Addressing the treatment gap for perinatal depression within an integrated primary health care model. Development and feasibility study in the Dr Kenneth Kaunda District, North West Province

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Declaration

I declare that this thesis titled "Addressing the treatment gap for perinatal depression within an integrated primary health care model. Development and feasibility study in the Dr Kenneth Kaunda District, North West Province" submitted to fulfil the requirements of the degree of Doctor of Philosophy at the University of KwaZulu-Natal represents my own original work written by me. Any assistance that I have received during the research has been duly acknowledged. All literature and information sources have been acknowledged in the thesis.

This thesis has not previously been submitted for a degree or any other qualifications to this or any other institution.

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Dedication

This PhD is dedicated to my husband Zunaid who has walked this PhD journey with me, and has supported me with his presence and his patience, to my daughter Naseera who has inspired me to improve not only my own life, but the lives of others, and my brother Fazal whose quiet influence encouraged my academic path.

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Abstract

Background: Perinatal depression (PND) is a common mental disorder (CMD) with onset either during pregnancy or in the postnatal period, with potentially harmful inter-generational impacts on families, and by extension on communities. In South Africa a combination of high prevalence rates for PND, an estimated treatment gap of 75 percent for CMDs, and a large medically uninsured population poses a public health and social burden. Compounding the issue, there is a lack of awareness of and minimal attention paid to PND in scarce-resourced primary health care (PHC) settings in South Africa. Consequently, screening, referral and treatment for PND is low to absent, as are targeted pharmacological and psychosocial therapies for PND. Internationally, evidence supports the concepts of both collaborative care and task-sharing to address PND in low-and middle-income countries (LMIC). In South Africa however, despite support for the integration of mental health services into general health care, promotion of perinatal mental health care, and endorsement of task-sharing in mental health care, promoted by a national mental health policy framework, there is an absence of clear strategies to address PND in the mandated maternity care guidelines in PHC. In response to this service and evidence gap, the aim of this study was to co-develop and evaluate the feasibility of a culturally and contextually appropriate integrated model of care for PND with PHC service users and service providers. The research aimed to contribute towards the body of evidence towards the development of integrated, PHC-based, task-shared collaborative care for PND in South Africa and other LMIC. The study was guided by explanatory models of illness and the UK Medical Research Council framework for complex interventions.

Methods: Set in an urban 24-hour service community health centre in the Dr Kenneth Kaunda District, North West province, and nested within the larger PRogramme for Improving Mental health CarE (PRIME) project, the study was undertaken using a phased approach. The first step was an in-depth review of the literature on task-shared care, integrated or collaborative care for PND, particularly in LMIC, and the platforms, models and cadres used in task-shared care for PND. These essential components for task-shared PND care in LMIC were identified and guided the development of the interview schedules for both service users and service providers. In-depth semi-structured interviews were conducted with 20 service users to understand their perceptions, attitudes to task-shared care and recommendations to address PND, using thematic analysis to analyse the data. This work comprised the first phase of the study. In the second phase, nurses (n=10), HIV counsellors (n=20) and operational managers (n=4) were interviewed to gauge their clinical understanding of PND, attitudes to task-shared mental health care and recommendations to address PND. This was followed by a participatory workshop which included nurses, managers and specialists to co-develop a model of care for PND. An additional six key informants were interviewed for institutional perspectives and guidance on the model. Framework analysis was used to analyse the data in this phase. In the third phase, a quasi-experimental cohort design was used to recruit perinatal care attendees (n=54) to evaluate depression outcomes, feasibility and acceptability of the model. Primary care nurses consulting women attending antenatal and postnatal services were trained to identify women with depressive symptoms using a short maternal depression screening tool, and clinical assessment. Pregnant and postnatal women (6-48 weeks postpartum) who had mild/moderate depressive symptoms were referred to an existing 9-session manualized counselling intervention addressing common triggers of depressive symptoms, based on cognitive behavioural approaches, provided by a co-located non-specialist counsellor. Women with

moderate/severe depressive symptoms were referred to both the counsellor and upwards for specialist assessment and treatment. Participants were administered a questionnaire including the Patient Health Questionnaire 9 (PHQ9).

Service users (n=31) identified by nurse clinicians and referred for counselling and/or further treatment were assigned to the intervention arm, and service users (n=23) not identified with PND by the nurse, but who screened positive on the PHQ-9 were assigned to the control arm. Participants were interviewed at baseline and four months after baseline to assess change in PHQ-9 scores. Qualitative process evaluations were also conducted with five service user participants and eight health workers after the four-month assessment to identify evidence of feasibility and acceptability, challenges and recommendations.

Results: The qualitative results from the first phase indicated support for task-shared care and produced service-user recommendations to address the need for psychoeducation, support groups and counselling, either at community or facility-levels for PND. The second phase service provider engagement (participatory workshop) culminated in the co-development of a task-shared, collaborative care model for PND, with strengthened referral pathways, based on the nurse clinician screening, diagnosing, and referring onward to either a facility-based non-specialist counsellor, a doctor or a mental health specialist. In the third phase, an evaluation of the task-shared, collaborative care model with strengthened referral pathways to a co-located psychosocial intervention delivered by non-professional mental health workers at PHC level, indicated a clinically significant decline in depression scores (10- point reduction) in the intervention arm from baseline (M=14.3, SD 2.9), and at four-month follow-up (M=4.3, SD 4.5). Qualitative data indicated that participants experienced

the counselling intervention as beneficial and acceptable. The non-specialist, co-located counselling was viewed by most nurses as beneficial although there were recommendations to streamline the screening and diagnosis process. Process indicators suggest that the model is feasible and acceptable.

Conclusion and recommendations: This study has contributed new applied knowledge regarding the development and evaluation of a task-shared, integrated, collaborative care model for PND at PHC level in South Africa, providing evidence of feasibility and acceptability of the model of care. The favourable results suggest the potential for a larger effectiveness study, based on the recommendations and lessons garnered from this study. At the time of this report, the policy developments within the mental health landscape demonstrate a level of awareness among a minority of policy-makers, researchers and health care providers of the need to promote perinatal mental health. However, the lessons from this study suggest that key policy level changes are required which include but are not confined to the adoption and reporting of mental health data elements and indicators for PND, and adaptations to the maternity guidelines to include detection in the form of brief screening, assessment, diagnosis and referral for PND. With reference to task-shared mental health care, the inclusion of social workers in counselling treatment plans, and the identification of appropriate cadres, trainers, training, and supervision for non-specialist mental health counsellors are critical factors that require concerted political will and effort.

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Acronyms

APC	Adult Primary Care
BANC	Basic Antenatal Care
CBT	Cognitive Behavioural Therapy
CHC	Community Health Centre
CHW	Community Health Worker
CMD	Common Mental Disorder/s
DKKD	Dr Kenneth Kaunda District
DOH	Department of Health
EPDS	Edinburgh Postnatal Depression Scale
FGD	Focus Group Discussion
HIC	High Income Country/Countries
HIV	Human Immunodeficiency Virus
KII	Key Informant Interview/s
LAMIC/LMIC	Low-Middle-Income-Country/Countries
MDG	Millennium Development Goal/s
MhINT	Mental health Integration Project
MRC	Medical Research Council
NCD	Non-Communicable Diseases
PMAD	Perinatal Mood and Anxiety Disorder/s
PC101	Primary Care 101
PHC	Primary Health Care
PN	Professional Nurse
PND	Perinatal Depression

PRIME	PRogramme for Improving Mental Health CarE
SCID II	Structured Clinical Interview for DSM-IV
WHO	World Health Organization

CHAPTER 1

Introduction

1.1 Background

Depression is a common mental disorder (CMD) that is the leading cause of disability globally, contributing significantly to the global burden of disease according to the World Health Organization (WHO, 2011) . Moderate to severe depression differs from short-term stress and daily mood fluctuations, and can seriously impair functioning and quality of life if untreated. There are many complex factors that add to this burden of disease. Low diagnosis rates, lack of resources, and stigma associated with mental disorders fuel a burgeoning depression rate. Although treatable, at its worst, depression may lead to suicide (WHO, 2011).

1.2 Contextualising depression through a gendered lens

Increasingly, gender is conceived as an innate determinant of vulnerability to depression due to an aggregation of risk factors; these include power differentials attributed to the control that men have over socio-economic factors, status and role of women within societies, access to resources, as well as susceptibility and exposure to mental health threats (World Health Organization (WHO), nd). Such threats may include gender-based violence, which is often directed towards women, as well as socio- economic biases including low educational attainment and income opportunities, lower social status and other, more subtle but present, biases compared to men (WHO, nd). It has also been suggested that women may be more vulnerable to depression as they generally experience greater personal change and numbers of life events, compared to men; these experiences are usually negative in nature, including experiences of humiliation for many women, as well as feelings of entrapment, which may elevate the risk of depression (Ngcobo & Pillay, 2008).

Gender-specific demands relate to roles and power differentials within partnerships including marriage, while limitations on female roles in terms of employment and other socially

gendered role limitations may contribute to a constellation of negative life experiences (Ngcobo & Pillay, 2008). Unwanted or unintended pregnancy, low rank, subordinate social status, traditional gender roles promoting passivity and dependency, and unpaid domestic and agricultural work may all contribute to women's susceptibility to depression (Fisher et al., 2012). Gender-based violence is also highly predictive of adverse mental health outcomes (Groves, Kagee, Maman, Moodley & Rouse, 2012). Interpreting the wider social and economic environment plays an important role in understanding the causation of the gender differentials in vulnerability to depression across countries. Nonetheless, the evidence, including a report on gender disparities in mental health (WHO, n.d.) indicates that the prevalence of depression is skewed against women, who generally are reported to be affected doubly in comparison to men.

The burden of depression for both men and women has been reported as highest in sub-Saharan Africa, compared to six other regions worldwide; these are categorised as Asia and the Pacific region; North America, Europe and Central Asia; the Middle East and North Africa; Latin America and the Caribbean; and South Asia (Yu, 2018), with the rates of depression for women almost double that of men in all regions. In South Africa, which is geographically the southernmost tip of sub-Saharan Africa, this is supported somewhat by results from a local population-based prevalence study, which found that mood and anxiety disorders were more common in women than in men (Herman et al., 2009; Seedat et al., 2008).

While depression in women worldwide is often considered to manifest as somatic complaints, this is perceived to be more likely in the case of African women (Ngcobo & Pillay, 2008). The physical manifestation of this mental disorder adds another layer of complexity for women, who may be misdiagnosed due to the physical complaint/s, and who may seek help

(incorrectly) for physical complaints, which may in turn cause delays in diagnosis and treatment, or misdiagnosis (Ngcobo & Pillay, 2008).

1.2.1 The burden of perinatal depression

The over-representation of depression in women compared to men can in part be attributed to their unique susceptibility to depression in the perinatal period (defined as the period including pregnancy, childbirth and the postnatal period) (Chowdhary et al., 2014). This is a particularly vulnerable period for women, who are susceptible to unique biological risks related to pregnancy as well as psychosocial adversity (Yim et al., 2015). Regardless of social status, all women can develop mental disorders during pregnancy or after delivery. Perinatal status does not necessarily confer protection from environmental and structural drivers of depression, nor does it mitigate the risks of depression for women who have to deal with adverse macrosocial factors. Undeniably, environmental drivers, socio-economic adversities including interpersonal violence, and lack of social and material support are well documented as risks for depression in perinatal women (Agrawal, Ickovics, Lewis, Magriples, & Kershaw, 2014; Groves, Kagee, Maman, Moodley, & Rouse, 2012; Patel, Rodrigues, & DeSouza, 2002; Schneider, Baron, Davies, Munodawafa, & Lund, 2018; Yim et al., 2015).

Despite being one of the most common non-obstetric health complications of maternity (Silverman et al., 2017), perinatal depression (PND) is a neglected area of focus in health practice. Core symptoms of depression such as fatigue and issues related to sleep are commonly confused with common features of motherhood and therefore often not diagnosed correctly. The serious effects of PND are evident in both high-income countries (HIC) and

low- and middle-income countries (LMIC). Suicide is the leading cause of maternal mortality in developed countries and also in young women of reproductive age in India and China (Fisher et al., 2012). While global estimates of PND vary widely in terms of prevalence in HIC and LMIC, the figures are significant enough to warrant attention from funders and researchers, who have increasingly recognized the value of PND research, and to some extent health providers, who are recognizing the importance of managing PND.

A review of PND prevalence (Arifin, Cheyne, & Maxwell, 2018) reported a range of global prevalence rates between four and 63.9 percent, across both HICs and LMICs. Estimates may vary within contexts and countries due to the deficiency of large population-based screening using standardized screening tools, and lack of comparable culturally adapted screening tools. This applies equally across different countries, as screening tools may differ, as do cultural norms and attitudes influencing the management and reporting of PND or PND symptoms (Arifin et al., 2018).

Significantly, women are susceptible to depression in the perinatal period, as a result of direct obstetric risks and psychosocial risks posing a double burden of risk for women (Chowdhary et al., 2014; Yim et al., 2015). In the build-up to promoting the physical health of the mother, and amid positive expectations of maternal excitement, joy and bonding that is an expectation of childbirth and the experience of raising children, little attention is paid to the risk of PND. This experience can thus be very distressing and confusing for the expectant mother. High prevalence rates (Fisher et al., 2012; Hahn-Holbrook, Cornwell-Hinrichs, & Anaya, 2018) and a large treatment gap for PND (Rahman, Surkan, Cayetano, Rwagatare, & Dickson, 2013) contribute a significant proportion of the burden of common mental disorders (CMDs) worldwide. Limited investment in public mental health, particularly in LMIC has led to a gap

between the services required and resources available for public mental health challenges, including PND (Chisholm et al., 2016).

The treatment gap for mental health services has wide-ranging impacts for the people who suffer from the illness and their families, as well as for employers and governments in terms of lost productivity and increased health and welfare costs. These effects are compounded for untreated PND, which can potentially affect caregiving and cause long-term harm to the infant's social and cognitive development, particularly as the time-frame surrounding childbirth and infancy is a critical stage of growth and development for infants (Silverman et al., 2017). Young infants are distinctly sensitive to their environment and quality of care, and they are therefore likely to be affected negatively by maternal stress, depression and hampered functioning (Fisher et al., 2012).

In the context of high prevalence rates for PND (Baron, et al., 2016; Peltzer, Rodriguez, Lee, & Jones, 2018; Rochat, Tomlinson, Bärnighausen, Newell, & Stein, 2011; Stellenberg & Abrahams, 2015) and a large treatment gap for CMDs in South Africa (Seedat et al., 2009), PND is a public health concern for health systems, policy-makers, researchers and health practitioners in South Africa.

1.3 Theoretical and evaluation frameworks

While health care in South Africa is carefully planned, legislated and implemented, health epidemics, health programs, research and health practice all impact within the public health care domain. Cognizance must be taken of the multifaceted elements that interact and influence health systems and care. Public health policies, local health care priorities and international funding and health-promotion agendas dictate health care practice. The presence

or absence of other health care programs, resources, training programs and personnel dynamics are underlying forces that influence health care. The somewhat complex public health care contextual landscape may be complicated further by the introduction of new care models, and the complexity is evident particularly within shared care or collaborative care models. Characterised as complex interventions, collaborative care models are team-based models which incorporate mental and general health care in the same setting utilising services of key health care providers including a doctor, a case manager and a mental health provider the (Archer et al., 2012).Taking these multiple contextual elements into account, a specific evaluation framework and theoretical paradigm were used to underpin this research study.

1.3.1 Methodological framework

The UK Medical Research Council framework (MRC framework) for conducting and evaluating complex interventions to improve health (Craig, Dieppe, Macintyre, Michie, Nazareth & Petticrew, 2008) was used as the overarching framework to guide the study. The MRC framework was identified as the methodological basis to develop and evaluate the packages of care in the PRogramme for Improving Mental health carE (PRIME) project (Lund et al., 2012) within which this study was situated. The MRC framework recognizes the complexity of interventions located within and outside the health system, the lengthy process of each component of an intervention, and the importance of each step in the process, including thorough formative work, piloting and/or assessing feasibility of an intervention, and practical issues in implementing interventions. Thorough foundational work is emphasised, including application of appropriate theory, using the best available evidence in the field, and testing through piloting and/or feasibility.

