but you would tentatively approach the subject (GMat1a)

Several professionals also talked about the importance of building positive relationships with others in the woman's family network.

just having a relationship with someone, um... and not just the woman, the whole family as well, I think that's quite important, if.. dad around, or any other, kind of, family members (IMH3)

The length of a relationship, and enabling continuity for women, while challenging for services to provide, was also seen as an important and valuable support to establish in helping to manage the transition between antenatal and postnatal circumstances for women.

I do notice that mums, I do think, see value in the health visitor antenatal contact, um, I have had mums say that that they do feel that it helps to get to know somebody before the --- baby arrives (ICom2)

7.6.2. Communication

Professionals talked about the importance of communication on three main levels: that of improving communication between services; of ensuring that women are not disadvantaged by lack of fluency in English; and ensuring that women receive clear communication about the services that are available to them.

7.6.2.1. Communication between services

Participants from mental health, maternity and community services recognised that communication between services is necessary, but was thought to be inadequate. Professionals talked about the need for improvements in structures to facilitate routine communication between different specialisms within the health service and community organisations.

we have these things for every other specialty, why not for mental health --- I mean, once you've set up a video conference, it really doesn't matter, if they've got the knowledge and time, the interest and the ability, they can, then can do that (IMat6)

One professional referred to the irony in the difficulties in communication between services for mothers and babies, where the importance of the relationship between mothers and babies is prioritised by psychological approaches within Parent Infant Mental Health Services

most professionals, health professionals, seem to deal either with mothers or with the babies --- and actually there are few who look at mother, mother and baby as a kind of unit, as a, as a dyad, and the relationship between the two and how.. and how [laughing] those parts of the services ought to, ought to find a way to speak to each other more really (IMH1)

A mental health professional talked about how she has tried to develop better communication between mental health and maternity services, while recognising that there are practical difficulties to overcome to ensure this is possible.

there's something that I try to do, in, if it's possible within the time that we have --- is to have a joint visit with the midwife or, the health visitor, they're not always identified, are they, at that time, um, so that could be difficult --- they might be allocated, but they're not actually on their books, because they haven't had the baby at that time --- it's all a bit difficult, it seems --- to get all three of us together would be ideal --- but with the midwife initially, and then maybe afterwards with the health visitor (IMH3)

7.6.2.2. Interpreters when needed

While many participants recognised the difficulties in developing ongoing networks, knowledge sharing and collaboration between professionals and services, a small number of participants also identified problems in communication between professionals and pregnant women. For professionals who work with migrant workers, there were concerns about limited use of formal interpreting services for women who do not speak English.

there seems to be an increase in GPs and other services that are now refusing to offer translators, or even telling --- clients to pay for translators if they want them, and I just think, um.. you know as a service, is something we have to be really aware of (ICom7)

Some maternity professionals described situations in which women's partners were interpreting for them in booking appointments and medical consultations, raising concerns about confidentiality and the ability of women to speak openly in the case of intimate partner abuse.

7.6.2.3. Communication with women about services

Some professionals expressed concerns that not all women were aware of services that were available to them. It was considered to be important to have routes of communication to inform women about their options, although it was also recognised that there was pressure on services in relation to existing demand.

I think we need to raise the awareness with mums that is absolutely what we're here for – to help them think about their emotional health and their relationship with their baby (ICom2)

I think we need to make it more aware that these centres are there.. um, and that if people want to use them --- that people will be there (IMH5)

In addition to raising awareness of services, professionals talked about encouraging openness to reduce stigma and increase disclosure.

I personally think what is good is, is getting the knowledge out there, and people not being scared to admit that there is a problem, I mean I think a bit of mental health is the taboo that you don't speak about it, but I think if we actually spoke about it, if we talked about it, if we actually.. you know.. addressed it, it would be much easier (IMat6)

it's trying to say to them, 'it's ok to say that you feel like that, because the sooner the better, that you can be helped and it can be dealt with' (ICom4)

7.6.3. Professional knowledge

In order to provide good services and share information between services, participants talked about the importance for women's mental health of professionals being knowledgeable about mental health and about local services.

7.6.3.1. Understanding of mental health

Although many professionals discussed the difficulties in accessing mental health services for pregnant women in need, all professional groups acknowledged the importance of being able to recognise and confidently address women's mental health needs, either through a direct response or through referral.

people with knowledge, people with understanding, people, uh, professionals basically --- either midwives or mental health nurses or whatever, but you need the diagnosis, you need the treatment, and then you need the people's support (IMat6)

I would like to see more of, is.. having um... sort of uh, greater awareness of mental health issues really across the board, so it's more, so instead of mental health being, like I say, this sort of place up the road --- that it becomes more embedded in what, in, in training of, of, of all sorts of professionals, so not just mental health professionals, but --- like midwives, and um, health visitors (IMH1)

Some professionals in mental health services talked about the value of maternity professionals being equipped to respond sensitively to women's distress, whereas participants in maternity roles emphasised the importance of referral to a responsive service. From both sides, there were clear concerns about demand and resources.

7.6.3.2. Knowledge of other services

Professionals in different services emphasised the importance of knowledge of where to seek additional involvement with needs that are more complex than the existing service can meet. Within mental health services, this may be an acute inpatient facility or out-of-area mother and baby unit, and within maternity and other primary care or community services, this was focused on specialist local services.

I think most of all we need to, we need to be, um, always up to speed with what agencies we have in the area, in the town --- we can do what we can do, but we need to know, of what we can't do, we need to know where we can signpost these people to go (ICom4)

they always say that they find [training] very beneficial, so that they know what to look for when they're um, assessing somebody --- and, you know, would this be, would this X, Y and Z problem be the right sort of thing to signpost to you (IMH5)

7.6.4. Community support by the community

Beyond directly providing services to pregnant women, participants recognised that existing community resources can be improved with professional support.

7.6.4.1. Peer support

Different kinds of peer support were identified by participants, including a buddy system for support by an identified individual, or informal groups.

at postnatal clinics, at health visitor clinics, in the school play ground, they'll probably see each other, you know, for their whole child's career, won't they --- so if you can form bonds now that they will go on, cause it's at least.. people often don't move anywhere else, they will be our grandparents in fifteen years time, you know if they've got those bonds with each other then -- - it's important (IMat8)

Some participants talked about the role that professionals can play to develop supportive peer relationships within social groups and enable women to recognise their common experiences.

I think when you do a group well, you can knock down those barriers, and it is about placing people, you know if I'm teaching a class, I move them around a lot so they're not sat next to the same people, so that, you know, there isn't this, you try and break down the hierarchy (IMat8)

7.6.4.2. Family support

Professionals talked about their roles in developing community support within families.

it's like a nested thing you know that [clears throat], that if we can support the, the families who can support the women who can support the babies and, and so on (IMH1)

For some professionals, this support was focused on the needs of the baby as primary, and the support for the family and subsequently for woman as a means to ensure future child health.

7.6.4.3. Partner support

Professionals talked about their role in encouraging women to expect support from their partners, and in providing advice to partners about supporting women's mental health.

I think for most women, they have a s.. a realisation that actually it doesn't have to be, or shouldn't be that way, um that they should expect and receive more help from their partners, both in physical practical terms, and emotional terms (ICom2)

I think it's a good idea for the pa.. for the um partners to be aware of --- of what to look for, cause it's not always the women that will --- admit to anything being wrong (GMat1b)

There was recognition that family, friends and partners have greater involvement in women's lives than professionals have, and are in an important position in providing ongoing support.

7.6.5. Summary

Many professionals discussed the importance of increasing capacity within services that would require additional resources, due to existing problems with accessibility and availability of specialist services to address women's mental health needs.

Additional improvements that participants described within existing primary care and maternity services would also require greater resources to enable time for communication between services, training and to build more emotionally supportive relationships with pregnant women with mental health needs. In the current climate of public sector cuts and increasing difficulties for women experiencing poverty, these wishes seem unrealistic. Professionals also talked about the importance of helping people within communities to develop resources to support each other, although participants talked about professional roles in supporting these developments, which places an additional demand on limited resources.

7.7. Professionals' Development and Support Needs

Many professional participants in this research talked about the emotional strain they experienced in providing services to distressed pregnant women under stressful working conditions where demand exceeded resources. Many professionals described the work as emotionally demanding in itself, due to the difficulties that women experienced in their everyday lives. They talked about their own needs in relation to emotional support and training, in addition to practical needs for enough

time to do a good enough job, and the ability to maintain appropriate boundaries within services.

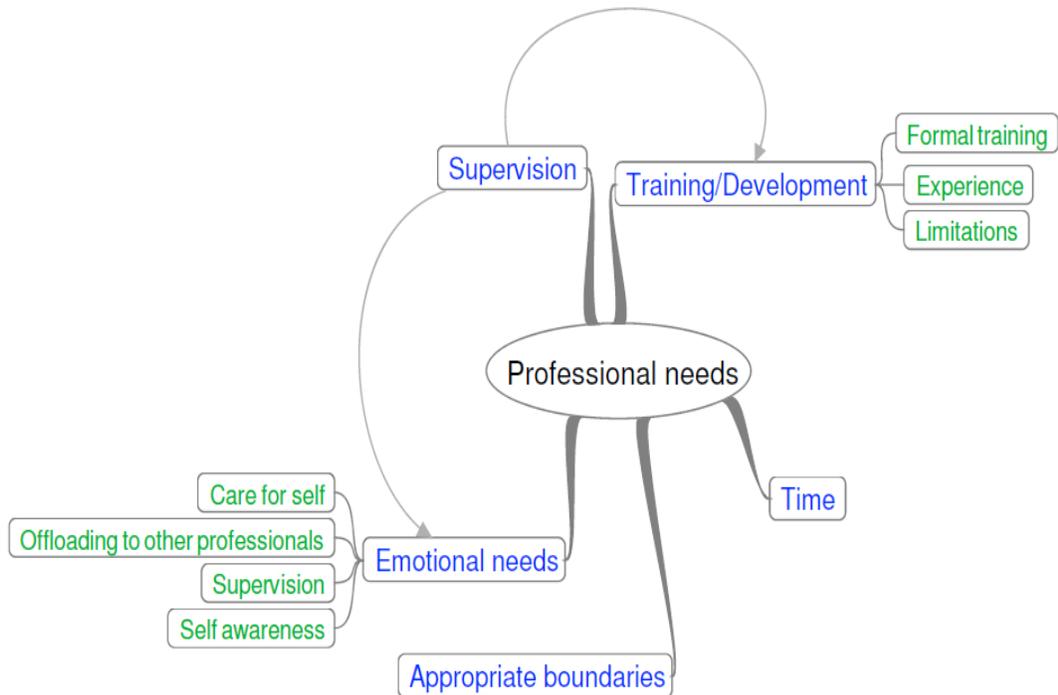


FIGURE 7.7 - PROFESSIONALS' DEVELOPMENT AND SUPPORT NEEDS

7.7.1. Training and professional development

Many participants acknowledged their own and fellow professional's training needs. Training needs were identified as relating to specialist knowledge and skills, in addition to the development of confidence through experience. Professionals talked about the limitations that they faced in accessing and undertaking training, specifically due to time pressures within their working lives.

7.7.1.1. Formal training

Participants recognised the need for opportunities to develop their knowledge of mental health and pregnancy. This was relevant for professionals in both specialist

mental health and maternity service roles. In general there was acknowledgement of the gap between the two fields of knowledge across different specialisms.

there's a gap in my own, I don't think I've ever had any.. formal training, you know, about pregnancy (GMH2d)

to be honest we don't have any real training, um, other than the kind of normal sort of listening, kind of, um, stuff that we do (ICom7)

I'm sure that um, some of the.. midwives and health visitors would know much more about kind of medical side of things and perhaps drugs for things, and, so on, but, but have a less broad..based.. training about, kind of, emotional development and wellbeing (IMH1)

Some mental health professionals discussed the value of mental health experience in pre-registration training for maternity professionals and general nurses, although it was frequently acknowledged by maternity professionals that this was limited and their knowledge about mental health was mainly developed after qualifying.

I think I probably did one day on postnatal depression, it's all, um, you know, once you become.. professional, you kind of follow it up yourself --- if you know that there are areas, well personally, I, if I know that there are areas in my practice that I need to improve, then I seek out the information through professional journals and clinical, clinical guidelines, and .. study days --- courses, that sort of thing (GMat1a)

Midwives described their pre-registration training as primarily focused on medical aspects of pregnancy and delivery, and development as a professional.

Several professionals described different types of knowledge gained by training that was experiential and had a greater impact on their understanding and their practices

than didactic sessions delivered by fellow professionals. Two participants described training they had received that involved service users in the delivery of sessions.

you know, it's only through list.. through listening to them, you, you, I think you learn more from .. um.. from people who have been through it, and come out the other end, than you do from professionals sometime (IMat6)

the mixture of emotion was mad, and then the, the sense of how let down they must be in our society, in this day and age, was, was just.. well, like I say, was absolutely mind-blowing (ICom4)

Other types of training that involved personal and reflective experiences within the training (the Solihull approach)² was described as having a significant impact both personally and professionally.

I think I did that at the time of my life when my little one was eighteen months, two, so it had a massive impact on me, and changed my practice, so I think the fact that we're all, all the health professionals are working with that training, now that's been a big thing (IMat8)

7.7.1.2. Experience

Several professionals talked about the value of personal and professional experience outside of formal training as important in developing their skills and knowledge.

I think now, sometimes intuition, is that you can look at somebody and think, 'I need to ask that question further, or I need to not talk for a while and let them..', you know, I think that experience has helped to deal with it, but we're not really trained --- we've not been trained for it (IMat8)

² The Solihull approach is a training process for professionals that is built on psychotherapeutic, child development and behavioural theory and employs experiential strategies for training sessions (Douglas & Brennan, 2004).

what we actually just get, I think get trained for in our midwifery, is the physical, don't you think [GMat1b]? --- you know, obstetric emergency, antenatal care, postnatal care, and breast-feeding --- the rest of it, we've all learned on the job (GMat1a)

Personal experience was identified as enriching understanding of both experiences of mental health problems and pregnancy and delivery. Some mental health professionals reflected on their firsthand experiences of their own or a partner's pregnancy and delivery, and community and maternity professionals reflected on how their understanding of mental health was informed by their own or relative's experiences.

7.7.1.3. Limitations

Although most participants talked about the importance of professional development and training opportunities, many described the difficulties they experienced in accessing training. For some professionals, this related to practical obstacles such as funding for training.

cause we're a charity, training like that comes up, again, we'd snatch it if it's free --- but if it comes up and it's not, then they won't let us all go (ICom4)

Participants talked about the pressures of managing caseloads and the difficulty of fitting training into their working weeks.

to do that study, I um, I'm expected to run my caseload, the same amount of people, and, but, with one day less a week really (ICom2)

you have to then juggle that with clinical commitments (GMat1a)

Caseload pressures and time were described as a difficulty for both those who said they needed training and mental health specialists who are able and willing to provide training

I have been asked to go onto the acute unit to do some training around antenatal and postnatal depression --- [sigh] I'm just so swamped... I, I need a ten day week --- you know to be able to, to do it (IMH5)

Midwives, health visitors and medical doctors working in maternity services described very limited amounts of annual mandatory training on mental health provided within their organisations. The time that professionals said was allocated for mandatory mental health training was between fifteen and thirty minutes per year.

I think [Colleague]'s just started putting, just being allowed to put mandatory mental health training in to midwives mandatory training --- [Colleague]'s just started doing that, but I think she has a fifteen minute slot, and it's very quick (IMat8)

Beyond the limited mandatory training, participants described other opportunities for training about mental health as being taken up only by those who had a personal interest in developing their skills and knowledge in this area.

some people will choose not to go to that, they'll get the flyers through, 'mental health, no bin that one', you know, whereas they'll take the ones that interest them (IMat6)

I have accessed some really good training --- because that's a personal interest and a personal motivation. I think there are lots of health visitors and midwives who, who don't have that same motivation (ICom2)

While some professionals talked about making time in their working week for additional training, some others described their time as too pressured to take on more than the core requirements of the job.

7.7.2. Time

Many professionals talked about work and caseload demands, with several professionals describing difficulties of feeling they were not able to do the work they aspired to within their jobs due to struggles to manage everyday workload pressures.

the more kind of problems you see and the more, you know --- the more you want to help, really --- and believe that you should help --- but that doesn't equate to having the time to do it in a, in your caseload (ICom2)

For some participants who provided a supportive role with other professionals, an important element of the role was to facilitate a thinking space, to enhance their ability to support the families with whom they work.

people need a place, a break, uh, a place where they can just think, and a place that, to reflect on what's going on, both with the people they're working with, but also with themselves (IMH1)

Without sufficient resources to manage everyday pressures, or time to reflect and develop skills to provide emotional support to pregnant women, some professionals acknowledged that these were obstacles to beginning conversations to explore emotional wellbeing and mental health needs.

I think probably midwives don't feel that they have time to listen to mums --- and so I think that that pressure equates to not asking for fear of the answer that you'll get (ICom2)

7.7.3. Appropriate boundaries

Several participants talked about the difficulty in accessing other, equally over-stretched services, and expectations by fellow professionals in those services that they would take on additional roles in supporting women's mental health. In

recognising the limitations on their abilities to manage demands, several professionals described the importance of maintaining boundaries within their roles.

*cannot be jack of all trades, because you end up not doing anything very well
(IMat8)*

For some professionals, this related to being asked to use their existing relationships and extending their role with groups that other services find hard to reach.

when you've got that constant pressure.. of other services saying, 'well, you know, can you do...', you know, it's really hard sometimes to always keep, you know, and I have got a lot better at that, you know, at saying, 'actually that's not my responsibility, and you need to be doing that' (ICom7)

Within this data, both views are represented. Professionals in specialist mental health and community services sought to support professionals in primary care services to provide greater support for women and prevent referral into over-stretched specialist services. However, participants working in midwifery and other primary care roles described their own struggles to manage workload pressures and expressed frustration with inaccessibility of specialist services for referral.

7.7.4. Emotional needs

In the light of the pressures described by professionals across a range of services, it is unsurprising that participants talked about feeling disheartened in working within limited services and described their own emotional needs to maintain their ability to provide services to women with emotional and mental health problems during pregnancy. Participants described a range of strategies for managing their own emotional needs, ranging from ways of caring for themselves, accessing formal and informal support from colleagues and developing personal self-awareness.

7.7.4.1. Care for self

Participants who talked about their own emotional struggles with their work had recognised their needs to manage the impact on themselves.

[name of place] is a good place to go --- and watching the sea --- I've done that before --- I'll go and watch the sea, if it really has got to me, and if I can, can't always, obviously, but if I can do, I'll go down and watch the sea (IMH5)

I do think that for self-preservation, to a certain extent, you do have to cut off from that (ICom2)

Both of these participants had found ways of disconnecting from the distress arising within their work, using strategies of dissociation from the emotion itself through 'cutting off' or by taking time away in a restful place. This strategy echoes some of the data from mothers who took part in this research. The need for time out in one way or another was seen as a necessity, but sometimes did not feel available within a pressured working day. One participant described an experience of vicarious traumatisation from information about abuse shared with her by a mother in a midwifery clinic. She described the emotional impact of the disclosure, and the effects she experienced of intrusive thoughts and difficulty with eating and sleeping.

we learned from that, in that --- on that day in question... we then decided that I should have cancelled the rest of my work for the afternoon --- and asked a colleague to do it, cause I wasn't really.. you know, professionally.. well enough, if you like, to work that afternoon (GMat1a)

The impact of working with women's distress was clearly profound for some professionals, several of whom were also struggling with pressures of everyday work demands.

7.7.4.2. 'Offloading' to other professionals

Participants found ways of managing the emotional strain of work through informal support with professional peers. Rather than a formal system within the workplace, this was described as using existing relationships within their networks to express their feelings rather than to discuss, explore or solve problems together.

you don't want an opinion, you don't want people to say what they think, you just need to be able to go 'wraaa' and just get it out, you know --- yeah, yeah, and leave it here, leave it here, not take it home, you know, we've got home lives, you know, out of work, believe it or not (ICom4)

a couple of them we'll see each other once, twice a month and have our own kind of like.. it's not so much supervision but it's just like, you know, 'uhh, this is really horrible, uuhhh' you know, [laugh] that kind of thing (ICom7)

There are some parallels with this use of professional contacts to feel heard and listened to, and the resource that is offered with 'listening sessions' for pregnant women within the services.

7.7.5. Supervision

On a more formal level, participants talked about the value of clinical supervision within their work roles. Participants described supervision as helping them to make sense of their own responses to events at work and develop their practice, such as helping to develop clearer boundaries in relationships with service users and other services.

by contacting my supervisor and going through the entire incident, and then I wrote it down as well, um, looked back on, because I know that in the moment, there are things that I could have done differently, and so looked back on that, so just to get some perspective on it (GMat1a)

Professionals talked about the importance of ongoing supervision to support development following training and to consolidate and apply learning to practice.

the training needs to be, um, uh supported by ongoing supervision, cause you can have lots of trainings that people go off on, on a training for this or a training for that, but unless somehow there's a way of keeping thinking about and reflecting on whatever the training is that you, that you've done and how it relates to actually, your day to day practice (IMH1)

Some participants talked about the importance of supervision, but expressed that they did not have access to frequent enough supervision, or the kind of supervision that they thought would be most helpful. This related to management supervision that was more directive, or peer supervision that was focused on practical solutions and less focused on opportunities for reflection and exploration.

I don't need support in knowing how to refer on, when to refer on, what to do, I'd like support in thinking about, you know, what's going on for that mum, how, you know, what is it generating in me, how do I feel about that situation, how is that impacting on the, you know, on what's going on between us in terms of, you know, the dynamic between the mum and I, and the mum and her family, so looking at that much more in depth (ICom2)

Psychologists and psychotherapists discussed their experiences of clinical supervision in relation to its role in improving the quality of their work and helping to make decisions about complexities that arise within therapy.

it's even more difficult when that, that dilemma about termination is brought into therapy and becomes the question that people want to talk about --- and that's where, kind of.. supervision seems to be.. uh, amazingly important (GMH2c)

For several therapists, a significant role for clinical supervision was focused on development of self awareness in relation to the impact of oneself on the work.

just trying to be aware, be aware of what's actually.. what's to do with you, I suppose, and like you say, supervision always is.. helpful for that 'what's to do with you, what's to do with the p.. the particular person there (GMH2b)

7.7.5.1. Self awareness

Participants in specialist mental health and community roles described the importance of self-awareness in managing their own and others' responses to the emotional demands of the work.

I didn't genuinely feel unhappy about work, but it's only through the, some counselling, and the ability to think a bit later on, that I thought well actually, that, I'm sure that that was what it was about (ICom2)
where there's um, mental health issues and depression and so on, can be so um, demanding, and exhausting for the, the health professional, so to have a, some understanding of one's own, how that can impact on us, as professionals (IMH1)

Self awareness was described as not only important for surviving at work, but also to improve the person's skills within their roles.

I find that with teaching that we do, it seems to offer.. a, a different perspective that, that can enable .. people, well it, well it works well, um..uh, I think a richer understanding of what's going on both in, in the people they're working with, and, but also in themselves, um... which crucially I think can offer you that place to sit outside it a bit and not be .. dragged .. --- in, and become part of whatever's.. going on (IMH1)

7.7.6. *Summary*

The idea of a ‘nested’ (IMH1, above, section 6.4.2) system for support locates the professionals as an outer layer, supporting communities and families to support women and in turn for women to support babies. However, when examining the data from professional participants in this research, professionals raised significant concerns about the stresses of delivering services to support pregnant women’s mental health in a context of high demand and insufficient resources. In order to deliver and maintain such a role, professionals need support for themselves and training to develop their knowledge and skills and to manage the distress that arises from their work.

CHAPTER EIGHT

DISCUSSION

8.1. Introduction

This research has focused on developing a comprehensive understanding of women's mental health during pregnancy in a context of high socio-economic deprivation. The priority for this research has been to inform service and community development to support women's mental health during pregnancy. This has been undertaken by examining data generated with women who have firsthand experiences of mental health problems during pregnancy, side by side with data from a range of professionals who work with this group of women. This set of data enables exploration of the relationship between perspectives of service users and professionals across a range of different mental health problems and professional contexts. The research has focused on one geographical area with a high level of socio-economic deprivation. The perspectives offered by professionals provide a broad oversight of their experiences of working with large numbers of pregnant women in this locality over many years, while data from mothers provide in depth elaboration and personal accounts of their own direct experiences.

In this discussion chapter, relationships between findings from the two sets of data will be explored in relation to existing research literature. Connections are drawn from findings from mothers' and professionals' data about what is needed to support women's mental health during pregnancy and what is needed by professionals to enable them to offer support. These findings can also be connected to both sets of

data in relation to the factors that were described as undermining women's mental health during pregnancy.

Participants' descriptions illuminate both the reliance on diagnostic frameworks for understanding mental health problems and the level of stigma present within language adopted by professional and lay communities. Although these descriptions reflect and produce internalised and pathologising ways of making sense of mental health, much of the data about factors that undermine women's mental health contradict these common linguistic resources. Both women and professionals gave comprehensive accounts of their understandings of these factors, which focused primarily on women's experiences, relationships and conditions of living.

Examination of data relating to women's experiences of services and professionals' experiences of work shows tension within and between accounts from the two groups, and illustrates the pressures existing within service relationships and the difficulties in building and maintaining trust.

There was significant agreement between mothers' and professionals accounts regarding the features of women's lives that undermine and promote mental health and the difficulties in accessing supportive services when needed. Although many participants described experiences of serious socio-economic deprivation, this was surprisingly a less prominent finding than women's early experience of problematic attachment relationships and traumatic events. These findings will be explored in detail below.

8.2. Relationship Between Mothers' and Professionals' Data

8.2.1. Descriptions of mental health problems

Data was sought from both groups regarding their descriptions/experiences and perceptions of women's mental health during pregnancy. The initial purpose of gathering this data was to provide a context for further data and analysis. The aim was to understand how women described their own mental health problems and to develop an understanding of the difficulties that a range of professionals encounter in their everyday experiences at work. This decision was based on early reviews of academic literature that suggested very little research was undertaken that did not use professional and academic *a priori* definitions of women's experiences of poor mental health during pregnancy. In keeping with the participatory intentions of this research, the broader and less specific/diagnostic term of 'mental health' was used to indicate the subject of the research, and participants were invited to provide their own understandings, definitions and meanings.

Although it was not expected that this sample would be representative of mental health problems in the general population, women described a wide range of problems. The professionals in the sample had a broader experience of work with women with mental health problems than a small sample of mothers could capture. However, like professionals' data, women's descriptions of their own difficulties ranged from relatively mild and common problems like anxiety and low mood, to problems that had a significant impact on their everyday lives. There were no women with primary psychotic diagnoses in the sample, however one woman talked about her previous experiences of delusions during a manic phase of bipolar disorder, and another woman described auditory and visual hallucinations induced by use of illicit drugs.

Within both sets of data, whilst not offering a generalisable and inclusive range of perspectives, this is a broad and wide-ranging sample that reflects the depth of difficulties that were experienced directly and indirectly by mothers and professionals in the local area. The data gives voice to the significant struggles encountered across a sample sought for maximum variation.

Data from mothers reflected much of the existing qualitative and quantitative literature in that there was widespread use of diagnostic terminology and descriptions of experience beyond diagnostic labels employed embodied expressions such as 'sinking' and the feeling of things 'coming down on top of' them.

In common with mothers' data, professionals described working with women with a range of mental health problems, from mild problems related to conditions of living, to problems that were more severe and enduring in nature. Professionals working within mental health services used predominantly diagnostic terminology that ranged from mild to moderate anxiety and depression to eating disorders, schizophrenia and bipolar disorders. Professionals who did not work in mental health services primarily talked about depression until asked further questions about other problems that they encountered.

Much of the professionals' data focused on issues related to depression and anxiety. This reflects findings in broader research literature that has identified these as common problems amongst pregnant women (for example, Evans *et al*, 2001; Flynn *et al*, 2006; Reid *et al*, 2009). Professionals talked about feeling they could understand mild to moderate anxiety and depression in relation to everyday stresses and difficulties in women's lives. Some professionals said that they could relate to these problems and that they might feel similarly in the woman's circumstances. Some professionals working in community and maternity service roles described a

different response to severe problems that they found frightening. They described feeling that they did not understand and were uncertain of how to manage more severe problems in community settings. This difference appears to reflect a perception of a qualitative difference between different types of mental health problems, with mild to moderate anxiety and depression seeming to be perceived as an extension of familiar and ordinary moods, and severe and enduring mental health problems existing outside of their everyday experience and understanding. This difference reflects the ‘otherness’ of more severe mental health problems, the lack of knowledge and understanding amongst community and maternity professionals, and the stigma associated with mental health problems. Within professionals’ data there were expressions of anxiety relating to women’s more severe mental health problems, particularly relating to professionals’ concerns about risk(s) arising from women’s distress and unresponsiveness of specialist services.

8.2.1.1. Terminology and stigma

Analysis of the data demonstrated that women’s and professionals’ descriptions of mental health problems predominantly relied on the use of psychiatric diagnoses and common expressions that are embedded in local cultural understandings of mental health. These descriptions both reflect diagnostic terminology and stigmatising ways of describing people with mental health problems. Terminology used by both professionals and mothers included derogatory expressions such as ‘doo-lally’ and ‘fruit-loop’. Both mothers and professionals used these terms as if quoting another third person (for example, ‘he might think I’m a total fruit loop’). Both sets of participants used this form of distancing this language from their own perspectives, but there was acknowledgement and reference to the stigma associated with mental health problems within the local culture. The diagnostic and other descriptions of

women's mental health problems reflect hegemonic ways of describing mental health that are embedded in bio-medical and diagnostic frameworks that illustrate a pathology-focused and stigmatising understanding of women's experiences of distress.

Two professionals expressed a preference for terminology of 'emotional wellbeing' above 'mental health', in part due to perceptions of stigma relating to 'mental health' as a term. Participants described the use of 'mental health' as denoting a problem, in the same way that they had experienced difficulties in using the term 'postnatal' to refer simply to the period after birth, due to the negative associations they encountered amongst service users and members of the public with the term. The use of terms that were not specifically related to a problem had become associated with problems through their use in everyday language. Thus the use of 'postnatal' had subsequently incorporated the meaning of 'postnatal depression', and 'mental health' or even 'mental' had become 'mental health problem'. No women expressed concerns about the use of the term 'mental health problem' to describe their experiences, but several used 'mental health' as an expression to describe a problem. Changes in the common use of language both reflect and produce associations with negatively appraised social roles, and can have a significant impact on opportunities and access to services (Corrigan, 2004). In a similar process, it can be seen that other stigmatised identities have undergone repeated changes in use of language in an attempt to evade these negative associations. If we take the example of the problem of poor cognitive function and related social impairment, the terms to refer to this condition have changed over a period of years from imbecility and idiocy to mental retardation and learning disability to the more recent use of the term intellectual disability (Reynolds, Zupanick, Dombeck, 2013). In this case, many previously non-

stigmatised descriptive terms have entered into common use as abusive and derogatory slurs. It can be seen that common use of terms related to mental health problems have become similarly stigmatised, and many people wish to avoid their use and seek a more palatable expression such as 'emotional wellbeing'. Although this positive intention exists, the change of terminology has not been successful in changing public perceptions of negatively appraised characteristics.

Examination of the data indicated some unease about 'personality disorder' as a term used by professionals to describe women's experiences of mental health problems, although this language is commonly used within academic and professional contexts (see, for example Conroy and Moran, 2006). Only one professional used this term on one occasion during interview, and used it with a degree of hesitation. Other professionals either did not discuss this category of diagnoses, or did so without using diagnostic terminology. For example, professionals described women as having been 'damaged' by their experiences in life, or having 'learned' behaviour on the basis of their experiences.

One woman described herself as having a diagnosis of borderline personality disorder. She presented a conflicted account of the diagnosis as both unwelcome and possibly genetic, although she also gave an account of her emotional distress as arising from a sense of low self-worth originating from childhood and adulthood experiences of violence and sexual abuse by her father and intimate partners. The account that she gave reflects the tension between her knowledge of the impact of her own experiences and the dominance of a bio-medical model to explain mental health problems. The other participants who used medical, hormonal and genetic explanations for their distress also gave accounts of emotionally painful experiences in their lives and difficulties within early relationships. Although the language of

description largely relied on diagnostic terminology, most participants did not use bio-medical frameworks to explain their mental health problems, and presented accounts predominantly focused on negative early childhood experiences, problems in adult relationships and social and material problems.

In much of the data, there is evidence of the stigma that has become associated with mental health problems and the terminology used to describe them. Although many participants talked about mental health problems arising from experiences that have caused understandable distress, much of the language used still betrays an internalised and pathologised identity. The stigma associated with mental health problems was linked to participants' fears of discrimination, loss of control of their lives, and reluctance to seek support. Professionals' data demonstrated concerns about management of mental health problems and anxieties about potential risks associated with women's distress.

8.3. What Undermines Women's Mental Health?

The analysis of themes within the data sought to engage with complexity and multiple perspectives rather than seek a single 'truth' regarding factors that undermine women's mental health during pregnancy. Although a single truth was not sought within this analysis, a broad consensus was found within the analysis of both sets of data primarily relating to the impact of trauma, relational experiences and social-material conditions of living in women's lives. These findings reflect earlier research that explored the impact on women's mental health of their life experiences including social disadvantage (Jasinski, 2004; Zelkowitz *et al*, 2008), lack of social support and distressing life events (Reid *et al*, 2009).

8.3.1. Life experiences and early relationships

The majority of mothers who took part in this research described distressing events in their early lives and relationships, including abuse, neglect and significant losses of close family members. These findings reflect recent research examining the impact of abuse on women's mental health during pregnancy. (Coles & Jones, 2009; Schwerdtfeger & Wampler, 2009). Many women described negative relationships with their own mothers. One woman who identified her mental health problem (bipolar affective disorder) as having primarily a biological origin also described conflict in her parents' relationship, her mother as also diagnosed with a serious mental health condition, and her father as an unhappy and uncommunicative man. Other participants described their mothers as experiencing mental health problems and the impact on their feelings of security as children. Professional participants reflected on routinely working with families that showed intergenerational patterns of poor emotional wellbeing and material hardship.

In cases where women identified significant adulthood losses in generating their distress, including losses of previous pregnancies and the death of close family members, these were combined with accounts of childhood experiences that may have affected their resilience to cope with later events. None of the mothers' data supports an understanding of poor mental health that relates solely to biology or adulthood circumstances and experiences, although it is acknowledged that this is data from a relatively limited sample that is not representative of the wider population located in an area with high levels of deprivation.

8.3.2. Socio-economic deprivation

Data from professionals and mothers both detailed conditions of serious socioeconomic deprivation within the area. Many women gave detailed accounts of

significant material hardship. Although the broad literature reviewed (Chapter 3) identified poverty and socioeconomic deprivation as factors associated with women's mental health problems, none of the qualitative studies included in the focused literature review examining published qualitative research (Chapter 4) explored the impact of material hardship on women's mental health in detail. Within this research, women clearly identified the impact of these experiences on their mental health, including stress and feelings of powerlessness to influence their circumstances. These data were produced prior to the recent cuts to welfare benefits, and it would not be surprising if recent developments were found to have exacerbated the distress experienced by already impoverished families in the local area.

Poor housing was frequently described as contributing to women's distress by professionals and individual women in the sample. Women and professionals both described mothers' difficulties in accessing adequate housing, and lack of control over their housing circumstances through eviction, problematic neighbours and neighbourhoods, controlling families and partners, overcrowding and unresponsive landlords. Participants described the erosion of women's mental health by the everyday lack of control and discomfort from poor conditions within their own homes.

8.3.3. Lack of control

Many women described features of their lives that did not support a sense of control, and for some women this was exacerbated by their experiences of emotional distress and inability to access appropriate care and support. Participants described feeling uncared-for and unprotected during their childhoods. Women's adult experiences in

their relationships with partners, communities and services mirrored their early experiences.

Some women reflected on their concerns about their ability to provide adequate care and protection for their babies and expressed anxieties about children being taken into local authority care if they disclosed concerns about their mental health. Beliefs about the likelihood of intrusive interventions were related by some women and professionals as a cause for reluctance to seek help. Thoughts about the possibility of both deprivation of liberty (under the Mental Health Act) and removal of children could exacerbate women's anxieties about further loss of control over important aspects of their lives, and result in reluctance to engage with services for potential support. In literature that acknowledges an imbalance of power between patients and professionals (for example, Stapleton *et al*, 2002) this anxiety about loss of freedom or loss of custody can feed into women's distress and more general feelings about lack of control over their everyday lives.

8.3.4. Lack of support and social isolation

Women's feelings of lack of support related to their descriptions of social isolation within their communities. Participants talked about having few opportunities to meet other pregnant women to share information and have time to talk together about their experiences. Some women described feeling that there was no space to talk about their emotions, and nobody available to offer support. Many women described feeling that maternity and primary care professionals did not have time for them over and above routine monitoring of their pregnancies.

Although much existing research identifies a range of factors that are considered to have a negative effect on pregnant women's mental health, it is important to bring these together and recognise the complexity of intersecting conditions that are

affecting women and professionals in the locality in which this research was undertaken.

8.3.5. *Multiple and combined factors*

Referring to reviewed literature in chapters 3 and 4, it can be seen that many of the factors identified within this research have been examined separately and in relation to specific mental health problems. However, in this thesis it is argued that a combination of factors embedded in a context of socio-economic deprivation has a significant negative impact on women's mental health during pregnancy. Poverty, and in particular the degree of relative poverty, is a powerful intergenerational form of adversity (Wilkinson & Pickett, 2010; Read & Bentall, 2012). The experience of poverty for multiple generations within one family can have ongoing negative impacts on family functioning and the lack of resources available to parents, particularly young parents, to protect their children from the detrimental effects. Families affected by poverty and other forms of socio-economic deprivation for many generations were described by professional participants within this research. However, although there are many women who experience socio-economic deprivation in the researched locality, not every woman in this area is likely to experience mental health problems.