Feasibility and piloting can be done multiple times, in an iterative process, promoting an

approach that emphasises thorough formative work and piloting before evaluating effectiveness. The MRC framework is based on four broad steps guiding large- scale research, including randomized control trials, but is appropriate for small scale research such as exploratory feasibility studies, which are used to guide further research. This guideline was therefore deemed appropriate to guide this feasibility study, using the processes outlined in black in steps 1 and 2 of the four suggested steps in Figure 1, and adapted for the study.

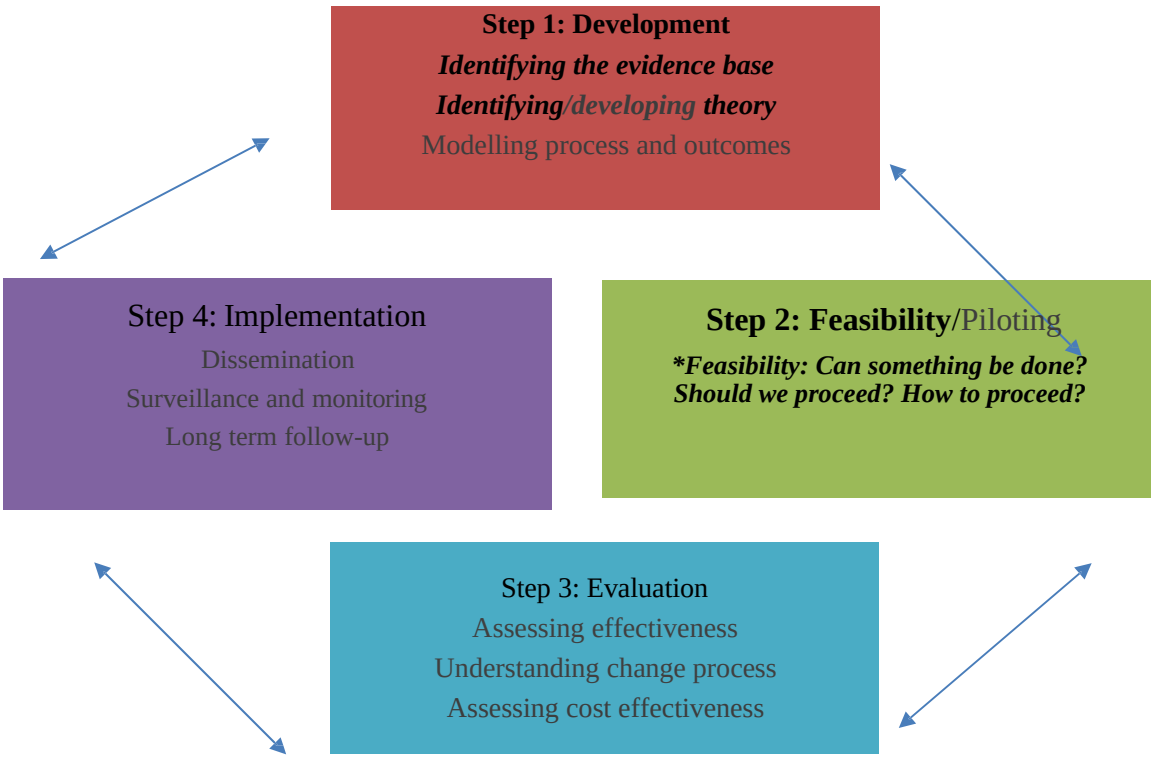

Figure 1:UK Medical Research Council framework to conduct and evaluate complex interventions to improve health

* The MRC framework does not provide explicit guidance on feasibility. Guidance for feasibility in Step 2 of diagram listed as expanded in Bowen et al. (2013).

Guided by the MRC framework, which proposes a thorough review of the literature in the developmental or formative phase, we conducted a thorough literature review detailed in Chapter 2 of this thesis, and which for the purposes of this study pertained to addressing PND at the primary health care (PHC) level in scarce-resource LMIC health care contexts. Given the differences in cultural and health care contexts within LMIC, it was evident that any intervention required careful understanding of how PND is perceived and treated in the local context.

1.3.2 Theory underpinning the understanding of context

For the formative research, we used Kleinman's explanatory model of illness (Kleinman, Eisenberg, & Good, 1978) as the basis to understand the triggers for depression in perinatal patients, to inform an appropriate treatment model. With health care being traditionally a 'specialist' domain, where health care is provided within specific policy guidelines, using the lens of explanatory models of illness ensured that attention was paid to cultural understandings in the analysis of the data generated during the formative phase, which was then used to inform the intervention that was piloted.

Explanatory models of illness are defined as understandings of illness and treatment within a health care system by healers, patients and other relevant stakeholders within the specified cultural context and beliefs of a society (Kleinman, Eisenberg & Good, 1978). Clinically developed (Aidoo, 2001) and relevant in countries such as South Africa, where alternative culturally based health systems operate in parallel to clinical health care, explanatory models typically seek to understand the way people understand an illness in relation to the cause, course and treatment options for their symptoms.

A distinction is emphasised between *disease* and *illness,* and the concept of cultural

constructions of clinical reality is described. Within this paradigm, the experience of *illness* is culturally defined, and is the human experience of sickness which may be more appropriately addressed using anthropologically and culturally suitable approaches, rather than purely biomedical care, which is focussed on treating *disease* (described as "abnormalities in the structure and function of body organs and systems" (Kleinman et al. , 1978, p. 141). Non-adherence with medical treatment and advice is also partly ascribed to social class differentiation between practitioner and patient. Better adherence and results for chronic patients utilizing folk practitioners rather than doctors are ascribed to 'explanation' and "greater concordance between the explanatory systems of the healer and the patient" (Kleinman et al., 1978, p.
141). The existence of culturally based mental health care in South Africa including that provided by religious, traditional and spiritual healers, social workers and counsellors in non-mental health settings (Seedat et al., 2009) signifies the influence of cultural and social beliefs and customs. Within the multicultural South African context, it is imperative to understand and treat illness according to the differing cultural contexts that exist, in order to maximise uptake of and success in treatment, as the experience of ill-health and the understanding of the illness are linked with treatment options and choices.

1.3.3 Framework underpinning the evaluation component

The study was divided into three phases corresponding with the first two steps of MRC framework for complex interventions.

- Study phase 1 corresponded with Step 1 of the MRC framework: Formative/developmental phase – service user engagement
- Study phase 2 also corresponded with Step 1 of the MRC framework: Formative/developmental phase –Service provider engagement
- Study phase 3 corresponded with Step 2 of the MRC framework: Evaluation of

feasibility and acceptability of the intervention

MRC Step 1, Phase 1: Taking into account the high PND prevalence rates in South Africa, the absence of clear guidelines to address perinatal CMDs in maternity care guidelines, a mental health treatment gap of 75 percent in South Africa, (Herman et al., 2009; Seedat et al., 2009), a treatment gap for PND is apparent. Therefore, in the formative stage, a qualitative and observational study was conducted to explore the mental health care needs of women in perinatal care, who were diagnosed with depression, utilising health care services within the PHC platform.

MRC Step 1, Phase 2: In the second phase, a qualitative study engaged PHC health care practitioners to explore their perceptions of PND, task-sharing, pathways to care and their roles in perinatal mental health care. A participatory workshop with service providers led to the co-development of a collaborative care model for PND. Key informant interviews provided institutional perspectives.

MRC Step 2, Phase 3: The third phase comprised an outcome and process evaluation of the feasibility study of the collaborative care model; this included PND screening and a task-shared psychosocial intervention for depression delivered by non-professional health workers.

1.4 Overview of the PhD study

1.4.1 The research context – Programme for improving mental health care – South Africa (PRIME-SA)

This study was nested within the UKAID Department for International Development (DfID) funded PRogramme for Improving Mental health carE (PRIME), a research consortium

comprising five LMIC (Ethiopia, India, Nepal, South Africa and Uganda), in collaboration with their respective health ministries, the World Health Organization, and academic and research institutions across the five countries and in the United Kingdom (Lund et al., 2012). The aim of PRIME was to "generate evidence on the implementation and scaling up of integrated packages of care for priority mental disorders and maternal mental health care in primary health care (PHC) settings" (Lund et al., 2012) in the five countries.

With reference to perinatal mental health, PRIME sought to address Millennium Development Goal (MDG) 3, one of eight goals that United Nations members sought to achieve by the year 2015, by addressing the highest priority mental disorders which directly affect women (e.g. depression). Based on the substantial body of evidence on the adverse impact of PND on maternal functioning and on the growth and developmental outcomes of their infants, PRIME sought to address MDGs 4 and 5 which focused on reducing child mortality and improving maternal mental health, respectively. This was done by explicitly focusing on depression in mothers, in order to improve maternal mental health outcomes by developing an integrated mental health care plan with an emphasis on improving access to cost-effective treatments through the maternal health care system. PRIME identified methods including qualitative focused formative studies exploring the experiences and needs of women to identify barriers to accessing maternal mental health services, with the goal of identifying health system deficits that could hinder interventions for mental health coverage, improve access and refine the mental health care plan to extend its impact. Evaluation of the impact/s of the package of care was planned with service users.

In South Africa, PRIME identified depression, alcohol use disorders and schizophrenia as the priority disorders that would be addressed through the research study, and perinatal mental

health was acknowledged as a gap that needed to be addressed (Baron et al., 2016; Petersen et al., 2015). PRIME was allocated a research site in the Dr Kenneth Kaunda District (DKKD) in the North West Province and developed a mental health care plan (Petersen et al., 2015) with the district health care stakeholders. This nested study was linked to the broader PRIME study in South Africa, but was carried out by the student.

1.5 Aims and objectives

The aim of the study was to develop and evaluate the feasibility of a culturally and contextually appropriate collaborative care model for PND, using a task-sharing approach at PHC level. The research aimed to contribute towards the body of evidence on development of integrated, PHC-based, task-shared collaborative care for PND in South Africa and other LMIC, and on task-sharing for PND. The process is described in this thesis in detail, using the MRC framework to describe the steps, including in-depth formative work, the co-development of the intervention with local health stakeholders, and feasibility. These phases, which align with the first two steps in the MRC evaluation framework (Craig et al., 2008), are outlined below. As already mentioned, the study was divided into three phases, with related objectives for each phase, with a concomitant publication output for phase 1, and phases 2 and 3 reported as sub-studies. The publication reported in Chapter 4, and sub-studies reported in Chapters 5 and 6 document the process of the study from the foundational investigation to the development and evaluation of the study.

1.5.1 MRC framework for complex interventions: Step 1

Phase 1: Formative study – service users

Objective 1 (Sub-study 1): A qualitative investigation of service user perspectives of the mental health care needs of women with depression attending perinatal services in DKKD.

Objective 1 (manuscript 1): *Perceptions of postnatal depression and health care needs in a*

South African sample: The 'mental' in maternal health care.

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https://bmcwomenshealth.biomedcentral.com/articles/10.1186/s12905-014-0140-7

This article described the explanatory models of illness used by women attending perinatal health care at four PHCs in DKKD diagnosed with PND, including the causes, course and treatment options available for their depressive symptoms. With regard to treatment options, in particular, the study explored the acceptability of task-sharing for the delivery of counselling interventions to inform the development of culturally and contextually appropriate perinatal mental health services within the resource constraints of PHC in South Africa, from the perspectives of service users. This study is reported in Chapter 4.

Phase 2: Service provider perspectives

Objective 2 (Sub-study 2): A qualitative investigation of service provider perspectives of the mental health care needs of women with depression attending perinatal services in DKKD.

Objective 3 (Sub-study 2): Co-Development of a collaborative care model for PND in DKKD in South Africa

This sub-study reported in Chapter 5 describes the three stages of service provider engagement that led to the co-development of an integrated, task-shared collaborative care model to detect and manage PND. These stages ranged from the initial exploratory stage, which examined the acceptability of task-sharing for the delivery of counselling for PND, to the practicalities involved in delivery of services to manage PND within the maternal and child health platform of care and the resource constraints of PHC in South Africa, and finally, the institutional perspectives on the delivery of services for PND in DKKD.

1.5.2 MRC framework for complex interventions: Step 2

Phase 3: Evaluation of the feasibility study

Objective 4: Conduct a feasibility study to evaluate the potential of a task-shared collaborative care model for PND which includes strengthened identification and referral pathways to a co-located psychosocial intervention delivered by non-professional mental health workers at PHC level for reducing depressive symptoms at four months after baseline assessment. Conduct a process evaluation to understand factors impacting on feasibility and acceptability of the collaborative care model.

Objective 4 (Sub-study 3): *Feasibility and acceptability of a task-shared collaborative care model for perinatal depression in Dr Kenneth Kaunda District in South Africa: Outcome and process evaluation*

This sub-study is reported in Chapter 6 and describes the outcome and process evaluation of the integrated, task-shared collaborative care model to detect and manage PND, in terms of the quantitative evaluation of the results and the feasibility and the acceptability of the plan using the process data, process evaluation data, as well as qualitative interviews with service users and service providers who participated in the study.

CHAPTER 2

Literature review

2.1 Introduction

The purpose of this chapter is to add a detailed and overarching review of the literature pertaining to PND. The literature base for PND is wide ranging, and this literature review chapter expands on the focal areas of the study reported in Chapters 4, 5 and 6, which include a background of PND as a mental health condition, the gap in services for PND at PHC level in South Africa, an overview of collaborative care for depression and for PND, management of PND in LMIC, and evaluation strategies to assess models of care.

This exercise was directed by Step 1 of the MRC framework, which was used to guide this study (Craig et al., 2008, 2013) and which requires identifying existing evidence about similar interventions that exist and assessment methods used to evaluate them. The MRC framework recommends that, in the absence of relevant evidence, a systematic review should be conducted and updated as the study progresses. However, the evidence base for this study does indicate the existence of high quality systematic reviews for aspects of PND, including treatment of PND using task-shared approaches. These systematic reviews are included within this literature review chapter, and the intent is to supplement the literature reviews in Chapters 1, 4, 5 and 6.

2.2 Background

2.2.1 The gendered profile of depression

Women are, by virtue of their physiology, more vulnerable to depression during their life course, being doubly at risk due to biological factors such as changes in gonadal hormones which may moderate neuro-regulatory systems associated with mood and behaviour (Freeman, 2002; Girgus & Yang, 2015; Piccinelli & Wilkinson, 2018), as well as structural biases embedded within social and economic contexts, which impact negatively on women (Patel & Kleinman, 2003; Patel, Rodrigues, & DeSouza, 2002). Women are twice as likely to

experience an episode of depression than men (Yu, 2018), and, while biological precursors certainly contribute towards the higher risks for women, factors related to gender-specific socio-economic disparities are a significant causal pathway for depression in women.

Marginalization of women may occur more markedly within certain contexts, particularly in low-income settings where entrenched biases against women may render them more vulnerable to mental health issues, including depression; furthermore, their consequent mental health issues may, if untreated, perpetuate a vicious cycle by exacerbating their marginalization. Certainly in the case of PND, this assertion is supported by higher prevalence rates in LMIC compared to HIC, although a recent study (Arifin et al., 2018) suggests that the often-cited 10 to 15 percent estimates for PND prevalence in HIC is an underestimation and should be revised due to the variability and range for prevalence in HIC where low-income women are generally disproportionately affected by PND (Alhusen & Alvarez, 2016).

The rationale for viewing PND using a gendered frame of reference is to highlight the additional vulnerability of women to mental health conditions such as PND due to physiology, as pregnancy and child-bearing are unique to women. Unintentional systemic biases within the health care system, such as the historical relegation of mental health, particularly at PHC, may compromise women's access to care for PND, thus aggravating this burden. Over the past two decades, PND has increasingly received attention from funders, researchers and clinicians, and the volume of research has highlighted the complexity in addressing the biopsychosocial precursors for PND, and the impacts of untreated PND. The relatively recent nature of the focus on PND could be attributed to the increased attention on mental health generally as a result of the Global Mental Health movement.