Recent epidemiological research has begun to examine the connections between childhood adversity and a range of mental health problems. Rather than exploring connections between single types of adversity and single diagnostic outcomes, research has shown interactions between a number of mental health problems and different experiences of adversity, particularly relating to family functioning, neglect, abuse, parental criminal behaviour and parental substance misuse (Kessler *et al*, 2010). A further large scale study examined the impact of childhood maltreatment

(physical neglect, emotional neglect, physical abuse, emotional abuse and sexual abuse) on outcomes for latent underlying mental health problems rather than distinct psychiatric diagnoses (Keyes *et al* , 2012). This research showed that early experiences of maltreatment had significant effects on mental health, across a range of subsequent problems that were classified as either internalising (mood and anxiety) or externalising (substance misuse and behaviour) problems. These frameworks were used in examining outcomes rather than exploring specific diagnostic categories, and showed that these underlying factors and gendered differences accounted for all variation in the data. This recent epidemiological research informs the understanding of findings from the current research, which provides in-depth and detailed accounts of women's experiences.

Recent psychological developments have presented a challenge to psychiatric diagnosis in the form of an integrative psychological formulation of emotional distress (Dillon, Johnstone, & Longden, 2012). This approach draws on attachment theory and links with recent research into neuroscience and is presented by mental health service users and professionals in collaboration. Rather than employing a theoretical understanding of biology as the driver of mental health problems, such research has begun to examine the neurobiological effects of childhood experience and adverse, traumatic events such as sexual abuse, neglect and witnessing domestic violence (Gerhardt, 2006; Nemeroff, 2004). Dillon and colleagues argue that most mental health problems originate in adverse life events such as trauma or negative early relationships, thereby forming the vulnerability to adulthood stresses. This is therefore not a simplistic stress-vulnerability model that relies on an unexplained bio-medical root of a problem that is triggered by stressful life events, but offers an explanatory basis for these vulnerabilities in childhood experience.

The data from participants' accounts of stigma and the factors that undermine women's mental health supports Dillon and colleagues' (2012) model of integrative formulation as an alternative to diagnosis. As Dillon and colleagues argue, research is beginning to confirm service users' firsthand experience that 'bad things that happen to you can drive you mad' (Dillon *et al*, 2012, p145).

Whilst the complex interacting features of women's lives were acknowledged by professional participants in this research as undermining women's mental health during pregnancy, it was not always possible for services to meet the mental health needs of women presenting in primary care, community and maternity settings.

In addition to the 'bad things that happen', it is argued that stigma, internalising and pathologising ways of understanding mental health problems produces additional barriers to help and support beyond the limitations of services to deliver care for pregnant women with mental health problems.

8.4. Women's and Professionals' Experiences of Services

There were parallels within the data relating to women's experiences of services and the professionals' experiences of their work.

8.4.1. Time, relationships and trust

Women described dissatisfaction about poor communication, insensitivity, and the impression that professionals' priorities were focused on tasks and ticking boxes. In common with participants in recent research by Raymond (2009), Eriksson and colleagues (2006) and Nilsson and Lundgren (2007), many women in this sample described professionals as not noticeably caring and 'just doing a job'. Findings by Côté-Arsenault and Freije (2004) were reflected in experiences described by a woman who had experienced previous perinatal losses, who felt that her emotional

needs were not met by health professionals during other recent pregnancies, which resulted in a subsequent antenatal loss due to dismissal of her concerns about the risks to the pregnancy as an emotional reaction to the previous loss. Some women talked about feeling unimportant in relation to service responses, an expression that resonated with their descriptions of relationships in early life. If early life adversity has produced an underlying vulnerability to emotional distress in adulthood, it can be seen that this is mirrored in women's experiences of feeling uncared for during pregnancy, a time when many women may reflect on their experiences of being parented while becoming a parent and potentially feeling concern about their ability to care for their own children.

A small number of women described occasions of a professional going 'above and beyond', generally by working more than their paid hours or extending their activities beyond their primary roles. Professionals described pressures within their work roles, difficulty in managing large caseloads and the need to prioritise basic tasks to ensure that minimum standards are met. Some mothers said that they thought it would only take a couple of minutes to ask how woman is feeling, and described positive experiences of professionals who took the time to talk and listen to them. Some professionals described a fear of asking women about their emotions, comparing this to opening a 'can of worms' and having no time to respond and no confidence in other services to accept referrals when a problem has been identified. Women's experiences of professional responses to their emotional needs were confirmed by professionals' concerns about their own ability to provide an adequate response, and subsequent reluctance to ask open questions that might potentially increase their sense of being inadequate.

Women talked about the importance of trusting relationships with consistent and available professionals. Professionals spoke about their recognition of the importance of trusting relationships and their awareness that service demands can make this difficult to achieve. While some women talked about fear of sectioning under the Mental Health Act, and removal of children, professionals described their recognition of mistrust within the communities in the local area. Professionals identified the need to balance women's needs with their own responsibilities for safeguarding, and expressed concerns about their ability to trust women to be honest about their difficulties particularly where these difficulties might raise concerns about safeguarding or risk to their own safety.

Both mothers and professionals identified a tension between the needs of the mother and the needs of the baby. There were considerable differences across the professionals' data regarding the placement of priority in this relationship.

Professionals whose roles were primarily in parent-infant mental health or midwifery placed the emphasis on the baby. Whilst recognising the needs of the mother, the focus of their work was to help the mother to safely carry and deliver the baby, and to build the mother's ability to form a positive relationship with the baby once it is born. Much existing research focuses on the baby as a priority, and gives justification for undertaking research into women's mental health as promoting the well-being of future generations.

Within obstetrics and mental health services, there was a greater priority placed on the mothers' needs until the child is born, after which the child has legal rights as a person. Before that time, several professionals expressed views that the mother should be supported, even if this meant using medication that might be harmful to the foetus where treatment of the woman's mental health is the primary necessity.

Some professionals described reluctance of GPs to continue to prescribe medication for women's mental health problems due to uncertainty about the safety of psychiatric medications during pregnancy.

8.4.2. *Knowledge*

Women described a lack of confidence in some professionals' knowledge. This was described as 'book knowledge', with women expressing concerns about professionals lacking in personal experience of childbearing and suggesting that this undermined the credibility of their expertise. Some women described a preference for advice from people who have had direct experiences, including advice that was given through internet chat rooms. Professionals voiced concerns about women's use of unreliable sources of information from the internet. Although no professionals described their own lack of experience of childbearing, many did express awareness of the need for training specifically in relation to areas that were outside their main areas of expertise. Professionals who did not have a specialist role in women's mental health during pregnancy acknowledged that wider knowledge and skills in this area would improve the services they could offer to women. Two non-mental health professionals specifically identified the value of training that was delivered by mental health service users and employed narrative accounts or experiential workshops that enabled the professionals to gain a greater understanding and empathy with people who experienced mental health problems. Recent developments in some mental health services in the UK have focused on developing training that involves mental health service users in delivering training emphasising lived experience (Perkins, Repper, Rinaldi & Brown, 2013). Although some professional participants expressed highly valuing these opportunities, they also connected training issues to service-related pressures concerning the availability of

time for training within their routine work. Some professionals expressed recognition that women's peers are often in better position than professionals to offer informal support beyond the limited professional time that is available.

Overall, mothers' and professionals' data frequently reflected varying perspectives on the same underlying issue of resource-related pressures. This issue related to both mothers feeling uncared-for and professionals feeling under pressure and unable to provide good enough care. It related to mothers' lack of confidence in professionals' knowledge and to professionals' feeling a lack of confidence in their own knowledge and concerns about the ability to find resources and time for training. Reflected as though through a prism of the two sources of data, the core issue behind these concerns relates fundamentally to poor resources within the community and within the services that can be offered. Mothers and professionals both encounter experiences of not receiving and not being able to offer something that feels 'good enough'. For mothers with poor mental health, this experience frequently resonated with relationships in their own early lives.

8.5. What do Women Say they Want to Help Support their Mental Health?

When asked what they thought was needed to support women's mental health during pregnancy, many participants described what they wished for from relationships with professionals and with peers. Women talked about the importance of a relationship with a caring, trusted, knowledgeable, available and reliable professional and opportunities for time to talk with other women about their experiences.

The underlying issues that women described as undermining their mental health during pregnancy related to feelings of powerlessness and desire for security and care that they described as lacking in their early lives and in many areas of their adulthood experiences. These issues can be seen as connected to what they felt they

would need to improve their mental health. Participants described few accessible resources that they felt promoted their mental health. Some women talked about supportive relationships, but these appeared less frequently in the data than descriptions of isolation, lack of support, and harmful relationships. A small number of women described internal resources, such as confidence from previous experience of pregnancy and parenting, and positive thoughts that were primarily about the baby they were carrying. In this research, as in previous research, the relationship with the baby was both a source connection and closeness (Sanders, 2008) and a source of anxiety about the woman's ability to provide good enough parenting for the child (Bennett *et al*, 2007; Tseng *et al*, 2008).

Women talked about their wishes for positive relationships with professionals who could offer consistency, reliability and genuine care. Some women described concerns about critical judgement from professionals. This may reflect perceived or actual reciprocal attitudes of mistrust and judgement between women and professionals. Some women related their wishes for non-judgemental professionals to their experiences of feeling judged. At the same time, some women raised dissatisfactions and lack of confidence in professionals' knowledge, commitment and communication skills. Women frequently talked about valuing knowledge based on experience rather than 'book knowledge', and described wishes for more contact with supportive peers.

Although participants talked about material hardship as a factor that undermined women's emotional wellbeing, no mothers or professionals focused on availability of material resources as possible solutions to women's mental health problems. In a locality with a long and deeply embedded history of socio-economic deprivation, and in times of increasing austerity, it is not surprising that this was not talked about as a

potential or realistic solution to the problems experienced by the women in this population. One professional talked about advocating for mothers with local authorities in relation to housing, but this was the extent of professionals' expressions of agency in relation to women's material hardship. Although there are many agencies that continue to argue for changes to the current approach to management of the economy in relation to the impact of austerity on women and families (for example, Family Action, 2012), this activity may not seem to be within the reach of professionals who are struggling to manage their front-line responsibilities to women on a day to day basis. In much of the professionals' data, there was also a lack of expressions of feelings of power and control over their working conditions and influence on the wider availability of resources and services in their communities. Recent research by Action for Children (Burgess, Daniel, Scott, Mulley, & Dobbin, 2012) identified similar experiences of powerlessness to intervene amongst professional research participants (police officers, primary school teachers, social workers and health professionals) in cases of suspected child neglect. Professionals identified the causes of increases in child neglect cases as general deterioration in parenting skills, local poverty and inter-generational problems. Many professionals identified barriers to intervening relating to the failure of other professionals to carry out their responsibilities in addition to reluctance by families to engage with services. Of relevance to this research, Burgess and colleagues identify limited resources and further cuts to public services as a significant concern in professionals' ability to intervene in cases of child neglect.

In examining the professionals' data, there is evidence that professionals were aware of the importance of care, trust, knowledge, availability and reliability in delivering positive services for women. However, much of the professionals' data also reflects

the everyday struggles that they experienced in delivering their services while under high levels of pressure and demand.

The picture developed by this data reflects a broadly impoverished and disempowered context in which there are few resources and few people with a sense of agency in relation to influence on the resources that exist. Although this research is based on relatively small numbers, the aim of sampling was to include as wide a range of relevant professionals as possible, and included well-informed professionals with knowledge of the local context and the challenges faced in providing services to pregnant women with mental health problems.

8.6. Services

8.6.1. Mental health services

Where women had direct experience of mental health services, their accounts presented a positive perspective. These positive accounts were in contrast with many professionals working in primary care settings and midwifery who expressed frustration with access to mental health services. As evidenced in this study, there are high levels of demand for time-intensive therapies, and insufficient resources to provide therapies for all who express a need.

Within mental health services, professionals gave contradictory accounts of service pressures and responsiveness. One mental health professional reported that she thought there were sufficient resources to meet demand within her team, whereas other mental health professionals from other teams discussed their awareness of pressures on the services in which they worked and in their knowledge of wider mental health provision in the locality. On the basis of the existing data it has not been possible to account for this contradiction in different professionals' accounts,

and this may raise questions for further research regarding perceptions of services by professionals within different roles and different teams.

Three mothers described experiences of psychological therapies. One had been seen by a clinical psychologist for cognitive analytic therapy, one was seen by a psychotherapist for cognitive behaviour therapy, and one attended group therapy that was delivered by a clinical psychologist. The participants who had accessed psychological therapies described feeling heard and being offered time to talk and reflect on their experiences. This was also the case for one woman who had built up a trusting relationship with a psychiatrist who offered support in managing her mental health problems through medication and advice. The three participants who had received one-to-one contacts within mental health services talked about their ability to develop a better understanding of their difficulties and how to manage them.

Participants described developing different ways of understanding and managing their mental health in ways that were consistent with the therapy models used by the professionals. Where this role was provided by a psychiatrist, the woman described her problems and management within a bio-medical model, with priority focused on genes, medication and social support strategies for management during the time when it was not advisable to continue with medication due to risks to her pregnancy. The woman who took part in the group therapy described building relationships with other women from the group, and being able to take on a valued role in offering support to a fellow member of the group after the sessions had ended. This participant had also subsequently set up a craft-based group with the support of her local children's centre and described feeling positive about working with her peers in building social support. None of the women described their mental health problems

as fully resolved, but each described developing resources for managing their distress in future.

Although the debate regarding efficacy of different types of therapy and the importance of non-specific factors such as the therapeutic alliance is not the focus of this research, it is relevant to consider the impact of different types of therapy on outcomes. Although it is not possible to generalise from this very small sample, the data suggests further questions about the links between the different approaches offered and the outcomes for women who used these services. Across the four different approaches used by mental health professionals, only the group therapy was followed by the woman building a peer support network and offering support to others within her community. This may be related to her professional background in addition to her experience of group therapy. She was one of two participants who had a professional training and had been employed in this role. The other participant who was in a similar situation was the woman who had used Cognitive Behaviour Therapy within mental health services. The approach that she described finding helpful was primarily focused on developing an individual model of her mental health problem and developing resources for managing it on her own. She did not describe developing any further social or networking resources for ongoing peer support. There are other potentially relevant differences between these two participants, and clearly this data does not give us sufficient detail to make causal connections between outcomes for these two women, but does provide information to generate further questions about the potential benefits for individuals and the wider community.

8.6.2. *Services and networks for antenatal mental health care*

The lack of confidence held by professionals and service users in maternity professionals' knowledge about mental health problems experienced by pregnant women reflects the findings of research by Rothera and Oates (2011).

Recommendations from the CMACE (2011) report are supported by the evidence from this research. Significant concerns arise in relation to the lack of progress with service improvements with particular reference to the importance of good referral pathways and rapid responses from specialist services, good communication between professionals, connected interdisciplinary care for women's mental health and obstetric needs, and regular, routine training for all clinical staff in the identification, initial management and up to date referral pathways for mental health problems. The CMACE report also highlights the importance of professional relationships with women during pregnancy.

The presence of significant adverse socio-economic conditions in the locality both underlines the importance of developments such as these, and illuminates some of the challenges for making progress. The lack of progress in developing integrated perinatal mental health services or midwives' confidence in primary care and mental health services from the 1990s through the 2000s (Stanley *et al*, 2006) has not been seen in this research as significantly improved, in spite of guidance from the National Institute for Health and Clinical Excellence (2007) in relation to the importance of clear referral pathways, supervision and training for relevant professionals and managed clinical networks. Although there is an existing perinatal mental health service in the locality, at the time of data generation, primary care and midwifery professionals expressed frustration with waiting times for counselling in the perinatal mental health service, inadequate responses from mainstream mental

health services and ongoing problems in communication between maternity and mental health services.

Although the CMACE (2011) report specifically addressed maternal suicide & accidental deaths connected to mental health problems, the findings and recommendations remain relevant to the broader issue of women's mental health during pregnancy. Although the most severe short-term outcome is maternal death, there are long-term effects on women and their families of the negative effects of mental health problems as identified within this study. In addition to disclosing previous suicide attempts and thoughts about suicide, when interviewed participants in this study described histories of self harm as a means of coping with their emotional distress. Women talked about ways of coping, or not coping with negative emotions that were harmful to themselves or their relationships. Several women described fears of the power of authorities, which had a negative effect on their preparedness to seek help from services. Women spoke of a lack of confidence in themselves as mothers-to-be, reflecting the external stigma and judgement about poor mental health that they encountered in their early relationships and current social worlds.

A recent review and synthesis of research focused on women's experiences of prenatal care showed that women wanted reasonable length waits for services, unhurried visits, continuity, flexibility, comprehensive care, meeting with other pregnant women in groups, development of meaningful relationships with professionals, and opportunities to become more active participants in their care (Novick, 2009). The review was not specifically related to women's mental health, but demonstrated common dissatisfactions with maternity services and wishes for improvements across a range of English speaking countries. These and other similar

findings (for example: Wheatley, Kelley, Peacock & Delgado, 2008; Luyben & Fleming 2005) can be seen to illustrate common expressions of care needs by women during pregnancy, which may be amplified by experiences of emotional distress during pregnancy. The review made recommendations related to the reported findings, but did not include information from professionals about the feasibility of these aspects of care. The current research has illustrated some of the difficulties that are likely to be encountered in aiming to implement similar improvements in the context of NHS provision within areas with high levels of demand and socio-economic deprivation.

8.6.1. Professional experiences

Many of the professional participants in this research described difficulties they experienced within their roles, including service related pressures and the emotional demands of working with distressed women.

Research examining reasons given by midwives in the UK for leaving the profession identified dissatisfaction with role & constraints within the work place. Midwives described dissatisfaction about standards of care and their ability to provide a positive relationship with patients, which would be based on mutual trust. Midwives talked about organisational issues, including staffing levels and management support as significant barriers to satisfaction within their work (Curtis, 2006).

Other research has explored features of nursing experience leading to burnout. These factors included client characteristics, difficulties with the nature of the work, demand-related pressures and inadequate resources (Taylor & Barling, 2004). Across many service contexts, there is widespread recognition of the strain experienced by professionals working in maternity and nursing roles (for example: McGrath, 1989; Sandall, 1997; Garrett, 2011). Although professional participants in the current

research recognised the need for ongoing training and development, they described considerable difficulties in balancing the demands of patient and task-focused roles with opportunities for professional development.

Participants within the current study described some resources for managing the impact of emotional demands of work. Many of these resources were discussed alongside awareness that access to them was limited. Professionals within psychotherapy and mental health roles described having access to appropriate and supportive supervision, but some community-based professionals described limited access to supervision, or access to supervision that was not what they felt they needed. Some professionals described struggling with the emotional demands of work, without mentioning supervision or particular strategies they could use to care for themselves in relation to this strain. Using reflective approaches to supervision have been shown to support professionals' resilience in working with complex interpersonal dynamics of parent-infant mental health services (O'Rourke, 2011).

Research into professional needs for self care outlines the effects on professionals of emotionally demanding work and the need for proactive/preventative self-care training (Shapiro, Brown & Biegel, 2007). Organisational changes have been argued to provide resources within midwifery teams by overcoming some of the problems leading to burnout amongst midwives, including fostering occupational autonomy, providing social support within groups of colleagues, and enabling the development of meaningful relationships with women. However, for organisational changes to be effective in reducing burnout and high levels of practitioner stress, it is important for caseloads to be manageable and for adequate cover to be provided to enable time for leave (Sandall, 1997). This issue of pressure and demand was one of the significant concerns raised by participants in this research.

As one of the professional participants in this research explained, the professionals within the locality need support to enable them to offer sustainable support to families, pregnant women and their babies. This notion of ‘nesting’ relates to the wider set of resources available to offer support, each level resting within a larger part of the system (for example: Orford, 1992).

The recent Francis Report into failures in an NHS hospital trust has highlighted the role of organisational culture, poor governance and problems with staffing levels, leadership and training resulting in ‘declining professionalism and a tolerance of poor standards’, reducing staff morale and generating risks to patient care (Mid Staffordshire NHS Foundation Trust, 2013, p. 45). The Francis report also identified inadequate structures for patient and public involvement as a contributory factor in the failures of front line services. The Francis report recommends building a ‘culture of compassion and caring in nurse recruitment, training and education’ (p. 76). In the light of this issue of a compassionate culture in health services, it has been argued that a fundamental shift in culture toward health service staff’s ability to care for themselves and each other in order to promote a culture of care for patients and prevent the collusion with poor practices arising from professionals’ unmet needs (Gallagher 2013).

The data from professionals within this research points to unmet needs within professionals at risk from burnout arising from the emotional demands of their work. Within this data, there is evidence that existing services need improvement in opportunities for professional support, in line with recommendations from the Francis report and further contributions relating to care of professionals to facilitate compassionate and sustainable working practices.

8.7. Peer Support

Given that the data in this study show women's desire for opportunities for peer support, the potential for group interventions to enable women to subsequently offer support to one another might both improve mothers' experiences of mental health and reduce the demand on professionals to support women.

Early community psychology work by Sue Holland (1988) involved working in a deprived community to develop from individual therapy with clinicians into groups where problems began to be conceptualised within social frameworks, and subsequently groups moved into collective social action to address underlying problems within the community.

Using Holland's model and findings from earlier research (Franks, Henwood & Bowden, 2007), I have worked with mothers of young children to set up a mutual support group in a similar, disadvantaged neighbourhood. The experience of this, earlier project enabled me to promote the skills and resources held within a community of women that could be brought together and facilitated to use research findings to develop a project that was meaningful to them. This group prioritised findings relating to women's struggles with identity when becoming new mothers with young children in a place in which idealised notions of motherhood were difficult to meet in deprived material and social conditions. The group of women developed a project to provide opportunities to explore neighbourhood connections and positive identities as a counterbalance to their experiences of a failing identity in living up to idealised standards of womanhood and motherhood.

Experience on this local, small-scale reflects developing work in different areas within wider developments in building social capital and mutual aid resources in the context of the mental health service user movement. (Munn-Giddings and Borkman,

2005). The development of mutual-aid based in reciprocal relationships and sharing of experiential knowledge resonates strongly with the wishes expressed by participants in this research. Munn Giddings and Borkman have identified the importance of using narrative storytelling for the development of knowledge within mutual-aid groups and the potential for regaining control that resonates with the findings of the current research relating to the distress arising from limited control in day-to-day life. Narrative storytelling has recently been taken up as part of a new approach to developing peer support and education across mental health services in the UK (Slade, 2012).

Other recent work has been undertaken in providing training for service users to develop skills to support constructive and close confiding relationships within supportive peer groups (Forsythe, 2011). Forsythe argues, on the basis of her small scale study, that peer support groups may be at least as effective as current NHS provision of brief Cognitive Behavioural Therapies through the Improving Access to Psychological Therapy programme, although the existing access is not as widely available as needed in this researched community. Such research connects to the current analysis of both professionals' and women's data identifying isolation and lack of support as significant in undermining pregnant women's mental health, women's wishes for opportunities for peer support groups, and professionals' acknowledgement of the limited availability of time, confident professionals, support and therapies for women with mental health problems during pregnancy.

Experiences of peer support by women with mental health problems during pregnancy has not been widely researched, although a recent meta-ethnography has identified important themes arising from a small collection of qualitative studies exploring peer support in the perinatal period (Jones, Jomeen & Hayter, 2013). Many

of these and quantitative studies have focused on peer support during the postnatal period and transition to parenthood, without examining the effects and subjective experiences of peer support during pregnancy. Some findings of the review by Jones and colleagues were relevant to the current study, including the importance of isolation; the benefit of validation by sharing common experiences amongst peers and the exacerbating experience of peer support with mothers who appeared not to be having similar difficulties. Such experience was argued to confirm women's appraisal of themselves as abnormal or failing as mothers, leading to further withdrawal and compounding their experience of isolation. In the case of first-time mothers and women with pre-existing mental health problems beyond postnatal depression, the current research suggests that further exploration of the experience of peer support during pregnancy is warranted.

8.8. The Importance of Place: Material and Economic Deprivation - Complex Challenges for Women and Professionals

The social and relational problems that were reported exist in a wider context of material deprivation. These conditions have an impact on pregnant women directly, through individual experiences of hardship and intergenerational patterns and on professionals' ability to provide support when faced with demand that exceeds their resources. The data analysed in this research reflects the documented high levels of deprivation and need in the researched community. Professionals described a high volume of demand for services and high levels of individual need. The pressure on resources as experienced by professionals, long waiting times and lack of services compounds the distress of individual women and limits professionals' abilities to respond. Considering the local situation at the community and systemic levels, rather than focusing on women's individual pathology or professionals' individual

inadequacies, the data and analysis suggest that poverty and associated social conditions and service resources both produce problems and prevent opportunities for professionals to offer effective help.

The use of an individualising and pathologising model of mental health potentially increases stigma, with the identification of a problem as internal and focused on deficit within a person. Women's mental health problems can place them in a disempowered position in relation to hierarchies of power embedded within services and family structure. Stigma associated with mental health problems is often considered to undermine an individual's credibility (Rose, 2009), and was described by research participants as presenting a risk to their trustworthiness as a parent.

Within women's data, an obstacle to help seeking and disclosure of distress related to a fear of powerful others, particularly professionals who could use statutory powers to detain women under the Mental Health Act or instigate child protection proceedings. Women who reflected on themselves in relation to mental health and relationships expressed internalised blame, and a sense of self as pathological. For some women this potentially increases shame and reluctance to openly discuss their distress and seek help, supporting previous findings by Corrigan (2004).

An alternative approach focuses at the level of the system and community, rather than diagnosing and treating problems as pathologies that exist within individuals. These aspects are explored further in the following section.

8.8.1. Systems

A systemic perspective focuses on the intersecting and contextualised influences on the person within an ecological framework (Kagan Burton, Duckett, Lawthom & Siddiquee, 2011). It enables us to consider the parts acting on each other in an interconnected whole. This approach allows us to take a perspective on the

individual women, families and professionals in interaction with the local environment of socio-economic deprivation.

A significant part of this process involves the recognition of relational and reciprocal influences within families and communities. The pregnant woman can be seen as sitting in the centre of concentric circles of support and influence.

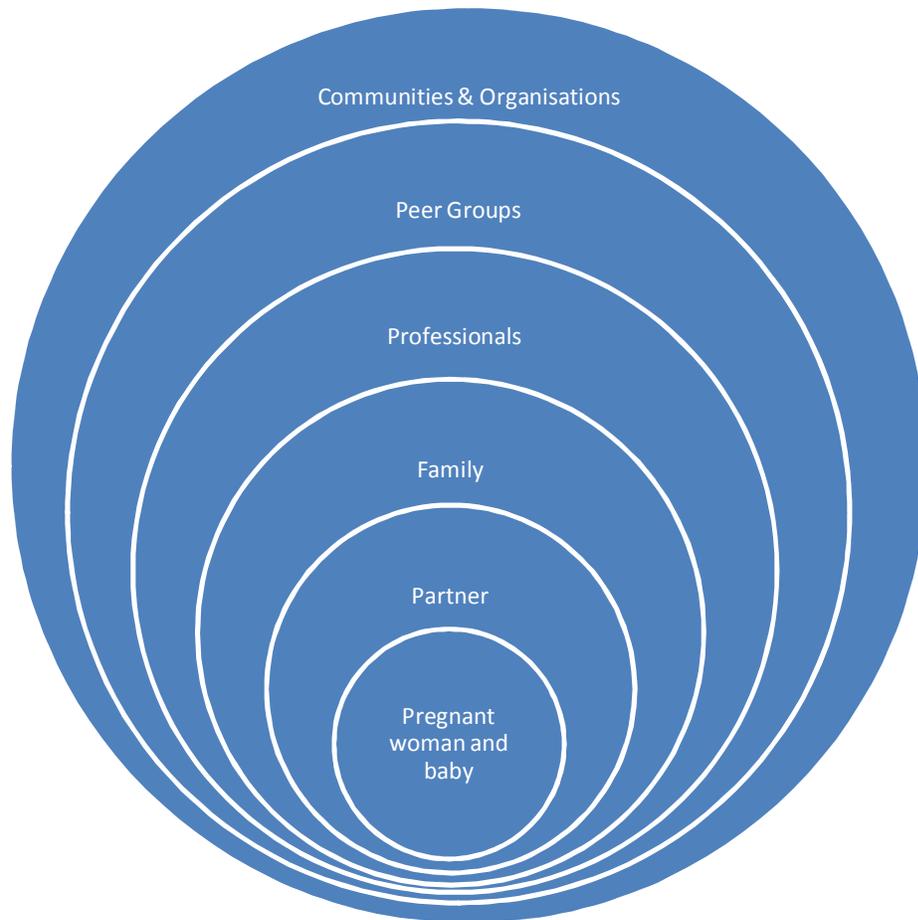


FIGURE 8.1 - AN ECOLOGICAL REPRESENTATION OF PROXIMAL SPHERES OF INFLUENCE IN THE LIVES OF PREGNANT WOMEN

Although pregnant women's babies are not yet born, many women talked about a developing relationship with the baby she was carrying. In this data, most of the women talked about their wishes to protect the baby. In some cases this related to the wish not to allow the baby to be harmed by medication, by violent partners or by

themselves. Women expressed having had concerns during pregnancy in their ability to break previous familial patterns of violence or neglect.

Several women described close and supportive relationships with intimate partners, although for some women, their partners seemed unable to help with their mental health, or were frightened by events like panic attacks. Some women described partners as too busy with work to offer support, or seeming to be unconcerned with the impact of women's distress. For other women, partners were abusive, controlling or violent and contributed to women's distress. Partners of research participants each exist within a system that includes their own mental health and influences from economic circumstances, familial background and current networks. These influences may be positive or negative for the partners, potentially also having a positive and supporting or negative and undermining impact for the mother. We can see intersecting influences from both women's broader lives and those of their partners.

Many women also described difficult or estranged relationships with parents, both in the present and during childhood. Some women talked about parents as controlling in adulthood and specifically in relation to the pregnancy. Early life experiences of trauma and neglect were identified as significant undermining factors for women's mental health. Including data from professionals, we can see that some currently pregnant women's own mothers had been previously known to services, and some women were taken into local authority care when they were children. A few participants described childhood abuse within their immediate and extended families. The extensive involvement of some women's family members, including fathers, uncles and cousins raises issues of intergenerational patterns of abuse within family cultures, further broadening out the systems of influence on women's mental health.

At one level removed from women's immediate networks are the professionals who work with women during their pregnancies. Like women's partners and families, professionals come to their work with a family background and a set of social and material circumstances. Although professionals and service users are often considered as separate groups, with professionals seen as detached and unemotional helpers, it is important to recognise that the emotional work of helping exists in a reciprocal relationship between people, embedded within a wider context (Hunter, 2001; Rayner, 2010). A few of the professionals within this sample described their own experiences of poor mental health, and many described ongoing organisational pressures and limited resources for self-care. These features all had an impact, positive and negative, on professionals' abilities to offer supportive services for pregnant women.

Many participants described the absence of supportive peer networks as a feature of their experience that undermined their mental health during pregnancy. There was a small number of women who talked about peer support as promoting their mental health, and a large proportion who expressed wishes for support from other women who share common experiences of mental health problems and pregnancy.

In the wider context, communities and organisations have an impact on the individuals and smaller sub-systems (such as families, professional relationships, teams and networks). Interacting parts of these systems can be seen in the current research, in which there are reciprocal problems with trust between professionals and mothers. These tensions arise from commonly held community-level representations of the power of authorities to impinge on individual freedoms, and the pressures acting on professionals to ensure safeguarding procedures are followed. Stigma about mental health problems within the wider community may also impact upon the

ways in which professionals perceive risks to children and mothers perceive the likelihood of authorities acting within legislative frameworks such as the Mental Health Act and the Children Act to curtail their freedoms.

Taking a broader systemic perspective enables the relocation of mental health problems within the structures that connect people. If the level of analysis shifts from the individual to the system, this produces alternative solutions at the level of the system, rather than with a pathologised individual. These possibilities will be considered further in Chapter 9.

8.9. Methodological Rigour

This research was undertaken with broadly stated aims at the outset, relating to standards of quality (see chapter 5).

Different approaches to considering quality issues included frameworks from qualitative research (for example: Yardley, 2000), Action Research (for example: Reason & Bradbury, 2001), and anti-oppressive, post-colonial research (for example: Strega, 2005). Areas of commonality across these approaches and others (such as CASP, 2008; Toye *et al*, 2013) included the usefulness of the research outcomes, comprehensiveness within the research data and analysis, transparency in the method, researcher reflexivity and reciprocity in relationships with the researched community. These issues will be examined below and present the relative strengths and limitations of this project.

8.9.1. Usefulness of the research outcomes

This research was designed with co-researchers and informed by consultation with professionals and managers within relevant services. The aims were to inform service and community developments within the locality to promote women's

mental health during pregnancy. These findings present a range of possible developments that are based on the evidence of women's and professionals' data. Recommendations arising from the findings will be outlined in the final chapter. Although my original intention for this study was to undertake a full cycle of an action research process with application and evaluation of developments arising from the research, the timescale for conducting this as a participatory process within an academic and public health context was unrealistic. As I will outline below, there were unexpected and time consuming obstacles to undertaking this research using a participatory approach. The obstacles to undertaking participatory research in regulated health-care environments constitute one of the useful findings from this research.

8.9.2. Comprehensiveness

There are a number of points arising from this research in relation to quality criteria of comprehensiveness. The main focus of the issue of comprehensiveness relates to the data and analysis.

8.9.2.1. Data

8.9.2.1.1. Sampling

One of the aims of the sampling and recruitment strategy was to generate as comprehensive a set of data as possible. This approach involved the co-researchers at a number of levels. Initially this pertained to the design and decision making process regarding who to approach as potential participants. Decisions were made by the team about the inclusion of patients and professionals from the NHS in addition to a wider community sample. Although this required a time-consuming submission for

NHS ethical review, it increased the range of participants who could be approached, and the avenues through which this was possible. Co-researchers had knowledge of about community resources that I did not have, and could make suggestions about places to go to seek out potential participants. As outlined in the Methodology (Chapter 5), professional and public participants were included from across a wide range of life experiences.

8.9.2.1.2. *Limitations in the comprehensiveness of the sample*

Although this research was conducted in a locality with a predominantly White British population, the sample also reflects a lack of ethnic diversity. There are small numbers of non-White British mothers living in the local area, and the sample within this research only includes two women from other nationalities. One of these was White-Canadian, and one White-South African. Although there are other local ethnic communities, it had not been possible to recruit from established communities of migrant workers or travellers. Information about the communities was provided from one of the professional participants who had a specialist role within these communities. This professional participant identified that it would be difficult to establish trust with either of these communities in relation to a research project focused on a highly stigmatised issue such as mental health. The research timescale did not allow for a focused period of involvement required to attempt to build trust with these specific communities. At the outset of the research, there was also an intention to include fathers, which was not possible within timescale of PhD. Only some professional groups were represented in the professionals' sample, there were no GPs and no social workers in the sample. However, many of the groups of professionals who work with pregnant women in the local area were represented.

8.9.2.2. Data quality

In addition to influencing sampling and recruitment decisions, co-researchers were important in generating a depth of data quality beyond what would have been possible if all data generation was conducted from the perspective and experience of a single academic and professional. For both sets of participants (mothers and professionals), the presence of co-researchers with lived experience of mental health problems during pregnancy enriched the data. In interviews with mothers, the co-researchers were able to develop a rapport based on common experiences that would not have been possible with an academic/clinical researcher who had not shared these experiences. In some interviews and discussions it was clear that conversations were constructed on the basis of those common experiences. In other interviews with mothers, co-researchers were able to ask questions out of curiosity about women's experiences of mental health problems that seemed familiar to me through my clinical work. I had a different perspective on the issues that was not always apparent to me at the time, and may have led me to assume that I understood an issue that was elaborated further due to the curiosity and questions from co-researchers. In interviews with professionals, co-researchers were able to ask questions that would have been difficult for me to ask due to prior relationships and my own knowledge and perspective.

8.9.2.3. Comparisons

The issue of comprehensiveness also relates to the ability to explore similarities and differences between professionals' and women's data. In this sense, the data reflects a metaphorical conversation between the data generated with mothers and with professionals. The mothers' data have presented a series of challenges to professionals, and the professionals' data have presented a response to these

challenges by illuminating their own challenges and difficulties within their work. This 'dialogue' between the two sets of data has enabled the development of a richer understanding of the tensions and complexities within the patient-professional relationship that could not be seen in data generated from only one side.

8.9.3. Data analysis

Comprehensiveness within the analysis is reflected in the extensive and multi-layered process of analysis of the data. The process of analysis included initial familiarisation beyond the data generation through full transcription of all data. Further familiarisation was revisited with co-researchers in reading and preliminary coding of transcripts. Indexing was carried out based on initial codes and notes from coding sessions with co-researchers.

Although I carried out all of the indexing of data alone, my aim in this process was to retain the influences from the work with co-researchers by using the notes and codes elaborated within the initial coding process. After all data was indexed, the next stage of analysis involved reviewing indexed data with one co-researcher and developing codes into themes (Appendix I). During this process, further decisions were made regarding changes to the over-arching themes and sub themes that were captured during indexing, but reconsidered in further discussion with a co-researcher. Some versions of separate themes collected in the indexing spreadsheet were either separated into more than one theme, or collapsed from more than one theme into one.

Once all of the data were indexed and summarised, the co-researcher and I drew out maps of themes (for an example, see Appendix J). Following this process we used the maps to guide further structuring and summarising of the data to share with the other co-researchers who had been less involved in the later, more detailed stage of

analysis and to present at professional training event. This thorough process involved returning to the data and reviewing our decisions throughout analysis and writing to check that the conclusions drawn were consistent with the data. There were some instances in which a theme was developed around a sense of the data that was based on a single instance or impression rather than found within the data, and in these cases the theme was discarded (Toye *et al*, 2013).