Historically, perinatal mental disorders have been acknowledged and discussed from the age of Hippocrates onwards, and a treatise on perinatal psychoses was published as early as the 19th century by French physician, Louis Victor Marcé (Glangeaud-Freudenthal, 2003). Despite the pioneering work by physicians such as Dr Marcé, which highlighted the peripartum as a period of vulnerability to specific serious mental disorders, and a large body of research into perinatal mental illnesses throughout the 20th and into the 21st centuries, there is a large treatment gap for non-psychotic perinatal disorders such as depression, particularly in LMIC public health care contexts (Gelaye, Rondon, Araya, & Williams, 2016; O'Hara & Wisner, 2014).

Major depression, bipolar disorder and anxiety disorders are the most prevalent perinatal mental disorders (O'Hara & Wisner, 2014). PND is a non-psychotic depressive episode ranging from mild to major severity, occurring at any time during pregnancy and up to 12 months after childbirth (Gelaye et al., 2016). Although depression is commonly experienced during pregnancy, historically, reporting and research placed greater significance on postpartum depression compared to antepartum depression (i.e. depression occurring during pregnancy). Not to be confused with 'postpartum blues' which has an early onset, peaking at the fifth day and resolving between the tenth and fourteenth days without treatment, postpartum depression is usually diagnosed from four to six weeks postpartum, and may continue unless treated.

According to the commonly used diagnostic manual for mental disorders, i.e. the *Diagnostic and Statistical Manual of Mental Disorders*, symptoms of PND include emotional lability, frequent crying, anxiety, fatigue, insomnia and irritability, and while the 'blues' is considered normal, it could evolve into full blown depressive symptoms if it lasts longer than two weeks.

PND may include several mood disorders following childbirth and may include anxiety and bipolar disorders, as well as depression. Undiagnosed, PND can continue well after childbirth, up to 24 months if untreated, with women at greatest risk during the first year postpartum (Williamson, 2009).

A systematic review of the prevalence of postpartum depression in LMIC including South Africa indicated a pooled prevalence of 19.6 percent (Gelaye et al., 2016), highlighting a significant burden (one in five postpartum women) of postpartum depression in LMIC. Increasingly, pregnancy has also been recognized as a major life event, and the changes related to pregnancy, including physiological, social and emotional, are being recognized as factors that can give rise to depression. Results of a systematic review of antepartum prevalence in 20 LMIC including South Africa indicated a pooled antepartum depression prevalence of 25.8 percent (Gelaye et al., 2016), attesting to a significantly high burden (one in four) of depression in pregnant women in LMIC settings.

Given that this review suggests that, certainly in many LMIC, the burden of antenatal depression is higher than postnatal depression, the implications for detection and treatment of PND highlight the antenatal period as pivotal for beginning the detection and treatment process. This is particularly the case as antenatal depression often extends into the postnatal period, and depressed mood in the antepartum has been identified as a risk factor for postnatal depression (Robertson, Grace, Wallington, & Stewart, 2004). The high prevalence of PND in LMIC provides ample evidence for funders, researchers and health policy-makers to address a mental health condition that potentially has far-reaching intergenerational ramifications.

2.2.2 Description and aetiology

The current edition of the *Diagnostic and statistical manual of mental disorders*, (currently DSM-5) does not address antenatal depression specifically but describes postpartum depression as *Major Depressive Disorder with postpartum onset*, defined as "within four weeks of delivering a child". The manual describes women with postpartum Major Depressive Episodes as often having severe anxiety and panic attacks, highly variable attitudes towards the infant including "disinterest, fearfulness of being alone with the infant, or over-intrusiveness that inhibits adequate infant rest" (DSM 5, p. 423). Postpartum mood episodes are distinguished from the 'baby blues', which affect up to 70% of women during the first ten days postpartum, are transient, and do not impair functioning. The manual further cautions that mood and anxiety symptoms during pregnancy, the baby blues and a personal or family history of mood disorder increases the risk for the development of a postpartum mood disorder, although the risk factors, recurrence rates, and symptoms of postpartum-onset mood episodes are similar to those of non-postpartum (antenatal and non-perinatal) mood episodes:

the postpartum period is unique with respect to the degree of neuroendocrine alterations and psychosocial adjustments, the potential impact of breast-feeding on treatment planning, and the long-term implications of a history of postpartum mood disorder on subsequent family planning (DSM 5, p 423)

A significant body of research expounds risk factors for PND, generally categorized as either of biological or psychosocial origin. Biological risk factors include advanced age, gestational diabetes (Silverman et al., 2017), hypothalamic-pituitary-adrenal dysregulation, inflammatory processes, and genetic vulnerabilities (Yim et al., 2015). Multiple socio-economic risk factors for depression in the perinatal period include low educational attainment, poor housing and

low income (Patel & Kleinman, 2003), food insecurity, economic hardships (Coast, Leone, Hirose, & Jones, 2012), unwanted/unplanned pregnancy, stressful life events, physical and emotional abuse, low social support, history of depression or mental illness, untreated antenatal depression, low self-esteem, poor intimate partner relationships and increased somatic symptoms (Demyttenaere, 2004; Stewart, Robertson, Dennis, Grace, & Wallington, 2003; van Heyningen et al., 2016), as well as chronic strain and poor partner or mother relationships (Yim et al., 2015), and perceptions of reduced self-efficacy (Popo, Kenyon, Dann, MacArthur, & Blissett, 2017).

Serious adverse experiences such as childhood abuse also increase the risk of psychiatric disorders in pregnant women, and a history of childhood physical and/or sexual abuse have been identified as risk factors for antenatal depression Gelaye et al., 2016). The association of having experienced childhood abuse with experiencing PND is thought to be rooted in disruptions to the neurobiological stress response system; this demonstrates the devastating effects of physical and psychological damage from early abuse, which can be traced later to a biological underpinning of depression for victims of abuse in the perinatal period (Gelaye et al., 2016).

Adding to the complexity of psychosocial stressors, childhood abuse is also associated with a greater risk of abuse in adulthood, and pregnant women who experience intimate partner violence are markedly more likely to experience antenatal depression, and social, emotional and physical isolation, as well as separation and loss, combined with the volatility associated with the abuser, underpin the associations between intimate partner violence and PND (Gelaye et al., 2016). In addition to emotional distress, intimate partner violence in pregnancy is also associated with greater food insecurity and alcoholism (Schneider et al., 2018). The risk factors for PND are evidently numerous and the multiplicity of risk factors reveals the

complexity of PND and consequently, the difficulty of navigating appropriate treatment options.

2.3 Impacts of perinatal depression

2.3.1 Physiological and psychosocial impacts

High rates of relapse of depression during the perinatal period can perpetuate the cycle of PND. Antenatal depression (also referred to as antepartum depression) is associated with adverse behavior and health outcomes, including poor nutrition, poor self-care, inadequate antenatal care, increased substance abuse, pre-eclampsia, low birth weight, obstetric risks, preterm delivery, postpartum depression and suicide (Gelaye et al., 2016). Depressed women are less likely to care for their own needs and to seek and receive perinatal care or adhere to recommended health guidelines (World Health Organization, 2008). Antenatal depression often continues into the postpartum period, and despite high prevalence rates, is under-recognized and under-treated in LMIC, possibly due to the prioritization of reducing obstetric-related mortality. Untreated antenatal depression is associated with obstetric complications, preterm delivery and almost twice the likelihood of low birth weight, compared to non-depressed women (Gelaye et al., 2016; Rahman, Bunn, Lovel, & Creed, 2007; Uguz et al., 2013), and both antenatal and postnatal depression were associated with compromised infant growth and motor development in a study in Bangladesh (Nasreen, Kabir, Forsell, & Edhborg, 2012).

PND potentially poses wide-ranging impacts, including association with poor infant attachment, cognitive, emotional, social and physical development aspects (such as stunting), behavioral symptoms (such as attention-deficit/hyperactivity disorder), as well as health and safety for infants (Madlala & Kassier, 2018; Shrivastava, Shrivastava, & Ramasamy, 2015; Wemakor & Mensah, 2016; Wolford et al., 2017). In addition to physical effects such as low

birth weight, incomplete immunizations, chronic and acute diarrhoea associated with PND, exclusive breastfeeding practices are also negatively affected, and early complementary feeding may be introduced resulting in malnourishment (Madlala & Kassier, 2018). Insecure mother-infant attachment associated with postpartum depression is supported by evidence from a South African study in an informal settlement in the Western Cape province (Tomlinson, Cooper, & Murray, 2005). Epidemiological evidence suggests that infant mortality is also associated with PND (Leung & Kaplan, 2009; Benedict Weobong et al., 2015), as is accelerated risk of childhood illnesses, febrile illness and diarrhoea (Adewuya, Ola, Aloba, Mapayi, & Okeniyi, 2008; Guo et al., 2013; Rahman, Iqbal, Bunn, Lovel, & Harrington, 2004).

Gelaye et al. (2016) reviewed a number of studies across countries, including Barbados, India, Bangladesh, South Africa, Brazil, Ethiopia and Pakistan, that link PND with reduced mental and motor development in infants. A South African study reported compelling evidence to support child behavioral problems at age two, as well as evidence of stunting, both associated with PND (Avan, Richter, Ramchandani, Norris, & Stein, 2010). Evidence for delayed language development at age 12 months may also be associated with PND (Quevedo et al., 2012). Developmental milestones and quality of life may be negatively affected during the crucial growth period for children of the first 1,000 days of their life and early childhood, while the lifetime economic impacts due to childhood stunting and adversities have a wider and more pervasive effect on communities and social capital growth (Smith Fawzi et al., 2019).

Quality of life and adverse health outcomes are also risks for the mother and the family; while suicidal ideation and suicide may be the most severe adverse outcomes (Shi, Ren, Li, &

Dai, 2018; Sit et al., 2015), the universal symptoms and effects of chronic depression impact negatively on routine daily functioning, self-care and relationships. When women's self-care is affected due to difficulty in daily functioning caused by depression, their ability to care optimally for their infants is also compromised. The combination of change, physical and emotional stresses, and hormonal fluctuations may impact on well-being, bonding and general productivity (Madlala & Kassier, 2018). Untreated, PND has the potential to cause and sustain negative developmental and functional impacts for individuals and, by extension, the societies to which they belong, both in the short term and potentially in a vicious long-term cycle.

2.3.2 The economic impacts of PND

The economic effects of perinatal mood and anxiety disorders (PMADs), which include PND, are acknowledged but are not as well documented as the social and health impacts. Recent studies indicate that PAMDs may be the most costly conditions during pregnancy and postpartum, with the majority of costs borne by employers and health care providers. Findings of a recent mathematical modeling study quantifying the societal impact of untreated PAMDs from conception to age five estimate the cost of untreated PAMDs in the United States of America at $14.2 billion for all births in 2017 (Luca, Garlow, Staatz, Margiotta, & Zivin, 2019). These estimates are based on the costs of untreated PAMDs through maternal productivity loss, greater public service utilization, including welfare and Medicaid, and higher health care costs associated with poorer maternal and child health. This model attributes 60 percent of the costs to maternal outcomes, of which the highest cost is related to loss of productivity, followed by health expenditure and obstetric-related health expenditure. The balance of 40 percent was attributed to child outcomes, of which the highest

costs were associated with preterm births, followed by child behavioral and developmental disorders and child injury.

Similar results were reported in a study undertaken to quantify the burden of childhood stunting in LMIC attributable to psychosocial risk factors and related lifetime economic costs (Smith Fawzi, 2019). The study reports that comparative risk assessment analysis using data from 137 LMIC, encompassing countries in Asia, Latin America and the Caribbean, North Africa and the Middle East, and sub-Saharan Africa, attributed 7.2 million cases of stunting associated with psychosocial factors. Of these, 3.2 million were attributed to PND, which was also the leading risk factor and which was associated with the highest economic cost at $14.5 billion. Low maternal education and intimate partner violence added to a joint cost of $29.3 billion per birth cohort. These recognized risk factors for PND may exacerbate an already complex psychosocial risk profile for perinatal women.

2.4 PND in South Africa

Current South African data on PND varies widely, with studies suggesting a prevalence of between 16 and 50.3 percent (Manikkam & Burns, 2012; Ramchandani, Richter, Stein, & Norris, 2009; Rochat et al., 2011; Stellenberg & Abrahams, 2015; van Heyningen et al., 2016; van Heyningen et al., 2018), compared to pooled global estimates of 17 percent (Hahn-Holbrook et al., 2018). These estimates are higher than estimates in many other LMIC, and the wide variation may be attributed to several factors. PND studies in South Africa are limited by the screening tools used and relatively small sample sizes (i.e. there are no comprehensive perinatal population-based studies on PND or perinatal mental disorders).

Commonly cited studies in South Africa have been limited to areas in four different provinces (i.e. the Western Cape, KwaZulu-Natal, Mpumalanga and Gauteng). These studies focused on diverse components, including either interventions, prevalence, risk factors or screening, and the varied contexts included informal settlements, urban primary care clinics and rural clinics (Cooper et al., 2002; Hartley et al., 2011; Marsay, Manderson, & Subramaney, 2017; McKenna et al., n.d.; Munodawafa, Lund, & Schneider, 2017; Murray & Cooper, 2003; Ramchandani et al., 2009; Rochat, Tomlinson, Newell, & Stein, 2013; Sorsdahl et al., 2015; Tsai et al., 2014). However, these studies span a number of years, from 1999 to 2018, so are relatively few in number when viewed against the backdrop of the evolving and wide-ranging primary care network in South Africa (Padarath, 2017) and in particular the present focus on maternal health (Ngxongo, Sibiya, & Gwele, 2016; MNCWH, nd).

The perinatal (pregnant women and women with young children under 12 months) population is a vulnerable group (Moussavi et al., 2007), and particularly so in South Africa, given the multiple risk factors for poor physical and mental health in the region. Studies in the sub-Saharan region of Africa which includes South Africa, highlight the risks associated with HIV infection, where women are more likely to be affected by HIV. Depression in turn has the potential to accelerate the progression of HIV infection, and Stringer et al. (2014) argue that the gains made in preventing mother-to-child infection and in antiretroviral medication adherence are at risk of being compromised if the issue of PND is not addressed adequately. The finding holds some significance for South Africa, particularly in the context of an estimated 30 percent prevalence of HIV in antenatal patients assessed at their first visit (The National Department of Health, 2019; Padarath, 2017; Woldesenbet, 2019) and the high PND prevalence rates recorded, including in pregnant HIV-positive women (Rochat et al., 2011; Rochat et al., 2013).

Additionally, the prevalence of CMDs, particularly depression comorbid with non-communicable diseases (NCDs) has increased. Co-morbidity of depression with NCDs, particularly in the context of high antenatal HIV has implications for rising multimorbidity in perinatal women in South Africa given the twin burdens of high antenatal HIV and high PND prevalence rates (Nydoo, Naicker, & Moodley, 2017), and rising NCD prevalence in younger populations (Syed, Alnuaimi,Zainel & Qotba, 2019), and the associated risks of non-adherence to antiretroviral treatment and NCD treatment in depressed populations.

2.5 Interventions for PND

2.5.1 The global context

There has been a growing awareness of PND and recognition of the importance of treating PND both in HIC and LMIC. In the past decade, increased access to care in HIC has encouraged integration of mental health care with traditional medical health care. The increased focus on mental health may be somewhat attributed to evidence of the history of poor outcomes, including reduced lifespan, for patients in traditional care suffering additional burdens; these may include socio-economic factors, poor access to health care, and comorbid mental illnesses (Dossett & Shoemaker, 2015). This has prompted various 'integrated' models of care, including coordinating services for inpatients, co-locating mental health services at clinics and introducing primary and preventative medicine in psychiatric settings. While these models include elements of integrated care, most of them lack some elements of fully integrated services such as the stepped care, team-based care and interdisciplinary care associated with integration (Dossett & Shoemaker, 2015).

The focus on women's mental health, particularly during pregnancy and the postpartum period, has increased during the past two decades as well, combined with efforts to identify the most appropriate locus of care and to promote integrated care to target women with perinatal mental disorders (Stewart et al., 2003; Turner & Honikman, 2016; WHO Mental Health Gap Action Programme (mhGAP), 2010). Perinatal mental health is increasingly being recognized as a critical mental health issue with wide-ranging impacts. Consequently, the focus on addressing PND is predicated on improving maternal mental health to promote mother-infant attachment and prevent or halt the sequelae of PND, which can lead to developmental and mental health issues in the infant (Dossett & Shoemaker, 2015).