Through the use of Thematic Analysis, it has been possible to produce a comprehensive and detailed understanding of the research topic. This choice of method involves breaking down the data from each transcript into chunks of meaning and building an account that cuts across and integrates the multiple perspectives brought by different participants. This approach has been helpful in building a picture of the local knowledges about women's mental health during pregnancy, but risks losing the continuity of any one individual account, as an approach such as narrative analysis would retain (Braun & Clarke, 2007). However, with a relatively small number of participant accounts, a frequent re-visiting of the data, and a number of co-researchers able to retain an overview of, and to discuss the different individual participants, it has been possible for us to balance the benefits of a cross-referencing analysis with an ongoing awareness of the continuity of different accounts.

8.9.3.1. Triangulation

Different approaches to triangulation have been used in this research. It was not the intention to use triangulation to establish the true reality of the findings and analysis through convergence, but to develop a richly contextualised and comprehensive examination of the subject (Willg, 2001). Triangulation of data has included the use of individual and group settings for the generation of data. This has provided

opportunities to generate data from the interactions between participants in a naturalistic setting (pre-existing groups of mothers and professionals) in which participants jointly built accounts. Individual discussions provided opportunities for individuals to share information confidentially and anonymously that they may not have been comfortable sharing in an established group of peers. Both of these sources have enriched the data beyond the potential of only one source, and in both sets of data there was one person who took part in a group and an individual discussion. This demonstrated the benefits of using both approaches. The mother who took part in a group and then requested an individual discussion had been able to give a more detailed account of her experiences when speaking one-to-one, and had said very little in the group. The professional who participated in an individual discussion and then was part of a group discussion both prompted other professionals in their discussion and was prompted by their discussion to add further data that would not have been captured by the one-to-one discussion.

Additional benefits from triangulation have included the ability to explore the relationships between different groups of participants within the research setting. Generating data with both mothers and professionals allowed us to see the interactions between service users' perspectives and those of professionals in relation to the same topics, such as not feeling cared for and not feeling able to offer the level of care that was hoped for.

The reflexive advantages of triangulation between researchers made it possible to develop a deeper awareness of my own perspective through discussion with co-researchers. Through the process of collaborative data generation and analysis, and regular peer debriefing, the research team was able to build a more comprehensive

understanding of the subject and engage with the complexity represented within the data.

8.9.4. *Reflexivity in analysis*

Using a participatory approach has enabled the development of a deep level of analysis and understanding of the data and our own perspectives.

Discussion with co-researchers and differences between perspectives in the data have enabled me to reflect on my own perspective in relation to the subject, specifically where this has related to the services in which I have worked in the past. My concerns about service users' satisfaction with services have been challenged and I have been able to hear new perspectives on service users' experiences of different therapies. I have developed a new understanding of the difficulties experienced by professionals who work outside of mental health services and have been offered an insight into the conflicting perspectives of professionals who work in different mental health teams. Evaluation of quality within qualitative research identifies the importance of the impact of the researcher on the research and vice versa (Toye *et al*, 2013). Analysis of data with co-researchers has helped me to articulate for myself in the process of discussion how my views as a psychologist have affected my reading of the data, and has helped us to develop a balanced account of the data. Through this process I have been able to observe my own role within data generation with participants with whom I share similar views, and with whom there are significant differences in perspective. In generating data with co-researchers, there have been opportunities for me to hear how the discussions happened in ways that would not have occurred without the co-researchers' involvement. The participatory approach to data generation and analysis has enabled me to identify the differences between

my own and co-researchers' perspectives with particular reference to the influence of interpersonal, organisational and epistemological/ ontological contexts (Mauthner & Doucet, 2003). These contexts may have been less visible to me without the co-researchers' curiosity and questioning. This range of issues has included my role within services and professional structures, my relationships with other professionals and my views about some mental health diagnoses and service responses.

I had been aware of this as a concern as a psychologist, working in a system in which diagnosis is prevalent and the bio-medical model the dominant framework applied to mental health. During analysis of data with co-researchers, this issue of terminology was also discussed in relation to my own discomfort with this diagnostic language.

We discussed how the way of describing a person as having a 'disordered personality' seemed to me to be disrespectful, pathologising and failing to recognise the impact of life experiences and trauma in the aetiology and presentation of emotional distress.

Discussion with other co-researchers has offered me a new understanding of non-psychologists' views about psychologists' ways of talking. Through collaborative analysis of professionals' data one co-researcher discussed how she viewed psychologists' talk in the data as peculiar and difficult to understand compared with data from other groups of professionals. This co-researcher writes humorous poems and sent me a poem in a Christmas card to illustrate her view on the strangeness of psychologists' talk, including some of the data from psychologists, her own experiences of services and conversations with me.

She has consented to my request to reproduce part of her poem for inclusion in this thesis, and to acknowledge this work by name.

Here I sit with an empty purse
But thank goodness for parallel universe

Women you know are completely mysterious
But psychologists they are total hilarious

We travel apparently through tunnels or zones
And there isn't a box that fits in all of our moans

Psychologists suggest that talking's the way
But no-one understands a word that they say

Some are veggies and eat lots of soup
Others just talk in their listening group

Some don't have tellies, that's quite insane
And others think microwaves frazzle your brain

She may be strange and a little bit mad
But Wendy's one of the nicest friends that I've had.

(Debbage, 2011)

Prior to discussions with her, I did not have an appreciation of some of the ways in which my professional group is sometimes viewed. In sharing this humorous take on psychologists' peculiarities, this co-researcher gave an insight into her perspective, and also a reflection the developing friendship and balancing of power within our relationship. As a woman who has had personal experiences of mental health problems and services, her poem emphasises the madness that can be seen in the behaviour and language of psychologists from an outsider perspective. This poem reflects the difference between a joking collegial co-researching relationship and one that is based on the structural inequalities of therapist-patient. She told me that her

impression of me had changed during the time that my behaviour changed from being primarily maintaining professional boundaries to one in which I felt more relaxed and comfortable with personal disclosures and informal chat.

The process of reflecting with co-researchers has changed over time through changes in my own experience at work and changes in relationships with co-researchers.

During the course of the PhD my increasing distance from mental health services and a move into part-time work in sexual health services has occasionally placed me in a similar position to other professionals who have described difficulty in accessing mental health services on behalf of their clients. I was able to reflect on the reciprocal influence from the research activity on clinical work, and of the clinical work on my thoughts about the research. The data from professionals on both sides of the mental health/primary care division has been influential in enabling me to keep a balanced perspective about demands and challenges across the interface between services.

Developing relationships within the research team, increasing trust, the development of one close friendship and mutual support during the project has shaped the way that we have been able to work on the research together and explore the meanings within the data. The developing trust within our relationships has enabled the most involved co-researcher to be more comfortable with challenging my perspectives on the data and direction of analysis. In the early stages of the research I had been careful to hold back my own views and encourage the co-researchers to express their perspectives on the direction of the research. At later stages in the research process, these developed relationships facilitated more robust and frank discussions within the stages of analysis. This was especially important due to the different perspectives

that we each brought to the analysis. In some ways our conversations mirrored the different perspectives within the data across the two groups of participants.

Epistemological issues were addressed during sessions of data analysis, and while there were jokes about the strangeness of psychologists' talk and ways of thinking, it was possible to settle on a primarily critical realist approach to the data and analysis, in which we were able to consider the intersections of material, relational and social conditions on the content of the data. Although I had an ongoing interest in the discursive patterns and functions of the data, this was not taken up by co-researchers as a priority for the analysis, but primarily as a source of humour and good-natured teasing. These interactions seemed to function as a leveller of potential power-imbances between us. This reminded me of the mothers' data regarding the value of experience in preference to 'book knowledge' of professionals, and reflects the importance of participatory research in valuing expertise from lived experience. As a result of the participatory ethos of this project, a discursive focus on the analysis was not pursued, and the meaning developed within the analysis reflected a more grounded and less esoteric or academically focused account. Feedback I have received from one of the co-researchers on findings chapters from this thesis suggests that this process has been successful in capturing the subject in a language that is understandable and meaningful to a non-psychologist. The influence on the analysis of my own material and educational context (Oakley, 1992) has been balanced by the involvement of the co-researchers. This has made it possible to not put psychological theory and other academic priorities at the forefront of the process of data generation and analysis processes.

8.9.4.1. Production of different types of knowledge

Beyond knowledge about the subject (representational knowledge), participatory research can also produce knowledge through interaction with others in the research setting (relational knowledge), and critical analysis of morality and values in relation to life conditions of participatory researchers (reflective knowledge) (Park, 2001).

The tradition of participatory research emphasises the importance of how research can raise the critical awareness of the people involved (Freire, 1970/1996, Gaventa & Cornwall, 2001).

In addition to the representational knowledge produced through the participatory approach to this research, other research outputs have included relational knowledge and reflective knowledges (Park, 2001). Co-researchers and I have had opportunities to work together in ways that are not routinely available across the structural divisions between people in different roles. I have been able to develop different kinds of relationships with people I would normally only meet in constrained professional-service user relationship, in which there are interpersonal boundaries drawn by professional codes of ethics and the task-focus of health care delivery. Collaboration and the development of shared agendas for research outcomes has provided us with different frameworks for relating to one another, and different approaches to engaging in work together. Both co-researchers and I have reflected together on how relationships in this context have been more flexible and open than the relationships between professionals and service users that we have experienced previously. Co-researchers have reflected on how their experiences of working on this project have challenged their previous ideas of what health professionals are like, and the influence that they can have in producing new representational knowledge.

Development of reflective knowledge and the generation of critical awareness of life conditions have also been important for me. This has not just been a process for co-researchers, but researching as an insider into the everyday experiences and struggles of other professionals has opened up a greater insight and opportunity for reflection about my own professional life. Through the process of undertaking participatory research within the NHS and academic setting, I have become more aware of my own position in a hierarchy of power, in which my assumptions about my own level of influence have been challenged. This research has also been empowering for me through the development of my own critical consciousness, in that I have been able to identify and consider the personal impact of my experiences of mental health work and the systems in which I have been working. Exploring the narratives of professional struggles that are similar to my own has offered me a view into my own life through the lens of other people's accounts.

My friendship with one of the co-researchers has become an important source of reciprocal support beyond the research, largely arising from our ability to share experiences and information relating to life events during the analysis phase of the project. We have developed a productive working relationship, both within this research project and beyond such as her involvement in delivering teaching sessions to trainee clinical psychologists about participatory research and presenting findings from this research to professionals.

8.9.5. Reciprocity in relationships with the researched community

One of the criteria for evaluation of participatory research relates to reciprocity with the researched community. In part this relates to the process of undertaking the research in a way that involved members of the research community as co-

researchers and participants as co-producers of knowledge. In the generation of data, the approach taken was one of flexibility and transparency, with data reflecting a conversation rather than an extractive interview. Although the process of research has not been as participatory with interviewees as with co-researchers, the use of loosely structured topic guide has enabled participant agendas to be explored within the data generation. Generation of data was not focused on specific diagnostic labels, but invited women and professionals to define their own understandings of mental health problems. This approach resulted in data that was inclusive of a wide range of experiences, and did not exclude participants on the basis of professional and academic definitions of psychiatric diagnoses.

8.9.5.1. Involvement of co-researchers

Different co-researchers were able and willing to be involved in different parts of project. All co researchers were involved in initial planning and decisions about the direction and design of the project, including the research questions that were important and the sampling strategies and groups that we should invite to take part. Co-researchers were not involved in various aspects of the research, primarily the activities that were required for academic purposes. These activities included the literature review, NHS Research Ethics application, and the keeping of reflective diaries. For some co-researchers, barriers to involvement included:

- Availability of time for activities, with managing other priorities including:
 - Working hours
 - Family commitments, including school holidays
 - Child care arrangements and acceptability of the use of available local crèches
- Lack of interest in some aspects of the research

- Lack of reading confidence in dealing with written materials at the level of published research
- Periods of illness and increased problems of mental health
- Dyslexia as an obstacle to dealing with indexed data on the computer screen.

Although I offered to read this through as we went along, this was not an activity with which this co-researcher wanted involvement.

Two co-researchers were more involved in generation of data while the third was unable to prioritise this activity due to her working hours and subsequently becoming unwell. Later in the process of analysis (after data was transcribed and indexed) she became much more involved in the analysis at a time when the other co-researchers became less involved. The different activities of the research process suited the interests, skills and abilities of different members of the research team, and they were able to opt in and out of different stages according to their own preferences.

8.9.5.2. Dissemination

Some dissemination has been undertaken within professional and academic contexts; however this has not included the wider population of pregnant women within the locality. Although extensive dissemination has not been feasible within the timescale and academic priorities of the PhD process, dissemination and engagement in development and application of the findings has been rescheduled to a later date beyond the time of thesis completion. As a significant aim and motivation for undertaking the research, this process remains a commitment of the research team.

8.9.5.3. Power

Power remains a significant issue in the participatory research process. Questions arise relating to the location in which power is held and how power is exerted through regulation, and the ownership of knowledge and research activities.

Power exists within a relational context and this research has aimed to alter the traditional position of professional power *over* service users to a position of ‘power with’ (Boser, 2007 p. 1064). This approach has enabled the use of my relative structural power as an academic and professional to negotiate with other powerful entities in the research environment. In this way, it has been possible for the research team to work together towards the aims of the research. Although I am in a position, through knowledge and status to navigate systems such as the NHS Research Ethics Committee and Research and Development Departments and University structures, these systems locate me at a lower level within the hierarchy. Working within these systems has been influential in the structure of the research team and the relational power that exists between us. This issue has been explored further in a published paper that explores the impact of systemic regulations on participatory research (Franks, 2013).

Throughout the research only one of the co-researchers was proactive in arranging meetings and finding and booking venues for meetings. This might suggest that there remained a lack of a sense of ownership of the research amongst the whole of the research team and that this activity was a greater priority for me and one other co-researcher. Having initiated the research, sought out people to join the team and taken a lead with the organisational requirements of the research, the responsibility and priority for the research had been established from the outset as primarily located with me. This situation reflects a significant compromise in undertaking

participatory research as part of a PhD and within publicly accountable institutions. As a result, some of the participatory intentions of this research have been limited by organisational timescales, regulatory processes, resulting maintenance of the status quo and my focus on working within standard research approaches because of the academic focus and demands of my role.

However, with these caveats, this research has made progress toward greater involvement of, and accountability to the researched population who are the focus of this study.

8.9.6. Contributions to knowledge

This research is unique in that it brings together different strands of knowledge and examines them through different lenses, which ultimately shed light on the complex subject of women's mental health during pregnancy. The different components of this research have included:

- Service user involvement at all stages of the research process has shaped the study and findings. This approach has facilitated the development of new knowledge through the advantage of proximity and trust within the researched community.
- Multiple perspectives during the analysis, including the research and supervisory teams and peer debriefing throughout
- Multiple data sources, including data from mothers and professionals, in addition to different means of generating data in groups and with individuals, has provided the opportunity to juxtapose accounts by service users and professionals talking about the same issues and embedded in the same context. Significant findings from this research include:
 - The nature and descriptions of women's mental health problems

- The factors that support and undermine women's mental health during pregnancy
- Experiences of using and delivering services
- What is needed to support women's mental health during pregnancy

This juxtaposition illustrates some of the tensions and points of agreement between women and professionals who work with them, producing new knowledge that can inform local developments, and which may be transferrable to other comparable settings.

- Analysis of data generated with professionals has added to existing knowledge about professionals' emotional struggles in working with pregnant women who experience mental health problems within a context of significant socioeconomic deprivation. Although there is existing research focused on professionals' experiences of powerlessness in relation to safeguarding (Burgess *et al*, 2012) and the stresses associated with work within pressured health systems (for example, Curtis 2004), this research shows the relationship between service users' and professionals' mental health in a way that breaks down the divisions between the 'us and them' of knowledge regarding patient-professional relationships.
- Theory informed by Systemic, Community and Critical Psychologies has enabled the development of a comprehensive picture of the impact of socio-economic deprivation and interpersonal relationships throughout the life span, thus weaving together a contextualised psychosocial understanding of the locality and features of women's experience that have a negative impact on their mental health. The lens of these theoretical approaches has focused

the analysis on the impact of power, stigma and fear on mental health and help-seeking.

This study has also illustrated the range of difficulties in undertaking participatory research in mental health (Franks, 2013).

- The difficulties associated with working in regulated public health service and academic contexts.
 - Stigma about people with mental health problems produced challenges in NHS Research Ethics review, arising from concerns expressed by the committee about the trustworthiness of people with mental health problems (see Appendix K for reflective research journal entries prior to and following the meeting)
 - Barriers arising from the requirements of co-researchers, including academic and employment status, which were overcome only through intervention from a research supervisor who was a professor within the university.
- The need for flexibility within the research project and the timescales due to co-researchers' inability to contribute at times due to their own health

The broad conclusions and recommendations arising from this research will be examined in the following chapter.

CHAPTER NINE

CONCLUSIONS AND RECOMMENDATIONS

9.1. Conclusions

The structure of this conclusions section is focused on the initial research questions and issues arising from the analysis of systemic influences on services and women's mental health.

9.1.1. Participants' understandings of mental health and factors that undermine and promote good mental health during pregnancy

Although many social and material features of life in this community were identified as undermining good mental health during pregnancy, the primary issues that were expressed as having a negative impact on women's mental health related to difficult early life experiences and problematic early and intimate relationships. These features of women's experiences were connected to socio-economic deprivation through intergenerational and systemic patterns in women's lives. Childhood development resulting from early experiences of trauma and neglect is argued to present adulthood vulnerability to stressful life conditions and to limit relational resources for interpersonal support (Dillon *et al*, 2012).

Lack of control over important aspects of everyday life including money, housing, access to care and support from community and services further undermined women's wellbeing. Community psychology theories that point to ecological conditions of living in the aetiology of mental health problems (Orford, 2008) include the material and social conditions that were identified in this research, in

addition to negative systemic and interpersonal contexts of women's lives (Ussher, 2011).

Within this research there were relatively few features of women's lives that were described as promoting their mental health, although it is acknowledged that the sample was focused on women with experiences of poor mental health. Features that promoted mental health mainly related to the opposite of conditions that undermined women's mental health, including access to supportive relationships in their communities and in services. Women experiencing emotional distress valued reassurance and information, particularly where that information was considered to be trustworthy due to its basis in their own, and other women's, lived experience rather than the perceived limited theoretical/book knowledge of professionals. Participatory approaches that focus on the involvement of service users in health research similarly prioritise and value the notion of expertise by experience in shaping developments that are meaningful and acceptable to those who use the services. Rather than approach the subject from an objectivist/expert stance (Rose, 2009), the approach used in this research has sought out expertise from women and professionals to inform future developments.

9.1.2. Women's experiences of services

Within this research, there was widespread use of diagnostic terminology and some use of derogatory and stigmatising language in relation to mental health problems. Pathology-focused and stigmatising understanding of pregnant women's experiences further undermined their willingness to disclose mental health concerns to professionals due to fear of potential consequences. Community, critical psychological and feminist approaches have aimed to shift the understanding of

individual distress away from medical models of internalised pathology into frameworks that take account of wider systemic influences (Hagan & Smail, 1997). Women in this research connected their experiences of poor mental health with circumstances that resulted in less power and control in their lives, and with limited access to care and support from services and their communities. These issues reflected a resonance between women's early life experiences and their difficulties in relationships with services. Women expressed anxieties about loss of power and control in relation to concerns about child custody and deprivation of liberty under the Mental Health Act. A salient model of relating appears to be repeated within women's early life experiences and adulthood experiences of services in which they can feel both neglected and fearful of the powerful influences of professionals. Women's accounts of using NHS mental health services were positive when the referral was taken up and resulted in an opportunity for individual or group therapies. However, this was not always reported as successful or available and some women described frustrations about lack of service response to their expressed needs. When women experienced therapy services, the approaches used by clinicians were connected to women's understanding of undermining factors, promoting factors and coping strategies. The only participant who experienced group therapy subsequently offered support to others and set up a group for peer support in her local community centre. The opportunity to offer support to others was described as promoting wellbeing and corresponds to theory and research focused on the individual and community-level benefits of peer support (Munn-Giddings & Borkman, 2005).

9.1.3. Professionals' views of services & experiences of work with pregnant women with mental health problems

A significant feature of professionals' data related to their struggles to provide good services in the face of widespread socioeconomic deprivation, limited resources and high levels of demand. In common with women's frequent descriptions of disempowered lives, professionals' data suggested limited experience of control over their working conditions, resources and demands. Many professionals were aware of the limitations of mental health services, and many of those working outside of specialist mental health services expressed concerns about the lack of availability of specialist care for distressed pregnant women. Professionals without a mental health specialism were aware of their knowledge limitations and additional limitations in relation to time available for training. Some professionals without access to appropriate and supportive clinical supervision expressed difficulties in managing the emotional impact of the work.

Professionals' data also showed tensions between services in relation to whether priority was placed on the needs of mother or baby, rather than an interconnected service focused on needs within the dyad. Although there is a Parent & Infant Mental Health Service in the locality, this resource is also limited and efforts to make connections between separate existing services have proved unsustainable, potentially due to pressures on services to meet immediate needs.

9.1.4. What is needed from services and from communities to support women's mental health

Data about women's needs to support good mental health were focused on services and community support. Within services, women felt they needed accessible,

supportive relationships with knowledgeable and trustworthy service providers. Access to appropriate care included the availability of reliable, consistent and trustworthy information. Women also felt they needed opportunities to meet with other pregnant women, supported by professionals within an informal setting. Professionals' data was focused on availability of specialist services, improvement of professionals' knowledge, support for women's families to support women, and the development of community resources. Beyond the expressed wishes within the data focused on women's needs, significant issues arose in relation to women's and professionals' empowerment to shape their own circumstances. The absence of feelings of control over conditions of living and working was pervasive within the data alongside expressions of feeling unsupported by wider systems.

9.1.5. Relationship between women's and professionals' data

There was a high level of agreement between women's accounts of their own experiences, and professionals' accounts of working with pregnant women with mental health problems. Many of the factors that were seen as undermining and promoting women's mental health were the same in both sets of data. There was a mirroring between some of the mothers' and professionals' data, particularly in relation to women's concerns about not being asked how they are feeling, and professionals' expressions that they did not have enough time to ask questions that might open up a 'can of worms'. Although both mothers and professionals were aware of the importance of reliability and trust within this relationship, there were professional concerns about being able to provide good enough emotional support due to service pressures, and women's expressions that they did not feel well supported emotionally. These difficulties existed in the context

of professional reports of feeling emotionally overwhelmed by the content and demands of their work in the absence of adequate support. Mothers and professionals' described concerns about professionals' knowledge of specialist areas in addition to professionals concerns about limited time for training and professional development.

Some professionals identified service user involvement in training as particularly valued due to the impact of service user accounts, echoing the emphasis placed by some mothers on their greater trust in information generated by experience over theory and learning from books. This commonality presents further support for the potential of collaboration between professionals and service users in sharing and developing knowledge, although the obstacle of time and resources remains a barrier to change.

9.1.6. Systemic perspective

Taking a broader systemic focus on the locality itself and the problems experienced by pregnant women and the professionals who work with them enables the development of an alternative to individualising and pathologising understandings of women's mental health. Both women's and professionals' data reflects problematic issues with the negative impact of stigma and fear relating to mental health problems. The reliance on the existing model of service delivery solely by experts in a context characterised by deprivation, high levels of demand and low levels of experienced power contributes to the levels of distress experienced by both service users and providers.

Examined through the lenses of critical, community psychology and systemic theory, the findings of this research shed light on the detail of women's and professionals'

experiences of difficult lives and working conditions in a context of poor resources and high demands. Potential resources to be found in collaborative working have not been widely developed where individuals struggle with overwhelming pressures and limited experiences of control.

9.2. Recommendations

Recommendations from this research are presented in five areas:

- Community development
- Service development
- Professional training
- Care for professionals
- Future research

9.2.1. Community development

In keeping with the original participatory intentions of this research, the primary recommendation relates to feeding back research findings to the researched communities and working together to develop community resources. Although there are significant findings in relation to the importance for mothers in this community to have access to peer support networks, it is important to avoid the assumption that professionals are best placed to generate plans for processes to set up resources to serve community needs, although the findings from this research suggest that women might wish for professional support in developing community resources. These findings point to the potential value of user-led collaboration, with professionals supporting rather than directing developments. This research does not have findings that give a clear idea of how this would be best developed within the local context,

and therefore the approach most likely to meet local needs and foster a sense of local ownership would involve community-led development.

Further developments that might arise from feeding back research findings to the community could focus on empowerment to act for social change on the basis of identified conditions of socio-economic deprivation that impact on women's lives in the community. Such developments could increase access to resources of power and control, with further potential for empowerment for both professionals and service users.

9.2.2. Service development

Findings from this research primarily point to the importance of reiterating recommendations from CMACE report (2011) and NICE (2010) guidance on services for pregnant women who experience complex social factors.

Recommendations from these reports emphasise the value of structures within services that support clear and timely processes for referral pathways and routes of communication between professionals from existing services, training for professionals, positive approaches to communication, transparency about issues arising from safeguarding concerns and routes for feedback from service users.

Connections between specialist services for mental health and obstetric care have been seen in this research to present difficulties for staff, particularly in relation to time for prioritising interdisciplinary networking. Without the ability for all sides to prioritise this work it is unlikely to result in meaningful change across services.

Findings from this research also point to the potential value of developing opportunities to break down barriers between pregnant women and the professionals who offer services. While research has shown that the relationship between patient and professional is an important indicator of outcome (Mead & Bower, 2002),

stigma, fear and lack of trust have been identified in this research as barriers to this important feature of effective services. Greater opportunities for collaborative working and training can break down barriers and increase awareness of commonalities between groups that have traditionally been located on opposite sides of the 'us' and 'them' divide.

Like the above section, and in keeping with the participatory approach to this research, it is unlikely that a researcher from outside of these systems is best placed to understand the most effective ways to make progress in the identified directions, although feedback of the identified issues to the range of professional groups included in this research is more likely to produce outcomes that will work within the local systems.

9.2.3. Training for professionals

The CMACE report (2011) and NICE guidance (2010) have both identified the issue of training for professionals to address the service needs presented by pregnant women who experience mental health problems. CMACE has emphasised the importance of regular, routine training for clinical staff to identify, assess, offer initial support and refer women as appropriate. NICE guidelines have also recommended training in responding appropriately to women's communication needs with particular reference to information and education. These issues were raised within the current research, although many professionals also identified difficulties with the limited time available for training within their routine practice. Additional barriers to regular training for all clinical staff relate to the optional nature of much training on women's mental health during pregnancy, and the very brief time made available for mandatory training in this area. Given the reported prevalence of mental health problems amongst pregnant women, development of

training needs to reflect more than just a special interest for a few professionals. On a policy level, there are improvements that could be made in this area, along with awareness-raising for professionals about the importance of women's mental health during pregnancy and accessibility of brief, focused training to address local needs. Professional research participants have also identified the need for improvement in pre-registration training for nurses and midwives, including opportunities for specialist placements for students in settings that incorporate broader experience than their primary focus of study.

Both women's and professionals' data indicates the value placed on learning that uses experiential knowledge, emphasising the importance of involving service users in developing and delivering training. This activity would provide opportunities for the development of more equally balanced relationships between mothers and professionals.

9.2.4. Care for professionals

Many of the above recommendations rely on a workforce of resilient, supported and well-trained professionals to support women directly through the provision of services and through development of opportunities to build capacity within the community. In order for this to be possible, professionals require adequate resources for everyday work and training, along with appropriate supervision, personal development and support to manage the emotional demands of working effectively with women who experience mental health problems. Several of the above recommendations potentially serve to reduce the 'us and them' split that disempowers service users and places excessive pressures on staff in under-resourced services. However, without professionals' ability to manage the emotional

demands of complex working relationships, potential developments such as these are unlikely to be successful and sustainable.

9.2.5. Future research

In keeping with the participatory and action research origins of this project, further recommended research would reflect an extended cycle of development, implementation and evaluation of actions from the above recommendations for development. This should include research into the experience of peer support for women during pregnancy.

Additional research should involve widening the range of key informants to include family members and carers of women who experience mental health problems during pregnancy in this and other localities. This research is limited in its generalisability to other dissimilar contexts such as larger urban centres, more rural areas and localities with less heterogeneous demographics. This research did not include firsthand accounts from women from sexual and ethnic minorities, and this is a current gap in the research that requires further investigation.

Other identified issues for future research include in-depth qualitative study to examine responses to different forms of psychological therapy, which was an unexpected finding of this research and warrants further exploration.

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LIST OF APPENDICES

Appendix A: Summary of research included in this literature review

Appendix B Information leaflet about the research

Appendix C: : Letter of favourable opinion from NHS Research Ethics Committee

Appendix D: Participant Information Sheets (Individual and Group discussions)

Appendix E: Consent forms (Individual and Group discussions)

Appendix F: Initial Discussion Topic Guides

Appendix G: Research team members involved in the data generation and preliminary coding

Appendix H: Example of a section of index spreadsheet

Appendix I: An example of theme development based on initial coding and indexing

Appendix J: Example of a collaboratively produced thematic map with post-it notes on a flip chart: what undermines women's mental health?

Appendix K: Excerpts from reflective journal regarding NHS Research Ethics processes

Appendix A: Summary of research included in this literature review

Authors/Year/Location	Purpose	Sample	Design	Findings
Bennett <i>et al</i> , 2007; Canada	To develop a theoretical model that explains women's processes of managing depression during pregnancy	Purposive sample of 19 women with psychiatrist diagnosed depression, recruited from mental health programme in Ontario. Varied ethnic backgrounds (not specified), aged 25-47 (mean age 36), all relatively high socio economic status and educational level.	Constructivist Grounded Theory. Data were collected through individual, in-depth, semi-structured, audio-taped interviews. Data were transcribed and analysed using Grounded Theory, including initial coding, writing of memos, development of themes and links, and use of constant comparative analysis.	A model is presented of women's journey from identification of depression as a threat to pregnancy, through a process of recognition of the problem, overcoming shame, identification of an understanding healthcare provider, developing knowledge and strategies for managing depression to taking control of their lives.
Coles & Jones, 2009; Australia	To explore previously sexually abused women's responses to perinatal professional touch and examination of themselves and their babies	Sample of 11 women who self-identified as having experienced childhood sexual abuse by a family member – recruited via advert in a free Mother and Child newspaper. Second group of 7 women recruited by newspaper article	Qualitative Thematic Analysis of semi-structured in-depth interviews exploring the impact of sexual abuse on mothering, and women's experiences of perinatal health care. Interviews audio-recorded and transcribed.	Main themes identified were: Safety issues for Survivors in the clinical encounter; Making the clinical encounter safer; Relationships with health practitioners; Access to services and; Health practitioners' knowledge of trauma and its effects.

Côté-Arsenault & Mahlangu, 1999; United States	To describe the experience of pregnancy after perinatal loss	Convenience/criterion sample of 72 women who were currently pregnant, between 17-28 weeks gestation and had experienced one or two previous perinatal losses. Age range was 19-44 years (mean age 32), majority White, middle class, married and well educated.	Descriptive analysis of open ended self-report questionnaire. Thematic analysis of data undertaken by members of research team independently and then reviewed to reach consensus.	Three overarching dimensions were identified from the data: Past Pregnancy, Current Pregnancy and Self. Within these dimensions were themes of pregnancy anxiety, significant time points, ways of coping, safe passage, social acceptance, 'binding in' (mother's connection with the baby), grief and loss.
Côté-Arsenault & Freije, 2004; United States	To explore the culture of support groups for women with pregnancies following previous perinatal loss, and examination of the impact of the groups on women who used them	Convenience sample of two established support groups identified, one in Midwest and one in Northwest United States. All members were women, except 3 men who were present one time each in different groups. Groups were made up of 90% White members and 10% diverse minorities. Age range was 21-47 years. Purposive sample of 12 key informants.	Ethnography of support groups for pregnant couples who had lost a baby in a previous pregnancy. Data included participant observation, 12 individual interviews, surveys and artefacts such as newsletters, video tapes, guided imagery CD-ROM and professional manuals.	Five paradoxes were identified reflecting conflicts between common cultural expectations of pregnancy and the women's own experiences. These were birth/death; pregnancy does/does not equal baby; head/heart; public/private; and hope/fear. Groups helped women remember lost babies, develop caring relationships and develop coping skills.

Erikson <i>et al</i> , 2006; Sweden	To investigate and describe how women experience and communicate about intense fear of childbirth	Purposeful sample of 20 women who experienced fear of childbirth. All women were born in Sweden, lived in rural and urban areas and had a range of educational levels. Age range was 24-41.	Grounded Theory approach to analysis of 'open and permissive' qualitative interviews. Analysis involved constant comparison, sorting of data into categories and description of categories through identification of category dimensions.	Fear experience was described in terms of 'manifestations' of mental or physical symptoms, related to when and how the fear fluctuated, and judgements according to perceptions of self and others. Ways of dealing with the fear included evading, processing and seeking help.
Furber <i>et al</i> , 2009; England	To explore the experiences of pregnant women who self-reported mild to moderate psychological distress within antenatal care	Purposive sample of 24 pregnant women in the Northwest of England who self-reported mild to moderate psychological distress to their midwife during routine antenatal care. Age range was 24 to 39. Sample size was determined according to principle of data saturation.	Qualitative Framework Analysis. Semi-structured interviews were audio-recorded and transcribed. Analysis followed five stages: familiarisation, identification of a theoretical framework, indexing, charting, mapping and interpretation. Constant comparison was used to develop broader categories.	Three main themes were identified relating to mild to moderate distress: causes (including past life and childbearing experiences); impact (taking over one's life) ways of controlling (positive and negative strategies).

Lutz, 2005; United States	To generate a theoretical understanding of women's experiences and perceptions of intimate partner abuse during the child bearing cycle.	Convenience/theoretical sample of 12 ethnically and socio-demographically diverse women who were abused by male partner during her childbearing cycle. Age range was 18-43 years (mean 29.7).. Sample drawn from an urban area in the Pacific Northwest United States, and recruited from healthcare providers at two clinics, word of mouth, snowballing, and flyers.	Dimensional analysis, a Grounded Theory method. Undertaken from Symbolic Interactionist perspective. In-depth interviews were audio-recorded and transcribed. Nine participants were interviewed twice, which involved participant validation. Interviews, field notes and memos were analysed and data collection continued until saturation was reached.	A model was produced under the core category of living two lives. Contexts include public and private life. Processes are: Pursuing the dream; Enduring for the family's sake; Engaging in a dynamic balance; Reconciling dreams with reality and Revealing and integrating two lives. Crystallizing events relate to endings in the relationship.
Nilsson & Lundgren, 2009; Sweden	To describe women's lived experience of childbirth fear	Self-selecting/criterion sample of 8 women attending a specialist clinic in Gothenburg. All women were pregnant and between 24-37 weeks gestation. Women with psychiatric diagnosis and vulnerability were excluded. Age range was 27-34 years.	Phenomenological qualitative interview study. Each participant interviewed once. Analysis included familiarisation, clustering and organising meaning units and formulating the essential structure of the phenomenon.	Findings presented as 'to lose oneself as a woman into loneliness'. This loneliness reflects women's facing their fear of childbirth alone. The essential components were feelings of danger, feeling trapped by the inevitability of birth, feeling inferior as a mother-to-be, and being alone.

Raymond, 2007; England	To explore the feelings of depression during pregnancy of women living in an area of socio-economic deprivation, and to identify the support mechanisms that they report as personally or potentially helpful for antenatal depression.	Self-selected sample/purposive sample of 9 women aged 23-40, from a variety of ethnic backgrounds with retrospective identification of low or depressed mood during pregnancy. Located in a socio-economically deprived area of North London, UK.	A constructivist qualitative interview study. One semi-structured interview per participant. Data was coded and categorised, and analysed for themes.	Five major themes, two of which are reported in this paper: Emotional isolation (including loneliness, pressure to be a good mother and fragmented health care); and Creating a safety net, relating to supports and services.
Rose <i>et al</i> , 2010; United States	To explore women's perspectives of patterns of intimate partner violence; influences on these patterns, and evaluations of resources in the women's residential settings.	A purposive sub-sample of participants in a quantitative intervention study for intimate partner violence. 27 women, aged between 14-32 years (mean age of 23.9 years). The majority of women were educated to high school level, were single and unemployed. The sample included a nearly equal proportion of African American and Caucasian participants.	Qualitative analysis of semi-structured interviews. Data was coded using both in vivo codes and a priori codes. Codes and categories were developed by consensus within the research team. The aim of the analysis was to identify how women dealt with abuse and the influence of contextual and conditional factors	Findings relate to a changing perception of self including self-doubt, self-care, and finding inner strength. Influences on this changing perception were perceptions of severity, influence of setting, and relationship with abuser/family support. Women reported mental distress and also that experiences of abuse led to greater mental strength, and emphasised the importance of protecting children.

<p>Sanders, 2008; United States</p>	<p>To explore the meaning of pregnancy after diagnosis with HIV</p>	<p>Purposive sample of 9 women who had been diagnosed with HIV prior to having a child. Participants responded to an advertisement, which offered payment of \$50 US for participation. Age range 34-53 (mean 36.5 years). Seven participants identified as Black, and 2 as White. Educational range was from grade 11 to Masters degree. The time from diagnosis ranged from 10-20 years prior to the research. Sampling continued to saturation.</p>	<p>Qualitative Phenomenological study focused on women's experience of pregnancy after a diagnosis of HIV. Transcribed interview data was read for a sense of the whole, and then coded into meaning units. These meaning units were then synthesised into the essence of participant experiences. External consultants were used for a third review and synthesis to reduce researcher bias.</p>	<p>Findings indicate a common experience of extreme emotional distress following diagnosis with HIV. Distress also related to women's concerns about HIV in relation to the baby, including fears of transmission, safety of medication, and concerns about the impact of pregnancy on her own health. Additional themes were women's experiences of stigma, experiences with health care professionals.</p>
<p>Schwerdtfeger & Wampler, 2009; United States</p>	<p>To explore and understand the lived experience of pregnant women who have self-reported a history of sexual trauma</p>	<p>Criterion sample of 10 pregnant women who had experienced sexual trauma. Participants ranged from 18-34 weeks gestation. Age range was 18-35 years. 9 women were Caucasian and</p>	<p>Descriptive phenomenological qualitative analysis of semi-structured open-ended individual interviews. Researchers undertook 'bracketing' of perspective</p>	<p>Four main categories emerged from the analysis. These were: Negative consequences of the sexual trauma; becoming a survivor; pregnancy as new beginning after sexual trauma and the integration of sexual</p>

		<p>1 was Mexican-American. Participants had a range of educational backgrounds, economic, employment and relationship statuses.</p>	<p>before beginning data collection and analysis, reflexive diaries were kept, member checks were undertaken, and internal/external auditors were used to review data, research processes and analysis.</p>	<p>trauma and motherhood</p>
<p>Tseng <i>et al</i>, 2008; Taiwan</p>	<p>To describe Taiwanese women's experience of prenatal depression</p>	<p>Convenience sample of 12 pregnant Taiwanese women scoring above 15 on Edinburgh Postnatal Depression Scale. 19-33 years old</p>	<p>Descriptive Qualitative Study. In-depth interviews, audio recorded, transcribed and analysed using content analysis for emergent themes, continuing until saturation. Coding checks by 2 researchers for 'dependability and confirmability'. Also used peer debriefing and respondent validation.</p>	<p>The primary theme was unbalanced commitment to motherhood. Sub themes: Multiple conflicting roles; Lack of social support; dissatisfaction with body image; future uncertainty; emotional instability.</p>

Appendix B: Information leaflet about the research

What's in it for you?