A large body of evidence suggests that both HIC and LMIC have grappled with finding the most appropriate and effective options for patient- and family-centered care to address perinatal mental health. Wide variability exists in terms of mental health systems and resources globally. Some HIC are better resourced than others in terms of specialist mental health practitioners and facilities. Mother-baby units (MBUs) catering for women with serious postpartum mental disorders, including severe depression, are an example of targeted inpatient care for women with serious perinatal mental disorders; these ensure that they are not separated from their infants and encourage the bonding between mother and infant that is expected during the crucial postpartum period (Stephenson, Macdonald, Seneviratne, Waites, & Pawlby, 2018). LMIC such as India have also made strides in this area and have successfully modeled an MBU in Bangalore, demonstrating the feasibility of such a model for serious postpartum mental illness using a "western" model of psychiatric care, thus showing the potential for adaptability of successful models of care in diverse settings (Chandra, Desai, Reddy, Thippeswamy, & Saraf, 2015).

With regard to CMDs, including common perinatal mental disorders, in both the private and public health care domains, collaborative, integrated and stepped-care models are increasingly finding favour, particularly in HIC. Collaborative care models encompass key criteria of multi-professional patient care, structured management plan, scheduled patient follow-ups, and enhanced inter-professional communication compared to non-collaborative care for chronic depression in PHC settings which commonly espouse the use of psychotropic medication, without proactive follow-up, monitoring and care. However, the settings may vary according to the prevailing health care models and income and insurance levels of the different population groups served, even within countries (Dossett & Shoemaker, 2015; Hodgkinson, Beers, Southammakosane, & Lewin, 2014; Olin et al., 2016; Weiss-Laxer et al., 2016). Whilst the evidence supporting the efficacy and utility of collaborative models is increasing in both HIC and LMIC, collaborative care for PND in HIC may differ from that offered in LMIC, due to the differences in availability of mental health resources. Chapter 5 provides more details on collaborative care.

Mental health teams in HIC may comprise multidisciplinary mental health professionals, including social workers, psychologists and psychiatrists, and the various sites of care may include the home, obstetric care, maternal outpatient wellness clinics, and paediatric care (Dossett & Shoemaker, 2015), while treatment options include pharmacotherapy and counselling therapies. In both HIC and LMIC contexts, psychotherapy-based interventions (including cognitive behavioural therapy (CBT) and behavioural activation and mindfulness therapies), specifically adapted to suit women in the perinatal period, have all demonstrated improvements in mental health, including symptoms of anxiety and/or depression (Lavender, Ebert, & Jones, 2016; Stewart et al., 2003).

Although LMIC may be required to deal with situationally and culturally specific health care

contexts and resource constraints, research in these contexts has shown that targeted interventions for PND can result in improved depression outcomes compared to routine care. Additionally, the success of task-sharing (i.e. the devolution of traditionally specialist mental health care to non-mental health service providers within PHC settings and in communities) is well documented and includes community-based health workers as delivery agents for therapy (Atif et al., 2017; Chowdhary et al., 2014; Rahman, et al., 2013; Sikander et al., 2019; Stewart et al., 2017).

2.5.2 The South African context

Notwithstanding a number of studies on PND over a lengthy period spanning at least 20 years in South Africa, PND is underdiagnosed, and protocols to detect and treat PND at PHC level are largely missing (Baron, et al., 2016; Padarath A, 2017). A large network of PHC facilities serves the majority of uninsured, economically disadvantaged patients in South Africa, providing access to a principally nurse-led health network, supported by PHC doctors including family physicians. At PHC level, integrated mental health care including perinatal mental health care is a recognized service gap in South Africa (Baron et al., 2016; English, Peer, Honikman, Tugendhaft, & Hofman, 2017; Petersen et al., 2016). Yet there is little indication for sustained health system-based interventions (Baron et al., 2016; Cooper et al., 2002; Dewing, Tomlinson, le Roux, Chopra, & Tsai, 2013; Hartley et al., 2011; van Heyningen et al., 2016; Munodawafa et al., 2017; Rochat et al., 2011; Rochat et al., 2013; Sorsdahl et al., 2015; Tsai et al., 2014; van't Hof, Stein, Marks, Tomlinson, & Cuijpers, 2011; van Heyningen, 2018). The Perinatal Mental Health Project (PMHP) based in the Western Cape is a notable exception (Honikman, van Heyningen, Field, Baron, & Tomlinson, 2012), providing evidence-based mental health support in obstetric care for women with PND from disadvantaged backgrounds, albeit in a geographically confined area in the Western Cape province.

Despite the inclusion of the detection and management of PND in the Adult Primary Care (APC) guideline for chronic care PHC service users, paradoxically, the gap in addressing PND in the mandated South African maternity care guidelines, i.e. Basic Antenatal Care (BANC) is conspicuous. The aggregation of a high prevalence of PND in South Africa (Cooper et al., 1999; Manikkam & Burns, 2012; Nydoo et al., 2017; Peltzer et al., 2018; Ramchandani et al., 2009; Rochat et al., 2011; Stellenberg & Abrahams, 2015; van Heyningen et al., 2016; Verkuijl et al., 2014) and an estimated 75 percent treatment gap for CMDs in South Africa (Seedat et al., 2009) underscore the need to address this issue, particularly in PHC settings which cater for the majority of the uninsured population of perinatal patients, and where specialist mental health resources are strained or absent.

Integrated mental health care has been trialed and implemented in PHC settings in South Africa, using aspects of task-shared care including psychiatrist-supervised nurses, nurse case managers and lay counsellors or community health workers (CHWs) to deliver psychosocial therapies. Examples of integrated stepped care at facility level include collaborative care to identify and manage depression in chronic care patients using a lay counsellor-delivered psychosocial intervention incorporating behavior change and CBT principles. These various studies and/or programs demonstrate the workable elements of PHC in South Africa that can be harnessed for integrated depression care and adaptation for PND care (Fairall et al., 2018; Honikman, van Heyningen, Field, Baron, & Tomlinson, 2012; Maconick et al., 2018; Munodawafa et al., 2017; Myers et al., 2019; Petersen et al., 2018).

Although high prevalence rates for PND do not necessarily equate to high severity rates, early identification and management of PND may minimize the risks of mild to moderate cases transitioning to severe PND. For a significant number of women, the causes of PND are

attributable to environmental, cultural, social and economic factors (Fisher et al., 2012; Silverman et al., 2017). Management and interventions therefore need to be tailored to capacitate and empower sufferers to address those triggers that precipitate and perpetuate PND. Mild to moderate PND may not be easily recognized and may not necessarily receive the same attention as severe presentations or perinatal psychosis, as symptoms may not be as immediately or conspicuously evident.

The number of somatic symptoms typically associated with childbirth and caring for a new-born infant may render screening for PND a difficult task, especially given the similarity of symptoms with those of major depression; these may include sleep and appetite disturbances, diminished libido, and low energy (Nonacs & Cohen, 1998). Consequently, severe postnatal depression may be more easily detected than mild to moderate postnatal depression which may be dismissed as the natural aftermath of childbirth (Robertson et al., 2004). The commonality of signs and symptoms of PND and major depression occurring at any time during the life course, including depressed mood, anhedonia and low energy, as well as suicidal ideation (Robertson et al., 2004), suggests that health workers trained to detect and manage depression in the general PHC population could be capacitated to transfer these skills to detect and manage PND at this level.

In response to concerns regarding the limitations of binary diagnoses which may promote a universal approach that may lead to over-treatment or under-treatment of patients with a mental disorder, a staging approach to psychiatric disorders has been mooted. Staging would allow for the re-categorization of patients with mild to moderate depressive symptoms (typically a mixture of mood, anxiety and somatic symptoms), as having a ‘distress syndrome’ (Patel, 2017), and low intensity interventions such as self-care, web-based psychological therapy and social support are proposed as strategies to manage mild to

moderate depression.

Early detection and management of mild to moderate depression using low intensity treatment may be viewed as pre-emptive care, promoting improved population-based mental health and reduced incidence of the disorders. This approach may help to empower patients with mild to moderate depression, acknowledging the centrality of the patient in the recovery process, capacitating, supporting and arming patients with adequate information to enhance and promote functioning while enabling the clinical sector to attend to patients with severe forms of depression (Patel, 2017). A pre-emptive approach to treating patients who exhibit depressive symptoms may be viewed in terms of a health-promotion and -prevention exercise to address depression, this in a context where a proportion of patients with mild to moderate depression may still progress to severe depression and require specialist care. Furthermore, this approach serves as an acknowledgment of the significant public health burden of impairment associated with depressive symptoms.

In summary, the evidence highlights two issues. Neglecting to address risk factors for PND comes at high social, health and economic costs. Prevention is key. The second issue highlighted is the importance of early detection and treatment of PND. Targeted efforts to address the psychosocial risks for PND, as well as early detection (including screening), and availability, affordability and access to evidence-based treatments for PND, are worthwhile investments to promote better mental and physical health outcomes for women and their children, and would provide economic benefits for the health sectors, employers, insurers and for the state as a whole.

CHAPTER 3

Research methodology

Introduction

This study employed mixed methods to achieve the stated objectives to a) qualitatively explore both service user and service provider perspectives on managing PND, and b) to quantitively and qualitatively evaluate a collaborative care model to address PND. This chapter provides a brief overview of the overall methodology of the thesis, with the specific methodology used for each separate sub-study reported in more detail in chapters 4, 5 and 6. This chapter provides the rationale for using mixed methods, descriptions of the research design and methodology used, including the research questions, objectives, sampling and data collection methods, as well as addressing concepts of trustworthiness and rigor, validity and reliability, and ethical considerations.

3.1 Mixed-methods research

The use of mixed methods in social science research is supported by the advancement of pragmatism in research, the argument that researchers in social sciences should not limit themselves to a particular paradigm and methodology, and that research methodology should be guided by principles based on best serving the research question at every stage (Cronje, 2014; Grey, 2018). As a theoretical perspective, pragmatism views ideology as true only if it works and generates practical consequences for society. It is viewed as a relatively old philosophy that has been revived recently and has regained some popularity, partly as it provides an epistemological justification for mixed-methods approaches (Grey, 2018).

This perspective allows for separate paradigms in research, as well as mixing of paradigms, promoting and legitimizing the mixing of quantitative and qualitative data within a single study (Grey, 2018). Within this school of thought, the research question, the theoretical context literature review and the proposed study context guide the paradigm and the

methodology, setting limitations for the framework and study. Combining both qualitative and quantitative data can provide more in-depth understanding of the research than separate analyses and studies, providing overall coherence across the analyses of a study.

The aim of this study was to develop and evaluate the feasibility of a PHC model for PND, and a mixed-methods approach was used to achieve this. A multiphase research design comprising three consecutive phases, each with corresponding sub-studies, was employed to examine the topic (i.e. addressing the treatment gap for PND at PHC level). In this design, the intention is to address a group of phased or progressive research questions that cumulatively promote a primary programmatic goal, rendering it a popular design for evaluation research and large-scale health research (Cresswell, 2014).

3.1.1 Rationale for using mixed methods

Given that mixed-method designs combine elements of qualitative and quantitative data, this approach was congruent with the aims and objectives of the study, as corroborated by previous research conducted on depression in this specific context, and on PND in other contexts (Khan et al., 2019; Lund et al., 2014; Petersen, Bhana, & Baillie, 2012; Petersen et al., 2019; Petersen et al., 2016). Mixed-methods study is also appropriate within the overarching methodological framework for this study, i.e. the MRC framework (Craig et al., 2008; Moore et al., 2015). This methodological framework comprises four concrete steps which guide the overall research process. This study was guided by the first two steps which are development and feasibility.

MRC Step 1: In phase one (i.e. the developmental phase), the in-depth formative work comprised preparatory research informed by the *Explanatory models of health framework*

(Aidoo, 2001; Gidron, 2013; Kleinman et al., 1978; Laws, 2016), which was used to guide the qualitative service user interviews.

Objective 1 (Sub-study 1): qualitative investigation to determine the mental health care needs of women with depression attending perinatal services in DKKD. This sub-study corresponds with step 1 the MRC framework which is the formative/developmental phase.

Service user engagement is reported in sub-study 1 in Chapter 4 as: *Perceptions of postnatal depression and health care needs in a South African sample: the "mental" in maternal health care.*

MRC Step 1: Phase 2 comprised service provider engagement, which included individual interviews and focus group discussions (FGDs). Following these interviews, a participatory workshop was conducted with key PHC service providers to co-develop a model of care for PND. This was followed by key informant interviews (KIIs) to provide a feedback loop and reinforce the workshop decisions, as well as to provide institutional perspectives. Two objectives were associated with this study.

Objective 2 (Sub-study 2): qualitative investigation to determine service provider perspectives of the mental health care needs of women with depression attending perinatal services in DKKD. This sub-study corresponds with step 1 the MRC framework which is the formative/developmental phase.

Objective 3 (Sub-study 2): Describe the co-development of a collaborative care model for PND in DKKD in South Africa. This sub-study corresponds with step 1 the MRC framework which is the formative/developmental phase.

Service provider engagement is reported as sub-study 2 in Chapter 5, titled *Development of a collaborative care model for perinatal depression in Dr Kenneth Kaunda District in South Africa.*

MRC Step 2: Phase 3, corresponding with the second step of the MRC framework and guided by Bowen et al. (2009), a feasibility study evaluating the collaborative care model (described in Chapter 6) was conducted. The research component in this phase comprised quantitative methodology using a non-randomly assigned cohort before and after design whereby a survey questionnaire was administered at baseline and follow-up to intervention and control participants in the study, and assessing PND outcomes over time through statistical analysis of outcomes on the survey questionnaire. Additionally, a review of the process data collected in parallel to the cohort study was carried out in order to inform recommendations, and qualitative process evaluation interviews of the collaborative care model were also conducted with service user and service provider participants. This was to add depth to the quantitative results, and to add contextual perspectives and details not available through the quantitative analysis (Moore et al., 2015).

Objective 4 (Sub-study 3): Conduct a feasibility study to evaluate the potential of a task-shared collaborative care model for PND which includes strengthened identification and referral pathways to a co-located psychosocial intervention delivered by non-professional mental health workers at PHC level for reducing depressive symptoms at four months after baseline assessment. Conduct a process evaluation to understand factors impacting on feasibility and acceptability of the collaborative care model. This sub-study corresponds with step 2 the MRC framework which is feasibility.

This process is reported in the sub-study (3) reported in Chapter 6 titled *Feasibility and acceptability of collaborative care for perinatal depression in Dr Kenneth Kaunda District in South Africa: outcome and process evaluation.*

The sequence of data collection methods was guided by the aims and objectives of each sub-study. The three steps applicable to this study are described in Figure 1 in the theoretical framework section outlined in Chapter 1, and in Figure 3a below. The research questions for each manuscript are mentioned in Chapter 1, but are restated below to expound the methodology linked with each sub-study. Using the results of the qualitative data as complementary to the quantitative research, as we have done in this study, is a common approach to mixed-methods design, particularly in settings where there is scant knowledge about the research problem (Grey, 2018). Qualitative data are also used to assess the feasibility and acceptability of the research output, in order to add a layer of depth to the quantitative analysis (Cresswell, 2014), and to support the recommendations of the study. The mixed-methods approach is thus shown to be an appropriate methodology for this study, particularly using the MRC framework as an overarching framework.

3.1.2 Summary of research questions

3.1.2.1 Phase 1 - (Sub-study 1): Formative interviews with service users

Qualitative methods

- How do perinatal women with depression understand PND, particularly in terms of the causes, manifestations, course, and treatment options?
- What are the existing pathways to care for perinatal women with depression, and how can these be improved to promote greater identification, access and demand?

3.1.2.2 Phase 2- (Sub-study 2): Service provider engagement

Qualitative methods

- How do service providers understand PND, particularly in terms of the causes, manifestations, course, and treatment options?
- What are the existing pathways to care for perinatal women with depression, and how can these be improved to promote greater identification, access and demand?