I hope that this would be an interesting and rewarding experience for lots of women:

- You would have opportunities to work with other women who have had similar experiences to you.
- You would gain some experience and training in doing research.
- You would have an opportunity to help change the lives of other women who are having emotional problems during pregnancy.
- You would be involved in an exciting new project, and may even find out about talents you didn't know you had.
- You may be able to earn some money or other benefits if we can get funding to do this research together.

What's the first step?

I am happy to talk to any mothers who might be interested. I'm not asking for any commitment at this stage. It would be just to talk through some ideas and see if you would be interested.

If you think this kind of project might be of interest to you, then please get in contact with me at:

Did you have emotional difficulties during pregnancy?



Would you like to get involved in some local research?
(with a difference!)

Leaflet version date: March 2009

What's it about?

Research should be useful to local people. It should be shaped by what you think is needed. I'd like to work together on some research about emotional problems in pregnancy. We can use our research to help improve things for local women who have similar difficulties.

Who am I?



My name is Wendy Franks. I'm a Chartered Clinical Psychologist (DClinPsy, CPsychol)

I have worked in the NHS in since 2002. I am now a full time research student at the University of East Anglia, supervised by Prof R Gray & Dr K Crozier. I'm working with local organisations like the Children's Centre and

Who is it for?

I am looking to work with women from all kinds of backgrounds, who have had experiences of psychological or emotional problems in pregnancy (for whatever reason). Your experience would be especially helpful if you have had difficulties in the past and have found ways of overcoming some of them. I am interested in working with women who have previously needed help from Mental Health and other services, as well as women who have found other help, and ways to cope with their difficulties.



What's the plan?

This is where the difference comes in! Unlike lots of researchers, I haven't made all the decisions about how the research should go. I have lots of ideas, but I think you can help! You would not be asked to be a research participant in the usual sense, but rather to be part of the research team. How involved you want to be is up to you.

Although I don't have resources yet to pay for your time, I hope that together we could apply for funding, once we have decided what is needed. I have a small amount of funds to pay for initial travel costs, and I can arrange some local crèche places.

(Personal contact details and details that identify the locality are removed)

Appendix C: Letter of favourable opinion from NHS Research Ethics Committee

Essex 1 Research Ethics Committee

Level 9
Terminus House
The High
Harlow
Essex
CM20 1XA

Telephone: 01279 413136
Facsimile: 01279 419246

17 December 2009

Dr Wendy Franks
PhD Student
School of Nursing and Midwifery
Faculty of Health
University of East Anglia
Norwich
NR4 7TJ

Dear Dr Franks

Study Title: Participatory Qualitative Research into Antenatal Mental Health (*location removed for anonymity*)
REC reference number: 09/H0301/69
Protocol number: 8

Thank you for your recent letter, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research

governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		21 September 2009
REC application		23 September 2009
Protocol	8	02 September 2009
Investigator CV		21 September 2009
Letter of invitation to participant: Professionals		
Letter from Sponsor		22 September 2009
Supervisor's cv		
Invite letter - mothers and partners		
Identification letter to professionals		
Interview Schedules/Topic Guides		
Participant Information Sheet: Group	2	01 November 2009
Participant Information Sheet: Individual	2	01 November 2009
Participant Consent Form: Individual		
Participant Consent Form: Group		
Referees or other scientific critique report		11 December 2009
CV's for (co-researchers' names removed)		
Poster and text for advert		
Training Plan		
Response to Request for Further Information		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0301/69	Please quote this number on all correspondence
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Yours sincerely

Dr Alan Lamont
Chair

Email: liz.wrighton@eeo.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Ms Tracy Moulton Moulton
University of East Anglia

Appendix D: Participant Information Sheets (Individual and Group discussions)



Faculty of Health
School of Nursing & Midwifery

University of East Anglia
Norwich NR4 7TJ
United Kingdom

w.franks@uea.ac.uk
www.uea.ac.uk

Participant Information Sheet (Individual Discussions)

You are being invited to take part in a research study. Before you decide whether to 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. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Part 1

Study title: Participatory Qualitative Research into Antenatal Mental Health in (location removed for anonymity)

What is the study about?

This study aims to find out about how pregnant women, their families, and people who work in maternity services understand mental health problems and experience services for pregnant women. The results of this research will be used to inform existing services, and may lead to the development of new services or projects. This research is being carried out by a team of researchers, including three mothers from the local community and one PhD research student/clinical psychologist who has been working in the NHS for the past 7 years. The local mothers who are involved in this project have received some research training, but do not have formal research qualifications. They are from the local community and are contributing to this study because they have experience of pregnancy, local maternity services, and some have experienced mental health problems. This participatory approach to research emphasises the importance of carrying out research with the involvement of people who have experiences of the research subject (mental health during pregnancy), and not just researchers from universities and professional services.

Why have you been approached?

We would like to talk with women with experiences of pregnancy (past or present), their families and professionals who work with antenatal and postnatal mothers. We would also like to talk to women who have had experiences of mental health problems during pregnancy. We think that by

asking community members and people who work with community members, we will learn more about what is needed to meet community needs.

Do you have to take part?

Whether or not you decide to take part is up to you, and will not affect any of the services you are entitled to receive from the NHS. If you agree to take part, you are free to drop out at any time. If you decide to drop out, you do not have to give any reason to anyone. Taking part in this study is not part of any treatment or care you are receiving treatment from the NHS. If you do decide to take part, we will ask you to sign a consent form, and go through the form with you.

What would you be asked to do?

If you are happy to take part, we will ask to meet you either at the *(location removed)* or agree an alternative with you if this is not convenient. The research will involve taking part in an individual or group discussion about your views on mental health in pregnancy. This is an information sheet about taking part in an individual, one-to-one discussion with a researcher, you are free to change to a group, if you would rather take part in a group discussion with researchers and other community members. Please ask if you would like to have a copy of the information sheet for group discussions. Whether you take part in an individual or group discussion is up to you. It is up to you to decide how much you say during the discussion. You will not be put under pressure to answer any questions or to say anything that you are not comfortable talking about. The discussion should take around 60 to 90 minutes. If you need to arrange travel or child-care to take part in this research, then we will reimburse you for these expenses.

At a later point we may also like to talk to you about the results of the study, to get some feedback from you about how well the results match up with your ideas.

We will audio record the discussions to make an accurate record of what was said. The content of the discussions will be written down, and the recordings will be destroyed at the end of the study. Your name and any details about you and where you live will not be included on the written version.

Risks and benefits of taking part

There are no medical risks or benefits involved in taking part in this research. Some of the discussions may include topics that are sensitive or upsetting. If you are upset during or after the discussions, then we can arrange for you to discuss your feelings with the clinical psychologist, who can also give you information about other sources of support. You may also find that talking about your experiences has a positive effect on how you feel about them. You will have opportunities to talk with women who have similar experiences to you.

Your participation in the study is confidential. However, it is important for you to know that there are some limits to confidentiality. If the researchers become aware of risk of harm, including harm to children or vulnerable adults, then we cannot guarantee full anonymity. Further details about how your data will be protected are in Part 2 of this sheet.

This is the end of part 1 of the information sheet. If you are interested in this research after reading this information, please read part 2 before you make a final decision about taking part.

Part 2

What happens if you wish to withdraw from the research?

If you decide during or after taking part that you wish to withdraw from the research, please let the researchers know. If you decide to withdraw from the research, your contributions to the discussion will not be included in the analysis and writing-up the research.

What if there is a problem?

If you have any cause for complaint, please discuss this with the researchers in the first instance. Hopefully we will be able to resolve any problem quickly and to your satisfaction. If you do not feel comfortable discussing your complaint with us, if you are not satisfied with our response, or you wish to make a formal complaint, then please contact Professor Richard Gray at the University of East Anglia on 01603 597132 for further information.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of East Anglia, but you may have to pay your legal costs.

How will your confidentiality be protected?

All the information about you (audio recordings, consent forms and written information) will be managed in accordance with the Data Protection Act (1998). How this will be done is laid out in this information sheet. Your data will be stored in a locked filing cabinet, in a locked office at the University of East Anglia. After you give consent, any data collected about you will be given an anonymous code, so that your name is not attached to anything you say in the discussions. Wendy Franks will be responsible for the secure storage of your data at the university. Other members of the research team will have access to your information for the purposes of making contact with you. The research sponsors, regulatory authorities and Research & Development audit may also seek access to your data for monitoring of the quality of the research. All of these organisations are also bound by rules of confidentiality. You have a right to check the information held about you to make sure it is accurate. This information will be destroyed at the end of the study. No data will be transferred outside of the United Kingdom, and your data will not be used for any other purposes than this research project.

What would happen to the information?

Discussions will be audio recorded on a digital recorder. The digital audio files will be transferred and encrypted as soon as possible to a secure computer at the University of East Anglia. Audio recordings will be transcribed by Wendy Franks, and verified by Dr Kenda Crozier at the University of East Anglia. No identifying information (such as names or other identifying details) will be transcribed onto paper. After all of the data is collected, it will be analysed and used to write a report that describes the research and the results. This will contain some quotations, but not the names of who said what. The report may be used by local health service planners to get a better idea of what people in the community think. Articles may be written from the research and published in journals

read by other researchers and mental health professionals, but it will not be possible to identify you from any of these reports.

Who is organising and funding this research?

This research is organised and funded by the University of East Anglia. It is being carried out as part of a PhD being undertaken by Wendy Franks, in collaboration with members of the community in *(location removed for anonymity)*. Wendy's role in the research is supervised by Professor Richard Gray and Dr Kenda Crozier at University of East Anglia. All community researchers are Honorary Research Associates at the University of East Anglia.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Essex Research Ethics Committee.

Further information and contact details

If you require any further information about this research, please contact:

(information removed for inclusion in thesis)

If you agree to take part in this study, you will be given a copy of this information sheet and signed consent for you to keep.

Thank you for your time in reading this information.



Faculty of Health
School of Nursing & Midwifery

University of East Anglia
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United Kingdom

w.franks@uea.ac.uk
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Participant Information Sheet (Group Discussions)

You are being invited to take part in a research study. Before you decide whether to 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. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Part 1

Study title: Participatory Qualitative Research into Antenatal Mental Health in (location removed for anonymity)

What is the study about?

This study aims to find out about how pregnant women, their families, and people who work in maternity services understand mental health problems and experience services for pregnant women. The results of this research will be used to inform existing services, and may lead to the development of new services or projects. This research is being carried out by a team of researchers, including three mothers from the local community and one PhD research student/clinical psychologist who has been working in the NHS for the past 7 years. The local mothers who are involved in this project have received some research training, but do not have formal research qualifications. They are from the local community and are contributing to this study because they have experience of pregnancy, local maternity services, and some have experienced mental health problems. This participatory approach to research emphasises the importance of carrying out research with the involvement of people who have experiences of the research subject (mental health during pregnancy), and not just researchers from universities and professional services.

Why have you been approached?

We would like to talk with women with experiences of pregnancy (past or present), their families and professionals who work with antenatal and postnatal mothers. We would also like to talk to women who have had experiences of mental health problems during pregnancy. We think that by

asking community members and people who work with community members, we will learn more about what is needed to meet community needs.

Do you have to take part?

Whether or not you decide to take part is up to you, and will not affect any of the services you are entitled to receive from the NHS. If you agree to take part, you are free to drop out at any time. If you decide to drop out, you do not have to give any reason to anyone. Taking part in this study is not part of any treatment or care you are receiving treatment from the NHS. If you do decide to take part, we will ask you to sign a consent form, and go through the form with you.

What would you be asked to do?

If you are happy to take part, we will ask to meet you either at the *(location removed)* or agree an alternative with you if this is not convenient. The research will involve taking part in an individual or group discussion about your views on mental health in pregnancy. This is an information sheet about taking part in a group discussion with researchers and other community members, you are free to change to an individual discussion, if you would rather take part in a one-to-one discussion with a researcher. Please ask if you would like to have a copy of the information sheet for individual discussions. Whether you take part in an individual or group discussion is up to you. It is up to you to decide how much you say during the discussion. You will not be put under pressure to answer any questions or to say anything that you are not comfortable talking about. The discussion should take around 60 to 90 minutes. If you need to arrange travel or child-care to take part in this research, then we will reimburse you for these expenses.

At a later point we may also like to talk to you about the results of the study, to get some feedback from you about how well the results match up with your ideas.

We will audio record the discussions to make an accurate record of what was said. The content of the discussions will be written down, and the recordings will be destroyed at the end of the study. Your name and any details about you and where you live will not be included on the written version.

Risks and benefits of taking part

There are no medical risks or benefits involved in taking part in this research. Some of the discussions may include topics that are sensitive or upsetting. If you are upset during or after the discussions, then we can arrange for you to discuss your feelings with the clinical psychologist, who can also give you information about other sources of support. You may also find that talking about your experiences has a positive effect on how you feel about them. You will have opportunities to talk with women who have similar experiences to you.

Your participation in the study is confidential. However, it is important for you to know that there are some limits to confidentiality. If the researchers become aware of risk of harm, including harm to children or vulnerable adults, then we cannot guarantee full anonymity. Further details about how your data will be protected are in Part 2 of this sheet.

This is the end of part 1 of the information sheet. If you are interested in this research after reading this information, please read part 2 before you make a final decision about taking part.

Part 2

What happens if you wish to withdraw from the research?

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What if there is a problem?

If you have any cause for complaint, please discuss this with the researchers in the first instance. Hopefully we will be able to resolve any problem quickly and to your satisfaction. If you do not feel comfortable discussing your complaint with us, if you are not satisfied with our response, or you wish to make a formal complaint, then please contact Professor Richard Gray at the University of East Anglia on 01603 597132 for further information.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of East Anglia, but you may have to pay your legal costs.

How will your confidentiality be protected?

All the information about you (audio recordings, consent forms and written information) will be managed in accordance with the Data Protection Act (1998). How this will be done is laid out in this information sheet. Your data will be stored in a locked filing cabinet, in a locked office at the University of East Anglia. After you give consent, any data collected about you will be given an anonymous code, so that your name is not attached to anything you say in the discussions. Wendy Franks will be responsible for the secure storage of your data at the university. Other members of the research team will have access to your information for the purposes of making contact with you. The research sponsors, regulatory authorities and Research & Development audit may also seek access to your data for monitoring of the quality of the research. All of these organisations are also bound by rules of confidentiality. You have a right to check the information held about you to make sure it is accurate. This information will be destroyed at the end of the study. No data will be transferred outside of the United Kingdom, and your data will not be used for any other purposes than this research project.

What would happen to the information?

Discussions will be audio recorded on a digital recorder. The digital audio files will be transferred and encrypted as soon as possible to a secure computer at the University of East Anglia. Audio recordings will be transcribed by Wendy Franks, and verified by Dr Kenda Crozier at the University of East Anglia. No identifying information (such as names or other identifying details) will be transcribed onto paper. After all of the data is collected, it will be analysed and used to write a report that describes the research and the results. This will contain some quotations, but not the names of who said what. The report may be used by local health service planners to get a better idea of what people in the community think. Articles may be written from the research and published in journals

read by other researchers and mental health professionals, but it will not be possible to identify you from any of these reports.

Who is organising and funding this research?

This research is organised and funded by the University of East Anglia. It is being carried out as part of a PhD being undertaken by Wendy Franks, in collaboration with members of the community in *(location removed)*. Wendy's role in the research is supervised by Professor Richard Gray and Dr Kenda Crozier at University of East Anglia. All community researchers are Honorary Research Associates at the University of East Anglia.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Essex Research Ethics Committee.

Further information and contact details

If you require any further information about this research, please contact:

(details removed for inclusion in the thesis)

If you agree to take part in this study, you will be given a copy of this information sheet and signed consent for you to keep.

Thank you for your time in reading this information.

Appendix E: Consent forms for individual and group discussions



University of East Anglia

Faculty of Health
School of Nursing & Midwifery

University of East Anglia
Norwich NR4 7TJ
United Kingdom

w.franks@uea.ac.uk
www.uea.ac.uk

CONSENT FORM

Title of Project: Participatory Qualitative Research into Antenatal Mental Health in *(location removed for anonymity)*

Names of Researchers: Wendy Franks, *(co-researchers names removed for inclusion in thesis)*

Please
initial box

1	I have read and understand the information sheet dated November 2009 – (Individual) (version 2) for the above study. I have had the opportunity to ask questions and had satisfactory answers to all of my questions.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3	I understand that relevant sections of my data collected during the study, may be looked at by research supervisors (Prof R Gray and Dr K Crozier) from University of East Anglia, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my research records.	
4	I agree that my comments in the discussion can be audio recorded and written down, and that anonymised quotations can be included in reports of the research findings.	
5	I agree to take part in the above study.	

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

1 for participant; 1 for researcher (to be kept at University of East Anglia)

CONSENT FORM

Title of Project: Participatory Qualitative Research into Antenatal Mental Health in *(location removed for anonymity)*

Names of Researchers: Wendy Franks, *(names removed for inclusion in the thesis)*

Please
initial box

1	I have read and understand the information sheet dated November 2009 (Group) – (version 2) for the above study. I have had the opportunity to ask questions and had satisfactory answers to all of my questions.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3	I understand that relevant sections of my data collected during the study, may be looked at by research supervisors (Prof R Gray and Dr K Crozier) from University of East Anglia, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my research records.	
4	I agree that my comments in the discussion can be audio recorded and written down, and that anonymised quotations can be included in reports of the research findings.	
5	I agree to take part in the above study.	

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

1 for participant; 1 for researcher (to be kept at University of East Anglia)

Appendix F: Initial Discussion Topic Guides

Discussion topics for women:

What have women experienced as supporting women's mental health during pregnancy?

What have women experienced as causing problems for women's mental health during pregnancy?

What are women's experiences of services during pregnancy?

What do women think is needed from services and from their communities to support their mental health during pregnancy?