3.1.2.3 Phase 3 - (Sub-study 3): Feasibility study informed by service provider recommendations in Phase 2

Quantitative evaluation component of the feasibility study

- Does a task-shared collaborative care model for PND, which includes strengthened identification and referral pathways to a co-located psychosocial intervention delivered by non-professional mental health workers at PHC level, show potential for reducing depressive symptoms?
- Was the pragmatic, strengthened collaborative care model for PND feasible?

Qualitative evaluation component of the feasibility study

- Was the co-located psychosocial intervention for PND acceptable to service users and to service providers?

3.2 Setting

The study, nested within the PRIME research programme in South Africa (described in Chapter 1), was set in one of 16 clinics in the Matlosana municipality in DKKD, in the North West province of South Africa. The Matlosana municipality, or sub-district as it is also referred to, is one of four sub-districts that comprise DKKD (Figure 3b). The characteristics of the districts vary in terms of urbanization as well as the primary occupation and levels of employment of citizens. The North West province lags in comparison to most other provinces

in terms of formal housing, literacy and employment. The Matlosana sub-district is urban, with a strong agricultural and mining labour focus.

3.3 Research design

As described above, this study was a mixed-methods study using the MRC framework. The research processes are shown in Figure 3a.

Figure 3a: Summary of research processe

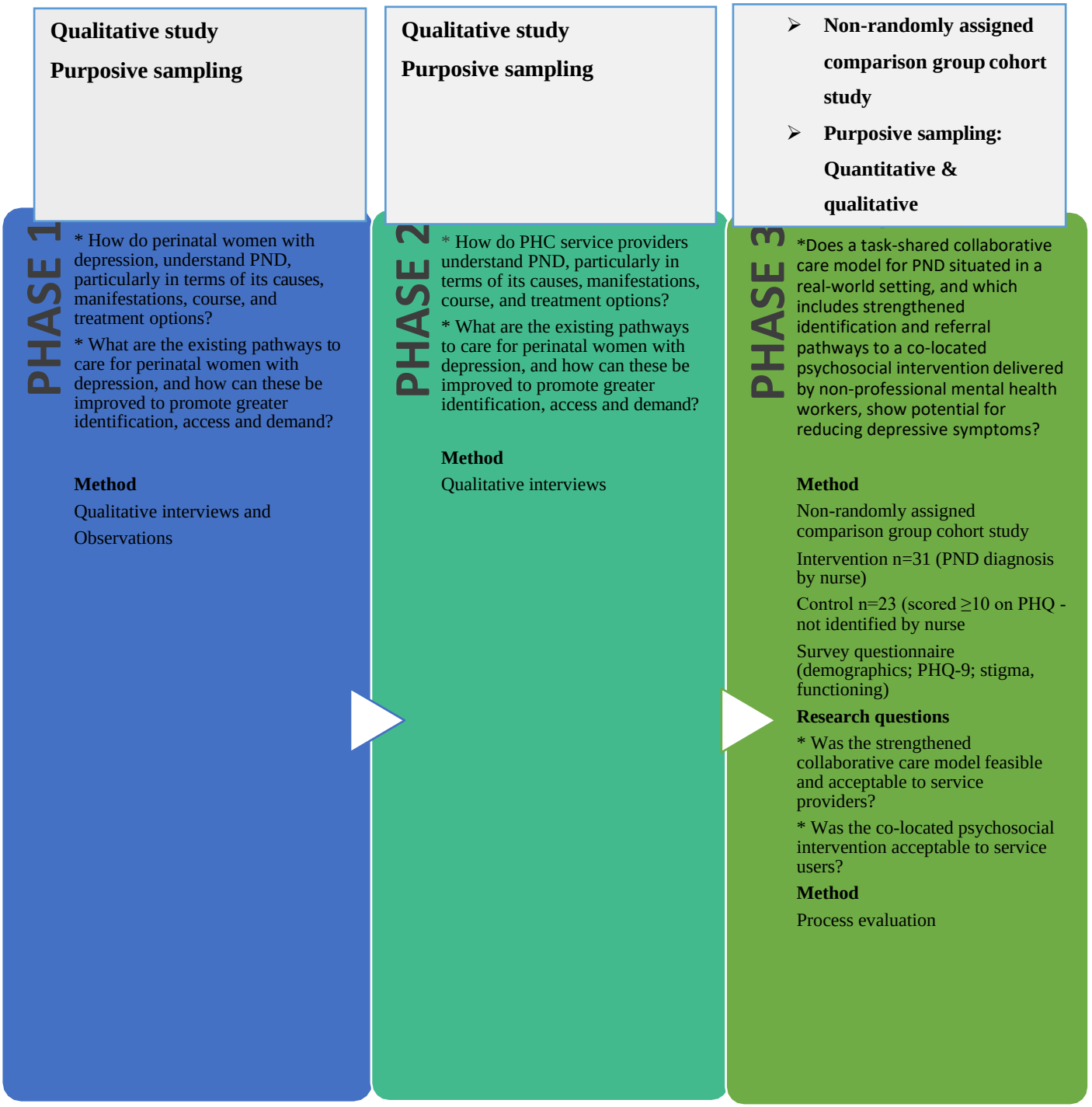

Figure 3b: Setting -Matlosana municipality, Dr Kenneth Kaunda District, North West province (indicated by red star)

Phase 1

Sub-study 1: Formative interviews with service users

Research design

Qualitative research is contextualised, conducted in real-life settings and highly variable, adopting varied theoretical standpoints and methods, and is used to understand the perspectives of participants in terms of their lived experiences and meanings, including participant's emotions, prejudices, and motivations; thus qualitative research provides insight into how things happen and reasons for the occurrence of particular events (Grey, 2018). Appropriate data collection techniques include observations, small group discussions and semi-structured interviews to investigate beliefs, attitudes and perceptions about standardised or prescriptive behaviour and/or views on a topic, as well as key informant interviews for contextual and institutional standpoints (Kirkman, Hammarberg, & de Lacey, 2016). This study employed semi-structured interviews and observations in Phase 1 to realise the objective of investigating service user perspectives of PND, and treatment options. Engaging with this category of key stakeholders to understand their health care needs, existing pathways of care, and acceptability of task-sharing for PND care was the first exploratory investigation planned and executed, following the MRC framework for complex interventions, and guided by Kleinman's explanatory models of illness (Kleinman et al., 1978).

Phase 1 Sampling

The specifically defined research focus necessitated the use of purposive sampling in the location of interest, a large 24-hour CHC catering for maternity services. A single CHC was used to sample participants as it catered to a sufficiently large perinatal patient population to preclude the use of multiple smaller clinics for the limited qualitative sampling required. PHC service users attending perinatal health services and who

screened positive for PND depression, were identified as the population of interest.

Criteria for inclusion

Adult women attending perinatal services at a clinic in the Matlosana sub-district who were diagnosed with depressive symptoms.

Phase 1 Instruments

The Edinburgh Postnatal Depression Scale (EPDS) (Appendix 1), a brief 10-item screening tool for antenatal and postnatal depression, commonly used internationally and validated in South Africa (De Bruin, 2004), was used to identify service users who met the criteria for perinatal depressive symptoms; this was confirmed using the Structured Clinical Interview for DSM-IV (SCID II) (Appendix 2). The EPDS is a self-report short questionnaire that can be administered by a non-specialist mental health practitioner; it is used in both clinical and research settings for antenatal and postnatal depression screening. It was developed for women who do not consider themselves unwell (making it more acceptable for use), is simple to use and can be completed in less than five minutes. Both tools were translated from English to Setswana and were administered by two bilingual (English and Setwsana) clinical psychologists. This process was used to identify potential participants who met the criteria for inclusion in the study, and the data were not used for statistical analysis.

Guided by explanatory models of illness (Aidoo, 2001; Kleinman et al., 1978), examination of the literature on addressing PND in LMIC, and the program objectives, we developed a semi-structured interview guide for service users (Appendix 3). Service users were interviewed at the PHC facilities at which they were recruited. Ten follow-up interviews, combined with observations of the home and the mother-infant dyad, were conducted with a sub-sample (Appendix 4).

Permission was granted by the operational managers for use of private cubicles (where available) at the clinics to use for the service user interview. With the participants' consent, semi-structured, audio-recorded interviews were conducted in Setswana by two clinical psychologists to explore participants' experiences and explanatory models of PND, their symptoms and coping strategies. Ten follow-up interviews were conducted with available participants from the first wave of interviewees two months later in their homes as these included ethnographic observations of the mother and child dyads prior to the follow-up interview. The objective of the follow-up interviews was for participants to confirm earlier findings, to gain a better understanding of participants' home environments and social contexts, and observe their interactions with family members and infants. The analysis of the first and second set of interviews was combined. Participants received a R50 (USD $3) supermarket voucher at each interview as a gesture of appreciation to acknowledge their time.

Phase 2

Sub-study 2: Service provider engagement

Research design

A range of qualitative methods was used to realise the objective, which was to develop a contextually acceptable and feasible model of primary care for PND, in order to contribute towards the body of evidence towards the development of a PHC-based model of care for PND in South Africa and provide an evidence base for similar studies in other LMIC. This intensive process comprised three samples of participants and included engagement with key service provider stakeholders (Sample 1) to investigate their clinical understanding of PND, existing pathways of care, acceptability of task-sharing for PND care, and (Sample 2) co-development of an appropriate intervention to improve access to mental health services for service users with PND. In addition, there was further engagement with key stakeholders (Sample 3) to confirm our findings and for further institutional perspectives. Data collection

methods included semi-structured interviews, FGDs and a participatory workshop.

Sampling

Sample 1 consisted four PHC managers, 10 nurses and 20 lay counsellors.

Sample 2 consisted of 11 nurses, six operational managers, and one representative each from maternal and child health care, chronic care services, and mental health care.

Sample 3 consisted of six sub-district level key informants.

Criteria for inclusion

Service providers who were involved in the provision of maternal and child health, chronic care and mental health care.

Phase 2 Instruments

For sample 1, a common interview schedule was developed for the lay counsellor and PHC manager FGDs, and for nurse interviews (Appendix 5).

Sample 2 participated in a workshop to co-develop the intervention and were not interviewed individually and therefore did not require an interview schedule.

For sample 3, we used an interview guide for the key informant interviews after the participatory workshop (Appendix 6), that focused on key institutional perspectives from specialist, planning and managerial levels, and also served as a confirmatory process for the participatory workshop decisions.

Phase 3

Sub-study 3: Feasibility study

Research design

Influenced by positivist principles, experimental research methods involve 'truth-seeking' in comparison to seeking opinions and perspectives, using quantitative methods for analysis (Grey, 2018). The research design is usually deductive, that is, questions or hypotheses are usually a priori, with the intent of objective and valid results that are replicable. Principles of research design within this paradigm (e.g. experimental and control groups) are based on the natural sciences. However, Grey (2018) claims that the validity of research results emanating from experimental research should be treated with caution (i.e. not as definitive), although positivist-slanted quantitative methodology has historically been considered as more 'truthful' and accurate than qualitative work. The objective of this component of the study was to evaluate whether a strengthened, co- located, task-shared collaborative care model for treating PND at PHC level showed potential for depression symptom reduction in perinatal patients.

In real-world settings, including in this study, researchers seek to understand and work within these conditions, rather than control or remove them (Handley, Lyles, McCulloch, & Cattamanchi, 2018). Working within the constraints of the existing PHC system for perinatal care, this component of the study was guided by the activities and results of the previous two phases.

Sampling

54 women attending perinatal services at a CHC

Criteria for inclusion

Women who were either diagnosed with depression by the nurse consultant or not diagnosed with depression by the nurse consultant but scored ≥ 10 on the Patient Health Questionnaire-9 (PHQ-9) administered by a mental health trained professional employed by the project.

Phase 3 Instruments

For sample 1, a quantitative survey questionnaire was administered at baseline and four months after baseline.

For sample 2, a qualitative interview schedule was used to interview a subset of service users who received the intervention.

For sample 3, a qualitative interview schedule was used to interview service providers who participated in the intervention.

Informed consent procedures for all phases

Informed consent was obtained at each interview session after the researcher and mental health practitioners explained the purpose of the research, the voluntary nature of participation, and confidentiality and anonymity. In phase 1, consent was explained and obtained by two bilingual Setswana/English-speaking psychologists. In phase 2, consent was explained and obtained by a mental health practitioner and the researcher, and in phase 3, by mid-level mental health practitioners (four-year degree in Psychology). For each sub-study, participants received an information sheet which they were asked to read and indicate their understanding of, as well as keep for their personal records. They also received a consent form to sign, again after indicating their understanding of the contents, consent for audio-recorded interviews, and willingness to participate (Appendices 7, 8, 9 and 20). The operational manager of each facility was briefed about the research and given a copy of the institutional ethical clearances for the study (Appendices 10 and 12) and the provincial ethical clearance (Appendix 11).

Reliability and validity

In quantitative research, a positivist tradition defines theories of reliability (i.e. whether the result is replicable) and validity, which examines whether the means of measurement are accurate and accurately measure what they intend measuring (Golafshani, 2003). The validity of the instruments used, principally the EPDS (Appendix 1) and PHQ-9 (Appendix 13) are described in detail in the relevant chapters (Chapter 4 and Chapter 6).

Rigor and trustworthiness

Reliability and validity are mostly considered inappropriate concepts in qualitative research, although some researchers (Morse, Barrett, Mayan, Olson, & Spiers, 2008) encourage validity as a qualitative research concept to promote rigor by focussing on verification processes during the study, rather than establishing trustworthiness at the end of the study. Researchers agree that qualitative studies need to reflect credibility. An interpretive perspective of reality is open-ended, interpretive and situation sensitive or contextualized.

The criteria for trustworthiness are reflected in the terminology: credibility, transferability, dependability, and confirmability, and for authenticity as fairness (Creswell, 2000). These criteria are used to promote standards of evaluation of overall significance, relevance, impact and utility of research. Common processes to establish 'validity' in qualitative research include triangulation, member checking and audit trails (Creswell, 2000; Golafshani, 2003). We focused on strategies such as methodological coherence, theoretical sampling and saturation (Morse et al., 2008), in addition to triangulation, member checking and reflexivity. Researcher flexibility was a driving force to ensure an iterative verification process of ensuring congruence in questions, literature, recruitment, data-collection strategies and analysis. *Methodological coherence* aimed to ensure correspondence between the research

question and method of data collection. To this end, appropriate samples were recruited to match the research questions and overall aims and objectives. Data were collected and analysed concurrently in an iterative process; they were checked and rechecked to build a solid foundation and ensure reconfirmation of themes that were identified in data, and reconfirmed in new data, as additional transcripts were coded until saturation of data.

Triangulation was achieved through the use of different data collection methods and multiple sources (i.e. different categories of participants). In phase 1, qualitative interviews were supplemented by a sub-sample of additional follow-up interviews and observations of the households and mother-infant dyads. In phase 2, data collection methods included individual qualitative interviews with nurses and key informants, FGDs with two different cadres of service providers, and an expert group workshop with service providers to provide multiple sources of evidence. In phase 3, data collection included individual interviews with service users who participated in the study, as well as nurses at the facility, and a project employed counsellor.

Member checking was carried out in three different forums including follow-up interviews with service users in Phase 1 to confirm earlier findings and probe additional themes. For service providers, at the participatory workshop which followed the initial round of service provider interviews with nurses, and FGDs with managers and lay counsellors, the data related to pathways to care for PND, and task-sharing in relation to PND was discussed. This was an appropriate forum for discussion and member checking, as a sample of the nurses and managers previously interviewed in Phase 2 were present at the workshop. This presented an opportunity to ascertain what (if any) changes had occurred in the period since the interviews were conducted, and if the information previously collected and interpreted was factually correct. We also interviewed key informants after the

participatory workshop to confirm the crucial elements for the co-developed model of care and to elicit their unique perspectives as health system representatives.

Reflexivity encourages researchers to acknowledge their own biases, assumptions and beliefs. The centrality of the researcher within the study context necessitates a critical reflection on the social, cultural and other influences that may impact their interpretations. We have reported this in the discussion and limitations sections of the manuscripts and in this thesis.

An additional validity strategy mention in Creswell and Miller (2000) is *prolonged engagement in the field*. The research team engaged with gate-keepers for a prolonged period of four years, establishing a trusting relationship with key stakeholders in the larger PRIME study who were instrumental in facilitating access to sites and other stakeholders. Our sustained presence in the field allowed us to compare our interview data with observational data and immerse ourselves in the health context, to improve our understanding of the research environment.

Ethical Protocols

Ethical clearance was obtained through the University of KwaZulu-Natal (HSS/0880/011 and BFC587/16) and the North West province Department of Health. Ethical principals were adhered to at all stages of the study and included emphasising the voluntary nature of participation, informed consent, privacy when conducting interviews, anonymity and secure storage of data. These are described in more detail in the sub-studies reported in Chapters 4, 5 and 6. Recognized core practical principles and specific ethical issues expounded in Miles and Huberman (1994) guided the research team at every step. They included the following concepts:

- *Beneficence* – Avoiding harm and risk to participants while maximizing good outcomes. Care was taken to ensure confidentiality and anonymity of participants. The intervention was based on careful engagement with health providers, was based on evidence of efficacy, and was perceived to be of possible clinical benefit to patients. Participants who showed any signs of distress at any of the interviews were referred to the sub-district psychologist for assessment and further attention.
- *Respect* – Respect, courtesy and promoting autonomy of persons. All participants were treated with respect and courtesy, given the opportunity to participate or not, withdraw at any stage, and were voluntary.
- *Justice* – Non-exploitative procedures, careful consideration of procedures, consideration of fair costs and benefits for participants; this is related to beneficence. The absence of routine mental health services for this population was identified as a service gap, and the intervention had shown positive outcomes for PHC patients attending chronic care services in a previous study in the same health and geographical context. The 'procedure' (i.e. the counselling intervention) was offered to participants, but the option to attend the counselling sessions was an autonomous decision for participants, who could refuse or stop attending sessions at any point. Participants in the control arm received usual care, which included the option of pharmacotherapy and referral to specialist psychological services during routine care.
- *Non-coercion* – Voluntary participation, and choice to withdraw from the study at any stage was explicit in the information and consent documents, and reiterated by the research team.
- *Benefits, costs and reciprocity* – Study participants were given a voice to explain their perspectives, share their expertise and knowledge, and gain insight into a poorly understood and ignored mental health condition. Service providers were given training

to improve clinical practice and gain clinical skills, and service users were provided with options to help them to understand their mental health condition and treatment options.

- *Worthiness of the project* – Contribution to the gap in literature on integrating task-shared care for PND at PHC level in South Africa and other LMIC.
- *Competence boundaries* – The research team was supervised by an experienced, competent supervisory team, as well as a mental health-qualified research team, with additional training provided where necessary for the research assistants and for service providers.
- *Honesty* – Ensuring that the nature and purpose of the inquiry was explicit to participants.
- *Intervention and advocacy* – Referral for suicide risk where appropriate for participants who received usual care (control), referral to the clinician and social worker for patients experiencing harmful behaviour.
- *Research integrity* – Carefully conducting the study, according to the research aims and objectives and agreed study procedures, careful data recording and analysis, acknowledgement of literary sources and influences through citations in reporting.
- *Ownership of data* – Following the prescriptions of the funder to promote open access, manuscripts and study resources, as well as a data-sharing policy are available on request from www.prime.uct.ac.za.

Chapter summary

Chapter 3 outlined the rationale for using mixed methods, and the methodology comprising research objectives and methods employed in this study, including descriptions of each phase

and linked research activity and outcomes (Figure 3a). The descriptions are supported with the rationale for each activity. The methodology is supported further with discussion on the validity, reliability and trustworthiness of each method.

CHAPTER 4

Sub-study 1

Perceptions of postnatal depression and health care needs in a South African sample: the "mental" in maternal health care.

***This chapter comprises the publication detailing the service user engagement in Phase 1.**

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Abstract

Background: Maternal mental health care is a neglected area in low and middle income countries (LAMIC) such as South Africa, where maternal and child health care priorities are focused on reducing maternal and infant mortality and promoting infant physical health. In the context of a paucity of mental health specialists, the aim of this study was to understand the explanatory models of illness held by women with maternal depression with the view to informing the development of an appropriate counselling intervention using a task sharing approach.

Methods: Twenty semi-structured qualitative interviews were conducted with mothers from a poor socio-economic area who were diagnosed with depression at the time of attending a primary health care facility. Follow-up interviews were conducted with 10 participants in their homes.

Results: Dimensions of poverty, particularly food and financial insecurity and insecure accommodation; unwanted pregnancy; and interpersonal conflict, particularly partner rejection, infidelity and general lack of support were reported as the causes of depression. Exacerbating factors included negative thoughts and social isolation. Respondents embraced the notion of task sharing, indicating that counselling provided by general health care providers either individually or in groups could be helpful.

Conclusion: Counselling interventions drawing on techniques from cognitive behavioural therapy and problem solving therapy within a task sharing approach are recommended to build self-efficacy to address their material conditions and relationship problems in poorly resourced primary health care facilities in South Africa.

Keywords: Maternal, Postnatal, Mental health, South Africa, Task-sharing, Low income

Background

Maternal mental health is an internationally recognised public health concern (Ramchandani et al., 2009; Sawyer, Ayers & Smith, 2010; WHO, 2008) and the high burden of disease associated with postnatal depression is well documented in both HICs and LAMICs (Rahman, Iqbal, Bunn, Lovel, & Harrington, 2004; Wachs, Black & Engel, 2009). Non-psychotic depression related to childbearing commonly affects between 10 to 15% of women worldwide (Sawyer et al., 2010). In South Africa, current data suggest higher prevalence rates than these global estimates, with isolated studies on postnatal depression (PND) providing an estimated prevalence rate ranging from 16.4% in the township of Soweto to 39 % in Khayelitsha, an informal settlement in the Western Cape (Cooper et al.,1999; Hartley et al., 2011; Ramchandani et al., 2009). In addition, the prevalence rate for antenatal depression, a predictor of PND, (Robertson, Grace, Wallington, & Stewart, 2004; Rochat, Tomlinson, Barnighausen, Newell, & Stein, 2011) has been found to be as high as 47% in a study in rural KwaZulu-Natal . While maternal and child health is one of the top four public health priorities of the South African Department of Health, the emphasis is however, on decreasing physical morbidity and mortality (Strategic plan for maternal, newborn, child and women's health (MNCWH) and nutrition in South Africa 2012-2016).

However, in the face of a 12-month treatment gap of between 76% to 85% for people with severe mental disorders in low-income countries (Murray et al., 2012), and a75% treatment gap for common mental disorders in South Africa (Seedat et al., 2008), the high burden of maternal depression poses a public health threat (Mayosi et al., 2009). This is because PND can impact negatively on an infant's socio-emotional and cognitive development as a result of maternal neglect, poor maternal responsiveness and impaired attachment relationship between

mother and infant (Black, Baqui, Zaman, Arifeen, & Black, 2009; Wachs et al., 2009). In turn, poor socio-emotional and cognitive development impedes long-term human capital growth that is essential for socio-economic development in LAMICs, having long ranging negative developmental, social and economic costs (Fisher et al., 2012; Richter, Dawes & De Kadt, 2010; Wachs et al., 2009). Untreated PND is also a human rights issue as it compromises codes of social justice for children who receive substandard maternal care as well as compromised quality of life for women with maternal depression (Wachs et al., 2009).

Internationally, risk factors for maternal depression include dimensions of poverty such as low levels of education; poor housing and low income (Patel, 2003); food insecurity and economic hardships (Black et al., 2009); stressful life events such as physical and emotional abuse; inadequate social support; history of depression; antenatal depression; low self-esteem; poor relationships with partners (Fisher et al., 2012; Ramchandani et al., 2009; Stewart et al., 2003); and unplanned and/or unwanted pregnancy (Fisher et al., 2012). In abusive relationships, income disparities and patriarchal systems that favour men render some women particularly vulnerable as they find it difficult to escape domestic violence due to their economic and or emotional ties to the abusive partner. Notwithstanding this literature, in order to inform culturally and contextually informed interventions, there is a need to understand how PND is experienced or understood within cultural contexts in LAMICs in order to inform culturally and contextually appropriate interventions. In addition, within resource constrained health care systems of LAMICs, there is a need to understand how best to deliver such interventions. Contextually appropriate and cost-effective health care solutions for maternal depression need to be found (McPake & Mensah, 2008). Integration of mental health into primary health care and task sharing have been mooted as effective mechanisms to increase access to mental health care in LAMICs by the WHO and the South African Department of Health (WHO and

Department of Psychiatry and Mental Health, 2007). The objective of task sharing is to devolve tasks traditionally provided by specialist health workers to non-specialist health workers to provide increased access to quality health care at a lower cost (Fulton et al., 2011). Further, while many interventions for maternal depression in HICs favour home visits by nurses (Black et al., 2009), in LAMICs resource constraints dictate that lay health workers are a more feasible option, with sufficient evidence of that they can be used effectively to carry out educational and psychosocial interventions for maternal care.

Against this backdrop, using Kleinman's concept of explanatory models of illness (Kleinman et al., 1978) this study sought to explore the explanatory models of illness used by women diagnosed with PND, from low socio-economic backgrounds in South Africa. Specifically, the study seeks to understand the causes, course and treatment options available for their depressive symptoms. With regard to treatment options, in particular, the study sought to explore the acceptability of task sharing for the delivery of counselling interventions. This was with the view to informing the development of culturally and contextually appropriate maternal mental health services within the resource constraints of PHC in South Africa.

Methodology

Study site

The study was conducted in a community health centre (CHC) in the DKKD district in the North West Province. Economic activities in the district are predominantly mining and agricultural. The unemployment rate in the North West Province was 26.6% in the period the interviews were conducted, relative to 29.1% for South Africa as a whole (Statistics South Africa, 2012). Known as the "Platinum Province" with reference to its mineral wealth,

mining is the mainstay of the North West Province, and typically attracts male employees. Some men have multiple families or partners, often both at a family home, and at the mining district. This is partly a historical product of the lack of facilities at mines to cater for families who are consequently left behind at home, sometimes in another province for lengthy periods (Hickel, 2012). The CHC is located in an urban township with a mixture of formal and informal dwellings. The facility provides both antenatal and postnatal services as well as a childbirth delivery service. HIV testing is routinely offered antenatally, and most women in the district give birth at health facilities and are attended by midwives. Home observations situate the context in which participants lived. Homes could be categorised as formal brick dwellings, basic Reconstruction and Development Programme (RDP) houses (low cost state subsidised two-roomed homes with a kitchen and toilet), and informal shacks constructed with aluminium, cardboard and other materials. Access to electricity or inside ablutions is variable.

Design

A focused ethnographic qualitative research approach using in-depth face-to-face interviews, follow-up interviews and observations of participants in the home environment was adopted. A qualitative study was deemed appropriate given the exploratory nature of the research (Knoblauch, 2005). Kleinman's concept of explanatory models of illness (Kleinman et al., 1978) was used to guide the interviews. This framework typically seeks to understand the way people understand an illness in relation to the cause, course and treatment options for their symptoms. Focused ethnography is used to collect focussed information and assist with interpretations of cultures and systems.

Recruitment and Sample description

Fieldworkers explained the study to women attending services at the CHC postnatal waiting room. Women were randomly approached by a fieldworker in the waiting room and requested to participate. The criteria for participation in the study were women over the age of 18 not previously diagnosed with depression , who had given birth to a live infant who was at the time of the study aged between six weeks and twelve months old. Fifty-three women were screened over two months of which twenty women screened positive and were recruited.

There were no refusals. A first stage screening instrument, the Edinburgh Postnatal Depression Scale (EPDS) was administered to participants as it is commonly used worldwide and has been validated for use in South Africa (De Bruin, 2004). A cut-off score of 12 was used in this study as suitably predictive of PND (Matthey, 2004; Weobong et al., 2009). A second diagnostic screen, the Structured Clinical Interview for DSM-IV (SCID-II).was used by two clinical psychologists to confirm diagnoses for major depressive disorder. Twenty participants, who met the criteria for a major depressive episode were recruited into the study over a period of 2 months and recruitment ceased once saturation of data was reached. Participants with a history of depression were excluded to ensure the focus on postnatal rather than general or chronic depression. Participants were compensated for their time with $5 (R50) supermarket vouchers. All the participants were over the age of 21, and reported at least a basic primary school level educational attainment. The majority (80%) were unemployed. The sample is described in Table 4 below.

Table 4: Sample descriptive of women screened positive on EPDS and meeting criteria for major depressive episode

Demographic	N	Percentage
Age		
Below 21	0	0
21 -30	10	50
31-40	9	45
41-59	1	5
Level of education		
No formal schooling	0	0
Primary	15	75
Secondary	2	10
Tertiary	3	15
Marital status		
Married	5	25
Cohabiting	10	50
Single	5	25
Employment status		
Employed	4	20
Unemployed	16	80
Sources of income		
Salary only	8	40
Salaries and social grants	5	25
Pension and other social grants	2	10
Social Grants only	2	10
Social grants and other sources such as families	1	5
No minimum income (rely on families and other sources)	2	10

Note: Limited to women screened in waiting room of one primary health care facility in South Africa.

Data Collection

With the participants' consent, semi-structured, audio-recorded interviews were conducted in Setswana by two clinical psychologists to explore participants' experiences and explanatory models of postnatal depression, their symptoms and coping strategies. Ten follow-up interviews were conducted with available participants from the first wave of interviewees two months later in their homes. The objective of the follow-up interviews was for participants to confirm earlier findings, to gain a better understanding of participants' home environments and social contexts, and observe their interactions with family members and infants. The analysis of the first and second set of interviews was combined.

Data Analysis

The interviews were translated and transcribed into English with back-translation checks being applied by an independent English/ Setswana speaker. Thematic analysis was both theory and data driven. Interviews were guided by specific research questions but the participants were encouraged to respond to the questions and to add any related information that they wanted to share. This approach was used to ensure that the essential data that was required to assist with developing the intervention would be collected and that any other data that were collected not specifically related to the research questions but related to the interview would add richness and depth to the data and would be useful to guide the intervention. The data were thus coded using apriori themes based on the interview questions as well as emergent themes with the help of Nvivo qualitative software for data analysis. The first and second authors independently generated themes and coded the data. The generated themes and coded data were compared and consensus reached on the final coded data.

Ethical Considerations

Ethical approval was obtained from the Humanities and Social Sciences Research Ethics Committee at the University of KwaZulu-Natal (ethical clearance number HSS/0880/011), and the Policy, Planning, Research, Monitoring and Evaluation division based at the Department of Health in the North West Province. The information and consent sheets were verbally explained to potential participants who were then given the opportunity to read the information sheets and ask questions confidentially. Participants were recruited following informed consent in their preferred language i.e. either Setswana or English. Participants who met the criteria for a major depressive episode and/or suicidal ideation were referred for further assessment and treatment using existing referral pathways.

The methodological guideline for qualitative research reporting (RATS)(Clark, 2003) was adhered to in the reporting of the qualitative study in this paper.

Results

Emergent Themes

Symptoms of Depression

The most common symptoms described by participants included wanting to cry; not taking care of one's appearance and feeling the need to be alone; physical symptoms such as headaches and neck tension, sleeplessness and loss of appetite; feeling impatient, irritable and angry; and feeling down were also mentioned.

"I would feel angry for no reason. I would also feel like crying; feeling as if I am going through deep pain; feeling like wailing" (Case 11)

And

"One finds it difficult to sleep; doesn't have appetite; is too forgetful; is impatient, things like that" (Case 12)

Expected course and resolution of the depression

Participants indicated that they did expect to get better after receiving help.

"I would not lose my mind anymore; I would become calm after receiving help" (Case 9)

Causes of depression

Participants generally described their experiences of depression as being the result of adverse circumstances and life events that caused feelings of pain and sadness. While some participants understood the term "depression" and were able to verbalise and relate their symptoms as depression, others were not aware of what the term "depression" meant. Further probing with these participants regarding the cause of their symptoms elicited similar responses and themes that were provided by those participants who were aware of the term and meaning of depression. Key sub-themes included poverty and dependence; interpersonal conflicts, particularly with partners and families; unwanted pregnancy and social isolation.

Poverty and dependence

Poverty through associated stressors emerged as a pervasive causal factor of depression, in particular food, housing and financial insecurities as reflected in the quote below.