Discussion topics for professionals including health visitors and midwives:

What are their experiences of working with women with mental health problems during pregnancy?

What do they think supports and undermines women's mental health during pregnancy?

What do they think is needed to support women's mental health during pregnancy?

What do non-mental health professionals understand about mental health during pregnancy?

What training have non-mental health professionals had about mental health during pregnancy?

What training do non-mental health professionals need about mental health during pregnancy?

Appendix G: Details of the research team members involved in the data generation and preliminary coding

Participant Identity	Data generated with	Initial coding done by
GC1	WF, SD	WF, SD
GC2	WF ▲	WF, CW
GM1	WF, DD	WF, DD
GM2	WF ▲	WF, CW
IM1	WF, SD	WF, SD
IM2	WF, SD	WF, SD
IM3	WF ▲	WF
IM4	WF, DD	WF, DD
IM5	WF ☒	WF
IM6	WF, SD	WF, SD
IM7	WF ▲	WF, CW
GP1	WF, DD	WF, DD
GP2	WF ▲	WF
IP1	WF ☒	WF
IP2	WF ☒	WF
IP3	WF, SD	WF, SD
IP4	WF ☒	WF
IP5	WF, CW	WF, CW
IP6	WF, DD	WF, DD
IP7	WF ▲	WF
IP8	WF ▲	WF

☒ Preferred a one-to-one meeting

▲ Co-researcher unavailable

Appendix H: Example of a section of index spreadsheet

Mothers' data – what is needed to support mental health

location	text	code 1	code 2
IM4/27/1299	I had a couple of ladies come round not too long ago and say, 'well, we think that you would benefit from seeing this counsellor, and from going to this group' doing that --- and if they'd done that to begin with, while I was still pregnant --- I would have got a lot more out of it	advice and information	not just leaflets
IM6/29/1412	there's not really a lot of preparation for [husband] either, there's no one telling him, unless he reads it, what to expect, whereas I kind of envisaged that you'd have antenatal classes, and you'd look at the breathing, and know what to do and.. I feel like I'm going into it all a bit blind	antenatal classes	information for husband
GC1/42/2070	we were lucky enough to do two antenatals --- but I mean, we didn't even get to finish our antenatal because [eldest] came so early, um, and, you know, you don't get to see other people until you're like, thirty four weeks pregnant... um.. where, you know, if you're unlucky like me, and your children come at thirty five weeks, and thirty three weeks --- you might not even get to see other people that --- you know, could possibly then be in hospital with you at the same time	antenatal classes	peer support
IM6/8/383	if I had somebody who was very approachable, at times when there's been particular symptoms you think, '[intake of breath] is that something to worry about', I perhaps would either phone, or.. think that's not too much trouble if I pop in, but with him, it's kind of like --- 'oh, I'll see what it's like next week' and.. you know, I could, I felt I could have been putting myself at risk	approachable	available
IM7/31/1508	it's really has to be made aware, I mean.. there are cases where children do need to be taken in, and you know, Baby P.. should have been investigated further, obviously, but they're not just taken off you for no reason --- and the help is, you've got to .. get help	awareness	get help when needed
GC1/55/2726	it would be good to get a book.. before you're pregnant --- to tell you everything that's gonna happen properly [asked if this might be possible?] yeah, possibly not --- and even if it did come out, I'd probably go, 'oh yeah, but I wouldn't do it like that' so that [laugh]	book/ information	
IM1/32/1580	I've got this habit where I think oh people are telling me a load of crap cause they just wanted to get on [inaudible] and just go away, but at least then, like you can talk to one person about something, and then you can go and check it out with that other person --- and see if they suggest the same sort of thing	checking with others	information
IM1/33/1602	sometimes what works for one person don't work for the other --- so, it's nice to be able to get, sort of, different views and opinions	checking with others	information
IM1/31/1542	I think really there could be more community based things, like more, sort of, more information given out for um, pregnant women who have got mental health issues and stuff, where they can go to somewhere, like, say like a group here at the [Children's Centre]	community groups	information
IM1/32/1549	even if it's just once a week to discuss, like pregnancy and their mental health and how it's affecting them	community groups	peer support
IM1/32/1555	I think maybe something like that, a community based thing where anyone.. can just walk in if they need to --- like a drop in clinic, sort of thing --- I think that'd be quite a good thing --- that could help.. I know I would have used it, if there was something here like that	community groups	drop in
IM2/52/2559	the only thing else I think that would be.. really useful as a, a basis, you know that are baby cafes, and there are breastfeeding cafes and stuff in the local area --- there isn't, or I don't know of any, pregnancy cafes --- where you can go, when you're pregnant, and spend that couple of hours	community groups	peer support
IM2/53/2611	it's just, I mean, if it's, you know, once a week, for a couple of hours, where.. we can get together, and .. sit and have a cup of tea, and you can air your thoughts, and .. the feeling like you're not alone in what you're thinking	community groups	peer support
IM3/26/1281	yeah, just somewhere to go and just sort of... just sort of talk to, sort of, other people that are pregnant, or --- anyone really, and just sort of, people that actually.. want to listen and haven't got to rush off to .. sort of their next appointment or really just can't be bothered to give you, sort of time of day	community groups	support

Appendix I: An example of theme development based on initial coding and indexing

Mothers – what is needed

What mental health services should do

- Occupational therapy/activities (IM1/28/1356)
- Regular appointments with mental health professionals (IM2/37/1832)
- Time to talk through thoughts with professionals (IM3/35/1737)

Community services – by professionals

- Support for community groups/drop in clinic (IM1/32/1555)
 - Informal/unstructured (IM3/47/2309) & activities (GC1/42/2057; GC1/45/2227; GC1/46/2241)
 - More often (GM2c/44/2164)
 - Not just for depression (GC1/42/2043)
 - Antenatal classes earlier in pregnancy & meeting other pregnant women (GC1/42/2070; GC1/44/2156)
- Ongoing support, not time/age limited (IM3/48/2358)
- Pregnancy café – not just for breastfeeding (IM2/52/2559; IM2/53/2611; IM6/28/1383)
 - Flexible time, out of working hours (IM6/28/1383)

Community support – by community

- Peer support groups (IM1/32/1549; IM3/26/1281; IM6/29/1406)
 - Opportunity to get different opinions from different people (IM1/33/1602, IM6/34/1683)
 - Someone to talk to/Being listened to (IM3/26/1281; IM3/35/1720; IM7/31/1522)
 - Support as mum-to-be not just mental health (IM6/34/1683, IM6/35/1697)
 - face-to-face, not computer (IM6/35/1716)
 - emotional support (GM2c/47/2334)
- Regular contact with trained support worker with personal experience (like Home Start) during pregnancy (IM2/48/2361)
- Making supportive friends (IM3/41/2021)

Family support

- Support for family to help them support women

- Husband (IM6/36/1760)

Professional relationship with women

- Professionals to write letters to support claims/housing requests (IM3/31/1514)
- Being believed & given help when disclosing abuse (IM3/43/2104)
- Professionals who really listen (IM5/34/1681; IM5/38/1856)
 - Someone to talk to (IM5/39/1918)
 - Emotional support (GC2/31/1538; GM2c/44/2156; GM2c/47/2305)
 - Get things off your mind (IM5/37/1831)
 - Notice you're not ok even if you say you are (IM5/36/1766; IM5/42/2068)
 - Professionals who care, not just there for the money (IM3/50/2476; IM3/51/2510)
 - Being nice (GM2c/45/2237; GM2c/47/2305)
 - Approachable GP (IM6/8/383)
 - Realise you need extra support (IM6/33/1630)
- Reassurance that it's real and can be helped (IM5/1/28)
 - You're not going mad (IM5/38/1856; IM6/3/138, IM6/34/1672)
- Proactive professionals making contact with you (IM5/41/2044, IM5/42/2068)
- Regular visits (IM5/41/2044)
 - & reassurance about the pregnancy (IM5/3/142)
- Being able to talk & ask for help without being judged (IM5/35/1708; IM5/39/1903; IM7/31/1508)
 - Not taking baby away (IM5/38/1859; IM5/38/1895; IM7/31/1508)
 - Not going to be locked up (IM5/38/1871)
 - Informal – not written down (IM6/30/1449)
 - Young mums (GM2a/10/457; GM2c/46/2272)
- Understanding and help (IM5/37/1808, IM5/41/2021; GM2c/48/2378)
- Making women feel there's nothing to be ashamed of (IM7/30/1479)
 - Understanding that depression is an illness like any other (IM7/32/1579)

Communication

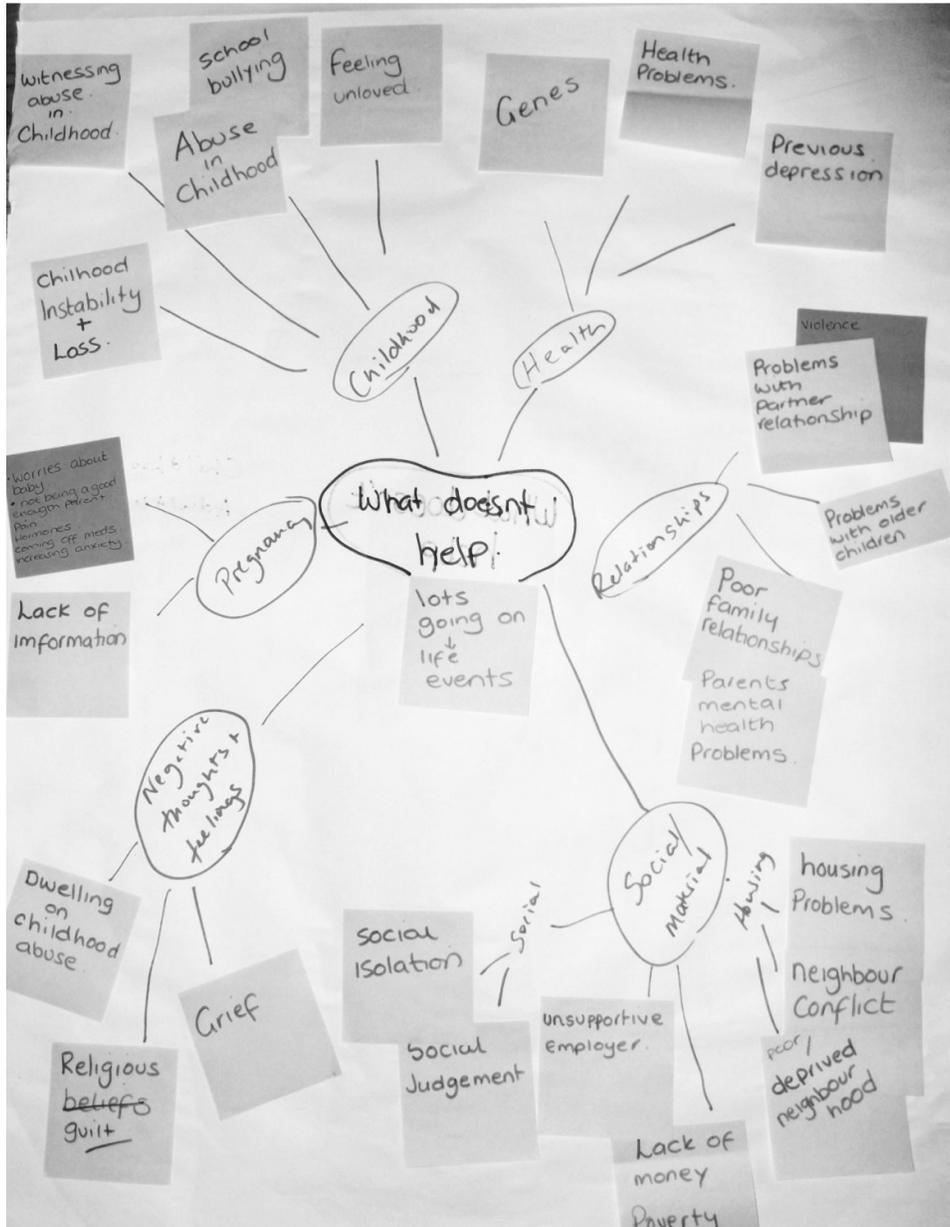
- Information about mental health groups and services available (IM1/31/1542; IM7/30/1458; GC1/42/2043)
 - Not just leaflets but visit and assess/guide (IM4/26/1288)
 - Earlier during pregnancy, not post (IM4/27/1299)
 - How to contact services for follow-up (IM5/42/2051)
- Information about mental health (IM5/34/1696)
 - That you can check with different people (IM1/32/1580)

- Not being brushed off (IM1/32/1580; IM3/26/1281)
- Information and advice/reassurance (IM5/34/1681; IM6/7/338)
 - about parenting (IM2/41/2026)
 - About birth (IM6/29/1412)
 - Informal, not in a book (IM6/30/1475)
 - In a book (GC1/55/2726)
 - Professional face-to-face, not computer (IM6/35/1716)
- Telephone helpline 24 hr advice (IM2/46/2244)
- Women need to say that they need help (IM7/30/1458)

Professional knowledge

- Medication research – safety of drugs/doses for pregnant women (IM1/28/1369; IM1/28/1375)
- Competence, advice about benefits (GM2c/45/2214)

**Appendix J: Example of a thematic map with post-it notes on flip chart:
what undermines women's mental health?**



Appendix K: Excerpts from reflective journal about NHS Research Ethics processes

Ethics continued: 05.08.09

This process has seemed incredibly excluding, even for me as a relatively research and NHS-aware professional and academic. I don't imagine how community members could navigate this system with anything other than a huge level of motivation and support to put together everything needed to get through the hoops. I can hardly remember all of the people I have been in contact with, from various organisations, to seek advice and guidance on completing the paperwork.

I have had advice from:

- my supervisors
- an NHS midwifery manager
- two people at the university REE department
- the Faculty of Health research office
- someone from PPIRES (Public & Patient Involvement in Research)
- someone from INVOLVE
- someone from the R&D office at NHS primary care trust
- two members of the R&D committee at the local hospital

Several of these people have sought advice from their colleagues and got back to me.

There are issues to be resolved including:

- Research Passports/levels of pre-engagement checks
- Letters of access/agreement between UEA & Trusts (and which trusts!)
- IRAS forms
- R&D approval
- Honorary Contracts
- UEA ethics

Each time, it seems that there is a new level of bureaucracy to deal with. Some of this relates to my being a student at the university, and university structures overlaying NHS structures. However, this is also a way in to the system, giving me credibility and access as a registered PhD student with faculty supervisors.

Particularly overwhelming, has been the amount of documentation to deal with in the process. Frequently, when I have asked what I think is a relatively straightforward question; I am often sent another lengthy document to plough through as reply. My own attention span and powers of concentration are challenged by all of this documentation, uncertainty and confusion. I am a literate and relatively well educated professional who is struggling with the amount of documentation that I have to both consume and produce in the process of negotiating access to this research activity. Without making assumptions about non-professional/non-academic community researchers, I think this does clearly exclude some within the population from engagement in research.

NHS Research Ethics committee meeting 15.10.09

The meeting was running late, and I waited until around 5:50 pm before I was called in. The person before me was presenting a clinical trial evaluating Asthma drug intervention for children, and at the end of the meeting I could hear laughing, and he came out smiling and saying thank you...

There was a wait before I went in, during which I could hear them talking, but not much in the way of content. I was invited in and seated at a small table at the front of the room, with a U-shaped arrangement of tables with perhaps 10 or 12 people seated. I was asked if I was ok, as the committee were aware of the personal circumstances which caused me to ask for a later time (father-in-law's funeral on that day). I said I was fine. They introduced themselves and explained that a few members would take a lead on the questions, and all might chip in at times.

The initial question was from the lay member (a bereavement counsellor) regarding inclusion criteria and diagnosis. I gave a short background on the service that I work in, which uses diagnostic criteria for access, and that this can sometimes exclude people from accessing services. I explained that it was important for the study to be inclusive rather than exclusive, and therefore all women who considered themselves to have/have had mental health problems during pregnancy would be eligible to take

part. The lay member said ‘so you’re asking them to diagnose themselves’. I said that I considered diagnosis to be a medical process to be carried out by doctors, and that rather than diagnosis; we were asking people to identify themselves as having had mental health problems, not to diagnose themselves with any illness.

This much of the meeting I remember pretty clearly, the rest of the meeting seemed to go from bad to worse and I remember feeling upset at times, angry at times and unsure of myself. My impression of some members of the committee was that their style in the meeting was quite inquisitorial, interjecting and pressing for clarification before I had finished a sentence at times. For example, I had been asked about training for the co-researchers, and I started to say that we would be developing the training collaboratively, and I was interrupted by one member with what seemed like a barely disguised scowl and dismissive tone saying something like ‘sorry, what do you mean by “developing collaboratively”?’, and so on.

Very early in the meeting, I was asked – ‘so, these women you have co-opted into your research...’, I felt I had to respond by saying that I did not feel I had ‘co-opted’ anybody, and that they volunteered to take part, and were responsible for helping to develop and design the research from the outset, so that it was their research as well as mine.

I was asked to explain: Where do these women come from? I was explaining the process of how the women had become involved through recommendation from my professional contacts and was challenged about doing this without ethical approval. I explained that I had sought advice, and it was my understanding that I did not need ethical approval to have community members consulting on the development of research. There were some expressions of concern about the process, and I replied that in my awareness, researchers (like many of us at this meeting) seek out colleagues to collaborate on research together in relatively informal ways, according to skills and interests, and that a similar process applied to the development of this research team. The important skills for the community members of the research team were their local knowledge and their expertise by experience of both pregnancy and mental health problems.

I was concerned about stigma from the ethics committee members in regarding the co-researchers as risks to be managed, particularly in relation to their experiences of mental health problems. One memorable phrase in relation to risk in managing difficult situations during data gathering was ‘These women with psychiatric

illnesses...’ I had explained that I would always be on site and available to help out during data gathering if there were any problems that the co-researchers felt they couldn’t manage. I explained that I would have to be there not least because the data would have to be taken by me to the university once the discussions had been recorded.

By the end of the meeting, my opinion was that members of the ethics committee did not consider the co-researchers to be equal to me and to other academic/clinical researchers, and most of their concerns were about how the situation could be regulated to protect them from harm, and protect others from harm by them. It was not said, but because of the way they spoke to me, I felt that they perhaps thought me naïve or ill-considered in undertaking this research in this way. At one point, I was disagreeing with them about the relative risks of the co-researchers having one to one conversations with research participants without me being in the room. We had discussed that we would begin by having joint conversations in small groups with me and another co-researcher present while we all developed our understanding of the processes of the data gathering, and that this would be part of the training/development of all of our skills. A member of the committee was expressing concerns that there would be times when a co-researcher and research participant might be alone in a room together during data generation. I said yes, that was the plan, and asked them whether they thought something improper might occur in that situation. The ethics committee member referred back to the co-researchers’ experiences of psychiatric illnesses, and that it was important for the committee to think about the potential for harm or discomfort to them as well as to participants. Unfortunately, a lot of the detail of the meeting seems unclear in my memory, but I am very clear that I had felt angry and upset with the way I was questioned at times, and the unspoken way that the committee seemed to disregard the value of having community members involved in the research, and seemed to regard them as a problem to be managed by the experts (i.e.: them and me) within the process of the research.