"If I could get a job and also continue with my studies. If I could make sure my children, mother and my siblings live a better life; where there is nothing to bring me pain; when there is no day

in which we go to bed without having eaten. That's when I may feel my life has really improved." (Case 5)

In South Africa, there is significant reliance on the child support grant (CSG), an initiative of the State's Social Assistance Programme to combat abject poverty and hunger, and whose beneficiaries are poor children under the age of sixteen. Recipients are usually mothers or caregivers (Social Development). Sometimes the CSG was used to supplement food purchases for the household, and there was also reliance on other family members' social grants such as state old age pensions. The CSG at the time of the interviews was $29 (R290) per child, per month. In response to being asked who buys the food at home, one participant responded

"It's my mother. She is the one who used to buy 50kg of maize meal after getting her pension money. So this month that has been difficult for her to do as she wasn't able to get the usual pension money. So I managed to buy some maize meal using the grant money I get for my children." (Case 5)

And

"I earn a living from the children's welfare grants." (Case 2)

Poverty renders mothers dependent on state support and/or families. These supports are often inadequate or withheld, resulting in feelings of despair and helplessness. Combined with a lack of education and formal marketable job skills to enable them to generate income, participants became trapped in a negative cycle of dependence and poverty. The situation was exacerbated in some cases where, because of poverty, the mother was rendered dependent on an abusive partner and unable to extract herself from the abusive relationship due to financial dependency. This was the case for a significant proportion of respondents (seven).

"*You try to leave your parents' place to go and stay with your partner, and when he hurts you, you would not know where to go from there; you feel like there is nothing that you can do. And you end up continuing to stay with this person as you have no other alternative."* (Case 14)

Partner Conflicts

Serious conflict with partners emerged as triggers of depression including rejection by the partner, lack of material and/or emotional support, disinterest in the child and denial of paternity; physical abuse; and infidelity.

Rejection/lack of support by partner

A number of participants (nine) reported that although their partners acknowledged paternity, they did not provide financially for the children. Nor do they assist with parenting or provide emotional support to the mothers.

"*Yes, one thing that pains me the most is that the father of my child never comes to check on us. That's what I am always worried about. He does make phone calls saying he would come over for the weekend, but he never does that. I would tell him about some of the child' needs that are lacking and he will ask me why I can't provide for the child's needs with Zuma's money; he will be referring to the grant money […] He never denied that he fathered my child. Ever since the child was born he has never done anything for him; I mean nothing at all. Not even to buy him some clothes. Mind you the child was born in July when it's usually very cold. I have been struggling trying to make ends meet using only the grant money I get for my first child. His child is a year old and knows how to walk but, he has never seen him".* (Case 2)

Infidelity

Six participants also reported that their partners were unfaithful to them, reporting this as a major stressor.

"When the baby was two months old, I hastened to come back as I heard that he was staying with a girlfriend at our house and she was using my things." (Case 18)

And

"His aunt asked him why he never told them about the pregnancy, why it took him so long and why he wanted me to commit abortion. He told them that he has a girlfriend in Lesotho whom he has promised to marry, thus he is afraid of disappointing her" (Case 1)

Associated with infidelity was the stress of the spectre of HIV and other sexually transmitted diseases. There seemed to be little discussion or negotiation or an inability to negotiate around issues of protection and prevention as evidenced below.

"When I was eight months pregnant I came here to test for HIV and I was very concerned that I could be infected as he has been unfaithful" (Case 5)

And

"He continues to go and collect other people's infections and bring them to (me)" (Case 13)

Intimate partner violence

Some participants (six) also reported experiences of intimate partner violence as triggers of depression.

"…When he comes home from visiting his friends or from drinking alcohol; when he arrives drunk like that and finds us sleeping, he has the tendency to be violent; he will take objects and

hit me with them while hurting me in the process… So I always think about this thing; it really affects me mentally." (Case 10)

An added economic burden associated with material support was the expectation of financial support from the male partner's family members sometimes at the expense of the woman and her child.

"I always get to hear what they say about me in my absence. Like they say I use up their brother's money. My mother in-law would say how much trouble she went through while raising her son" (Case 20)

Unwanted Pregnancy

Having had an unwanted pregnancy was itself a significant stressor and reported trigger of depression for varied reasons. Women who were unhappy in their intimate relationships viewed an unwanted pregnancy as a complication that bound them unwillingly to the relationship. This is articulated in the quote below.

"And I wondered as to what I could do. I could see that being pregnant with this child meant I could no longer leave the marriage unit. Committing abortion was no option as I knew I was HIV positive, or else CD4 count would drop down and I will start to become sick which means I would be taking a risk". (Case 13)

Reasons for unwanted pregnancy included unplanned pregnancy; inability to support the child and lack of support from the partner. In response to being asked how they felt when they realised that they were pregnant, responses included

"Imagine a situation whereby you are pregnant and you tell this person who impregnated you about it. After telling him, he starts behaving in a way that shows he is not with you in the

situation. You start to wonder, 'am I going to handle all this by myself;' you don't see the importance of keeping the baby. I am unemployed, so who is going to help me raise the child?" (Case 2)

Exacerbating Factors

Lack of Supportive family relationships

Lack of support from parents and/or family was reported by 14 participants and contributed significantly to the burden of depression. The respondent quoted elsewhere above who experienced intimate partner violence further elaborates.

"…When I report this matter to my family they would tell me that he is my husband and he has paid the dowry therefore there is nothing that they could do. I have told myself that I am all alone in this matter. There is no one who cares about me." (Case 10)

Lack of support from the partner's family was also reported by 7 participants as particularly difficult to deal with and contributed to their stress.

"The in-laws didn't accept the baby. The reason for the way they act is because they say that before coming to give birth my family should have written them a letter letting them know about the pregnancy, and another letter should have been written to them after the child had been born. That's what is demanded by their culture. So, all that they are doing (not acknowledging the child) is because now it was as if they were never involved at first". (Case 2)

Social withdrawal and unhealthy thinking

Social withdrawal and unhealthy thinking which are symptoms of depression also functioned to exacerbate depression, trapping people in the negative cycle of depression and/or social withdrawal

"There are times when I am not able to look after myself properly. Like there are times whereby I would shut myself in the house and ensure I don't go anywhere" (Case 11)

And

" So in regards to people out there may be if a friend comes and says ' I have just come to see you'; you don't really have the interest to chat with the other person or even face the person." (Case 10)

A disturbing number of participants (seven) reported suicidal ideation or suicide attempts.

"I overdosed some pills; sometimes I would drink jik." (Case 1)

Although voluntary termination of pregnancy (TOP) is legal in South Africa and available to public health care users, there seemed to be a lack of education among some women about these services and when to use them as some of the respondents indicated that they were informed that their pregnancies were too advanced to carry out a TOP. This participant attempted suicide as a result of her unwanted pregnancy. She felt that suicide was the only option to terminate her pregnancy.

"*That's the time when I tried to kill myself so that I could kill the child"*. (Case 15)

Excessive worrying, blame and distorted thinking in the form of repetitive negative intrusive thoughts was reported by eleven respondents. These harmful thought patterns influenced mood negatively. Unhealthy thought patterns maintain and perpetuate harmful thoughts and divert attention from making efforts to achieve their aspirations.

"Is there anything that would make me never think that I am a failure in life? I want to know because I am always miserable and this is due to the fact that I always blame myself for having children?" (Case 5)

"I get angry at myself for bringing children on this earth only to come and suffer just because of me." (Case 10)

And

"I blamed his father because I had told him that I wasn't yet ready for us to go and have sex. If it wasn't because of him I wouldn't be having a child and now the child has been born but he is now suffering. He (partner) has brought me problems" (Case 2)

Negative Behaviour

Other negative symptoms and feelings reported included acting out their frustrations by hitting their children, neglecting their hygiene needs and scolding them disproportionately, including their new-borns. They reported irritability and anger when interacting with their children.

"*Yes. I do beat them up. When I am angry I would also start to shout at them. Like I would yell and force them to sleep. When they don't sleep and start to cry I will slap them*."

(Case 4)

And

"Sometimes when I have to make her take a bath or wash her nappies I would feel too lazy to do anything and I would leave everything as it is". (Case 5)

Similarly, interpersonal violence is destructive to relationships and inappropriate as a solution to problems. Unhealthy behaviour such as the incident quoted below is indicative of extreme frustration and not having the tools to deal with such levels of emotion.

"So I was very furious; I took anything I could reach and tried to throw at him. I ended up getting a knife and stabbed him with it on the hand." (Case 20)

Treatment options for postnatal depression

None of the participants mentioned seeking any assistance for their problems either from religious, social or medical structures while one woman indicated that she did think about consulting a doctor for her depression but was afraid that her partner would not allow this. The absence of help-seeking could possibly be attributed to the overwhelmingly interpersonal and economic nature of the problems as the quote below illustrates.

"Depression is stress. At times your distress is elicited by your partner. At times your partner would not give you even a cent; nothing at all and that's when you become depressed."

(Case 10)

The problem related above and the attribution of the cause of depression suggests that in such cases medical intervention is not considered appropriate to address the problem, and the perceived stigma associated with articulating these issues might prevent help-seeking from religious and social structures. Task sharing in terms of devolving counselling duties from specialists to non-specialist health workers was acceptable for most respondents with eighteen respondents indicating acceptance of counselling from community health workers and sixteen from nurses. Anonymity rather than expertise in mental health care was the principal criteria for some women to accept counselling from nurses and CHWs.

"I need someone that I can talk to, especially someone who doesn't know me and that I do not know; someone who is not judgmental". (Case 2)

Attending a support group received mixed support. Some respondents expressed reluctance to attend support groups. Five respondents suggested group-based support as a useful intervention given that women would be able to share their problems with people in similar situations.

"When we have met as a group we would be able to discuss the things that cause us to suffer from depression and also find out how we can help each other". (Case 9)

In response to being asked if nurses would be suitable to lead support groups, this participant *responded*

"I wonder. I think they can try to offer some little help but, I think someone who has had an experience of suffering from depression should be the leader of a support group." (Case 9)

This particular quote shows a desire for empathy, understanding and personal experience related to depression as being desired qualities for a group leader. There is no expectation that the group leader would have a mental health or medical background.

Some women expressed a preference for treatment during home visits

"Since it may not always be possible (for people to attend counselling sessions at the clinic), I was thinking maybe door-to-door visits to people at their home could be done." (Case12))

Access was also a consideration for attending groups

"... In a site which I would only have to walk in order to go and attend the meeting because if it was in town, at times I wouldn't have money to go there". (Case 14)

Discussion

Poverty, unwanted pregnancy and interpersonal conflict including partner rejection and associated lack of material and social support as well as conflicts including domestic violence, emerged as significant stressors that triggered depression in common with local and international literature (Jewkes, 2002; Ramchandani et al., 2009; Robertson et al., 2004).These findings suggests that the reasons for maternal depression in women from low socio-economic backgrounds in the study site are not different to that of other maternally depressed women globally. Exacerbating factors included unhealthy thinking in the form of negative intrusive thoughts as well as social isolation which are typical symptoms of depression that maintain the depressive cycle. Suicidal ideation and suicide attempts revealed the depths of hopelessness that some of the women experienced.

Pregnancy and childbirth are particularly vulnerable periods for a woman, particularly first pregnancies as these involve changes to her body image, her identity as a woman, concepts of motherhood, changed intimate relationship variables and responsibility for a helpless infant. Combined with partner relationship problems and/or socio-economic difficulties, these contribute to many women's experiences of PND. The impact of childbirth is also in many contexts culturally determined (Wong & Fisher, 2009), and when it is not validated by the traditionally expected support structures such as families, it can be extremely distressing. Postnatal depression is especially evident in the context of unwanted pregnancies; rejection of the pregnancy by the partner, and lack of support for the woman and child from the partner's family. This needs to be understood within African culture where childbearing in women is highly valued.

Although poverty per se does not inevitably result in depression, experiences of living in poverty stricken conditions interrelate in a vicious cycle which impact on mental health status,

childcare and self-care (Wachs et al., 2009). Results of this study indicated that food, financial and housing insecurity rendered some women economically dependent on their male partners, which made them vulnerable to intimate partner violence and abuse. Low educational status combined with a depressed economic climate and high unemployment rates promotes economic dependence and contributes to a sense of hopelessness. A recurring refrain was the desire to find employment. For poor women with low educational backgrounds, few or no job skills and harsh economic conditions further reduced hopes of securing employment. In 2010/2011, increased social assistance, translated to an increase of 0.3 percent of the gross domestic product. Social welfare meant to be a buffer against poverty is increasingly the sole source of income in poor households.

A high rate of circular male migration related to employment on the mines (Hickel, 2012) and the common practice of polygamy or having multiple concurrent partners may contribute to the problem of infidelity, abandonment and low levels of support by male partners, which emerged as a prominent theme. While the African traditional custom of affiliation to ancestral lands encourages the practice of having a family based at the ancestral village/home, economic factors dictate work-seeking in more urban and economically advantaged areas. Long absences and distance to the workplace mean that spouses experience long periods away from each other, with men often taking up a second relationship at their workplace.

Results of this study suggests that the socio-economic/ family context causes additional economic burden on the male partner as he may be expected to support his extended family with limited resources possibly skewing the economic support in the family's favour and depriving the partner and child of economic support or causing friction between the parties

competing for financial support. This type of economic burden is not unusual as in South Africa, the male breadwinner is often the sole economic support for multiple households and one male can support up to 10 family members (Curtis, 2009). Patriarchal culture where men hold economic, cultural and religious advantages over women and engenders female dependence on men for their economic and social security also emerged as playing a role in PND in this study. Six women out of a total of twenty one revealed that they had experienced abuse by their partners. Women all over the world experience these issues (Gass, Stein, Williams & Seedat, 2011; Surkan, Kennedy, Hurley & Black, 2011), and although contexts differ according to regional beliefs and practices, interpersonal violence (IPV) is a reality in both high and low income settings (Abrahams, Martin, Lombard & Jewkes, 2013). In another study in South Africa 31% of women indicated that they had experienced some form of IPV in their most recent relationship (Gass et al., 2011). IPV renders women vulnerable to physical nonfatal and fatal health outcomes including suicide (Surkan et al., 2011) and intimate partner femicide (Abrahams et al., 2013). The destructive physical and psychological effects of IPV include greater risk of substance abuse and increased health care seeking (Gass et al., 2011), and contribute significantly to the burden of disease in South Africa (Seedat et al, 2009).

The lack of commitment from male partners who demonstrate little interest in fulfilling financial and parental obligations or fidelity in their intimate relationships compounds the socio-economic difficulties and creates fragmented families who are related biologically but who share few or no familial ties. Weak paternal bonds breed dysfunctional relationships in families and society as a whole. Infidelity on the part of the male partner was a common occurrence, particularly when the woman was pregnant or in the confinement period postpartum. There was also little mention of responsibility for contraception or concern for safe sex practices. In some cases any concerns about possible HIV infection that the women

voiced appeared to be after they realised that their partners had been unfaithful. A disturbing aspect is despite the high rates of HIV infection in South Africa, there seemed to be little negotiation of safe sex in intimate partnerships in the responses from this study. Additionally, despite the legalisation of termination of pregnancy and concerted efforts to promote contraceptive use, rates of unwanted pregnancy are unacceptably high in South Africa (Department of Health, 2012), and requires further investigation.

An interesting paradox was the concurrent self-blame and blame-shifting for participants' unhappiness. Many women either blamed themselves for making unwise choices, or blamed their partners or partners' families for their unhappiness and feelings of depression. The assigning of blame caused depressive feelings, unhappiness and repeated intrusive thoughts related to past hurts. The inability to attempt to break destructive behaviour patterns might suggest unhealthy thinking and faulty cognitive behavioural patterns which is disempowering.

The results of our study indicate that individual's personal experiences of social and economic factors may precipitate or exacerbate depression. The complexity of addressing symptomology of depression together with predominantly socio-economic causes suggests the need for multiple interventions at various levels of the problem. While social, household and economic factors often precipitate and exacerbate symptoms of depression, it is important to attend to the most proximal causes before attempting to deal with more distal-related events that are often out of the control of the individual. Alleviating the symptoms of depression through focusing on re-building a sense of agency through promoting self-efficacy and problem-solving approaches within a supportive group environment has been noted to help individual's cope

with their depressive symptomatology (Chibanda et al., 2011; Van't Hof, Stein, Marks, Tomlinson & Cuijpers, 2011).

The participants also voiced strong support for either individual or group-based counselling services and for devolving these tasks to non-specialist health workers. This type of intervention could be made available both at facility and community levels, depending on the cadre of health worker assigned. Encouragingly, participants who indicated a preference for groups expressed wanting the social support that would emanate from a group and being with others who would empathise with their feelings. This approach is encouraged by Dennis (2005) in a review of psychosocial interventions for PND, which suggests further research should focus on self- help groups (not led by a health professional) to evaluate lay support models for mild to moderately depressed women. In addition, groups would have the added benefit of allocating one health worker to a number of participants at the same time which would be more cost effective in terms of time spent on a single intervention, travel time and travel costs to the health care system and to the community. The social network of the group could also assist participants to build social capital and form social and economic networks.

At the community level prevention and mental health promotion interventions require a multi-sectorial response from educational, social development and health agencies. Concerted efforts need to be made to promote the role of men as caring, responsible partners and fathers. This requires sustained and targeted campaigns to address issues including domestic violence, the negative effects of multiple concurrent sexual partnerships, shared responsibility for contraception and shared responsibility for children. These community based interventions should be on-going at schools, places of socialisation, places of worship, health facilities and

other public forums. In addition, microfinance and income generating opportunities for women need expansion. Promising results from the IMAGE study (Kim et al., 2007) in South Africa which combined a microfinance program with training on HIV infection, gender norms and domestic violence indicate that economic and social empowerment of women can contribute to a reduction in IPV. This synergistic combination of economic empowerment with a public health intervention suggested multiple benefits for the women, their family members and the community.

Limitations

This study is limited to a small number of participants from a specific region. Within the ambit of the study i.e. PHC users, participants are not representative of all PHC users. There is a need for further studies in PND in other PHC sites in South Africa in order to adapt and standardise brief psychosocial interventions for women with PND. This approach will assist with sustainability of training and supervision mechanisms and continuity of selected psychosocial interventions.

Conclusion and Recommendations

The high prevalence rates for maternal depression in South Africa warrant far more attention than is currently provided at PHC level given that the majority of the population does not have private health insurance and will use PHC services. Notwithstanding the small sample, this study provided some valuable insights into the issues that mothers, particularly in low socio-economic groups face. As evidenced in this study, interventions for maternal depression require a multilevel approach. At the facility level, routine screening for depression should be made at all ante-natal and post-natal clinic visits up to a year after giving birth. In addition to availability

of anti-depressant medication for severe depression, such screening should be accompanied by referral pathways for psychological interventions that have been shown to be effective within a task shifting approach (Dua et al., 2011) to promote social support and empowerment of women to better manage the psychosocial stressors that have been found to trigger depression. To this end, evidenced-based brief targeted psychosocial interventions may be applicable to address the triggers and symptoms of depression. These may include techniques such as Cognitive Behavioural Therapy (CBT) to reduce symptoms of depression and co-morbid anxiety, and Problem-Solving Therapy (PST) techniques to help develop problem solving skills to address social and economic issues. (Petersen et al., 2013). These modalities can assist with symptom management and self-efficacy, but should ideally be accompanied by inter-sectorial actions to promote gender equity and socio-economic development.

CHAPTER 5

Sub-study 2

Development of a collaborative care model for perinatal depression in Dr Kenneth Kaunda District in South Africa

***This sub-study reports the service provider engagement in Phase 2 of the study**

Edited version was submitted for consideration to Africa Journal of Nursing and Midwifery

Introduction

Perinatal depression (PND), a condition which may be defined as depression during the antenatal and/or postnatal period up to one year post-delivery (Chowdhary et al., 2014; O'Hara & Wisner, 2014), is a global public health concern. Symptoms include depressed mood and anhedonia (O'Hara & Wisner, 2014) and may also include tiredness, insomnia, disinterest in the infant, intrusive behaviour affecting the infant's rest, anxiety, fearfulness of being alone with the infant, low mood, irritability and poor functioning (American Psychiatric Association, 2013). The high disease burden and social effects are extensively documented (Dossett & Shoemaker, 2015; Wachs, Black, & Eagle, 2009), potentially negatively impacting the woman's physical and mental health, interpersonal relationships and childcare, cause poor maternal-foetal attachment, preterm birth, delayed social and cognitive development of infants, insecure attachment and dysregulated arousal (Alhusen & Alvarez, 2016; Herba, Glover, Ramchadani, & Rondon, 2016; Kiernan & Huerta, 2008; Smith Fawzi et al., 2019). Research by Kersten Alvarez (2012) has shown that children's capacities to deal with stress and interact with peers in early school involvement has been shown to be negatively affected by their mothers' PND, manifesting as lower ego-resiliency, lower peer social competence, and lower school adjustment, compared to a community sample. Female children of mothers with postpartum depression fared worse than male children, showing lower verbal intelligence, contributing a double burden of risk for females.

Antenatal depression is associated with adverse neonatal outcomes including low birth weight, and is strongly associated with postnatal depression (Eastwood et al. 2017; Milgrom et al., 2008). Untreated antenatal depression may precipitate immediate and longer-term effects, as some characteristic symptoms of depression, including loss of interest in activities, withdrawal and negative affect, may affect maternal attentiveness and caregiving, potentially

compromising effective parenting (Lara-Sinisomo et al., 2018; Wachs et al., 2009). The implications for untreated PND are worrying in terms of decreased quality of life, potentially trapping children and mothers in an intergenerational cycle of poverty, poor health and adverse socio-economic outcomes (Herba et al., 2016).

A key consideration is that while globally maternal and childcare focusses on health care, social determinants are a pivotal focus to drive the move beyond mere survival to encourage positive developmental progress (Rasanathan, 2018). Studies suggest a prevalence of between 16 and 50.3 percent of PND in South Africa (Manikkam & Burns, 2012; Ramchandani, Richter, Stein, & Norris, 2009, Rochat et al., 2011; Stellenberg & Abrahams, 2015; van Heyningen et al., 2016; van Heyningen, Honikman, Tomlinson, Field, & Myer, 2018), compared to (pooled) global estimates of 17.7% (Hahn-Holbrook, Cornwell-Hinrichs, & Anaya, 2018). These statistics highlight the perinatal population in South Africa as particularly vulnerable to PND, compared to perinatal populations globally.

The importance of integrating mental health care into routine perinatal health care is recognized in both HIC and LMIC settings, but is particularly challenging to implement in LMIC public health perinatal care settings. This is due to health system deficiencies, such as limitations in capacity in terms of expert resources (Katon 1999) infrastructure, and policies. In South Africa, these limitations are exemplified by the lack of integration of mental health care into the basic antenatal care (BANC) strategy (Ngxongo, Sibiya, & Gwele, 2016). BANC was developed as a quality improvement guide in response to high maternal and neonatal mortality (Ngxongo et al., 2016), with a focus on reducing morbidity and mortality; this focus on physical health is evident in the checklist for each perinatal visit and the guidelines for physical symptom care. The only reference to mental health care is at the six-

week check-up, where assessment of mental status is required. CMDs such as depression are unlikely to be detected within this traditional focus on physical health (Manikkam & Burns 2012), and the absence of mental health indicators in BANC is a challenge for holistic person-centred perinatal care in South Africa.

Notwithstanding these health system deficiencies, there is increasing recognition of the importance of screening and treatment for PND, with collaborative, integrated and stepped models of care increasingly being viewed as the optimal approach in resource-scarce settings (Dossett & Shoemaker, 2015; Olin et al., 2016; Weiss-Laxer et al., 2016). Shared care or collaborative care models are evidence-based packages of care comprising multidisciplinary teams providing enhanced care to patients. They have proven to be effective in treatment outcomes for depression including PND, compared to general practitioner or usual care (Dossett & Shoemaker, 2015; Olin et al., 2016). Outcomes may differ due to contextual issues including health care systems, availability of appropriate personnel, tracking systems and reimbursement schemes (de Jong et al., 2009). Typically, collaborative care in high- income countries comprises multi-professional teams that include mental health professionals working with a general practitioner and case manager (Agius, Murphy, & Zaman, 2010, Weiss-Laxer et al. 2016). Collaborative care for perinatal primary care in low-resource settings generally embraces task-sharing, and varies depending on availability of mental health specialists.

Given the estimated 83% medically uninsured population (Statistics South Africa, 2017), and the drive to increase ANC first-attendance rates before 20 weeks (Massyn, Padarath, Peer, & Day, 2018), the majority of women seeking perinatal health care in South Africa most likely

receive free health care from PHC facilities. These currently offer limited opportunities for identification and treatment of PND.

Following the qualitative investigation of the mental health care needs and pathways to care for PND conducted with perinatal patients in DKKD (Kathree, Selohilwe, Bhana, & Petersen, 2014) described in Chapter 4, this study aimed to address the service gap for PND. The objective of the study was to conduct a qualitative investigation with service providers of the mental health care needs of women with PND in DKKD, to guide the development of a model of care for PND.

Objective 2: A qualitative investigation of service provider perspectives of the mental health care needs and pathways to depression care for perinatal service users.

Objective 3: Sub-study 2: Co-Development of a collaborative care model for PND in DKKD in South Africa

Methodology

Setting

The study was located in the Matlosana municipality, an urban sub-district in DKKD in the North West Province, South Africa. DKKD was recommended by the National Department of Health as a research site for the PRogramme for Improving Mental health carE (PRIME), a multi-country research consortium partnered with ministries of health in each of five member countries to integrate mental health care into PHC (Lund et al., 2012, Petersen et al., 2016). This study was nested within PRIME in South Africa. The Matlosana municipality has an estimated population of 398 676 with an almost equivalent female to male ratio of 49.99 and 50.1, and 36.7% female headed households (STATSSA 2012). The unemployment rate at the

time of the study (2016) was 30.5% compared to national norms of 27.1% (STATSSA 2016). The population uninsured for health care was 84.5% compared to national norms of 83%. In terms of public health services, the region is serviced by 16 PHC facilities including two 24-hour community health centres with antenatal and childbirth delivery services, and two tertiary facilities, all of which provide some mental health care. PHC facilities are serviced by a PHC doctor who can prescribe psychotropic medication, and nurses and doctors have the option to refer patients for specialist mental health care at PHC and tertiary levels. Specialist in-patient mental health care is available at a tertiary level in a neighbouring sub-district.

Sampling

Service providers: Criteria for inclusion

The selection criteria for service providers were that their role included the provision of PHC services in one or more clinics in the PRIME implementation site, and/or holding a PHC managerial or coordination role. Participants included HIV counsellors, PHC operational managers, PHC nurses and sub-district-level key informants.

Samples

Sample 1. Semi-structured interviews and FGDs were conducted with a range of managers and PHC service providers who were involved/potentially could be involved in perinatal mental health care. These included separate heterogeneous FGDs with four PHC operational managers (n=1), given their dual roles as managers and professional nurses providing consultation and treatment, FGDs (n=3) with 20 HIV counsellors given their counselling role and potential to diversify their role to include counselling for PND, and semi-structured interviews with nurses (n=10).

Sample 2. 20 service providers including PHC operational managers, nurses, doctors, maternal health providers, mental health specialists and key sub-district health stakeholders were included in a participatory workshop co-facilitated by the Matlosana sub-district PHC coordinators and managers and the research team.

Sample 3. A subset of five key informants from the participatory workshop and one additional key informant were recruited. The sample description is provided in Table 5.1.

Table 5.1. - Phase 2 Sample descriptive of service providers

Sample characteristics of service providers				
Description	**Category/Role**	***n***	**Qualifications/Competencies**	**Interview details**
PHC operational managers	Operational management and clinical care	4	Four-year nursing diploma. Additional qualifications varied among participants and included midwifery and nursing management	One FGD consisting of four clinic operational managers
Nurses	General health services at PHC	10	Four-year nursing diploma. Additional qualifications varied among participants and included primary health care, HIV management, psychiatry and midwifery	Ten individual semi-structured interviews consisting of nurses at four clinics
HIV counsellor	Pre/post-HIV testing and counselling at PHC	20	Training in HIV pre/post-testing and counselling, and any combination of TB, adherence, PMTCT and general counselling skills training provided by non-governmental organizations	Three FGDs and one individual interview with HIV counsellors at four clinics
Phase 2				
Workshop – 20 PHC service providers				
Maternal health representative (n=1), chronic care services representative (n=1), mental health services representative (n=1), operational/acting managers (n=6) and nurses representing a number of facilities in Matlosana sub-district (11), and the research team, including the principal investigator and project site coordinator.				Participatory workshop to co-develop a care model for PND
Phase 3				
Sample characteristics of key informants				
Key informant 1	Mental health services	1	Degree	Individual semi-structured interview
Key informant 2	Operational management and	1	Diploma in nursing	Individual semi-structured interview

	clinical service at PHC			
Key informant 3	Medical services, coordination of district specialist teams, general coordination within PHC	1	Degree	Individual semi-structured interview
Key informant 4	Maternal, women and child health services	1	Diploma in nursing	Individual semi-structured interview
Key informant 5	Mental health services	1	Diploma in nursing	Individual semi-structured interview
Key informant 6	District manager	1	Diploma in nursing	Individual semi-structured interview

Data collection

Following written informed consent procedures, and with due acknowledgement of ethical considerations listed under ethical protocols, nurses were interviewed in their consulting rooms, while the PHC managers and lay counsellor FGDs were conducted in a space away from the general clinic area, where they were comfortable and there was a degree of privacy.

The participatory workshop was conducted at a venue within the sub-district DoH offices.

Two key informant interviews (KIIs) were conducted in participants' offices, and four were conducted telephonically. All service provider interviews were conducted in English by the researcher and the site coordinator. Service providers did not receive any tokens of appreciation, but were verbally thanked and acknowledged for their time and effort. Individual interviews varied between 30 and 60 minutes, and FGDs were approximately 60 minutes long.

Data analysis

Interviews in English were transcribed by an independent transcriber, and checked for veracity against the audio-recordings by the researcher. Framework analysis was used to analyse the service provider interviews. Developed in the 1980s for use in large-scale policy development, framework analysis is a systematic method to manage large amounts of qualitative data and is a popular method in medical and health research; it is situated within a broad grouping of research methods encompassing thematic or qualitative content analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013). These methods recognize similarities and differences in qualitative data which is in textual form, followed by identification of relationships and formulating descriptions and conclusions centred on specific themes (Gale et al., 2013).

The framework structure helps to reduce or summarize the data into frameworks without the full original accounts of the participants. In qualitative analysis, this is a useful tool to support answering the research questions in a manageable format. The framework matrices are characterized by "rows (cases), columns (codes) and 'cells' of summarised data" (Gale et al, 2013, p. 2). Data is reduced into manageable 'bites' in a structured format, using cases and codes as the units of analysis. In this study, interviewees were coded as the cases, and themes as nodes. Particularly with large data sets and multiple data sources, the facility to compare data within and across cases is important and is a particular advantage offered in the framework method. Reflexivity, rigor and quality issues are requisite, as in other qualitative analysis methods. The data captured in this study were homogeneous (i.e. covering a common issue) and were in a suitable format (i.e. semi-structured interviews), rendering framework analysis an appropriate method (Gale et al., 2013).

Gale et al. (2013) suggest using seven steps for framework analysis – these are transcription of data, familiarisation with the interview, coding, developing an analytical framework, applying the analytical framework, charting data into the framework matrix (in Excel), and interpreting the data. The process is similar to using NVivo software. NVivo is a qualitative software tool developed to organize and analyze data. Instead of an Excel sheet, data were imported into NVivo as anonymized labelled transcripts filed as 'cases', and themes were coded into 'tree nodes' and subthemes into 'child nodes'. Framework matrices were then created within the program and populated with the cases and their linked themes. Memos and field notes added a layer of data useful for the analysis. In Phase 2, using the NVivo software program for qualitative analysis, a framework was constructed using multiple data sources including service users, clinicians and lay health workers.

Table 5.2: Framework process for qualitative data analysis

Step	Procedure	Output
Transcription	Audio-recordings were independently translated where applicable and independently transcribed verbatim.	• Service user transcripts • Service provider transcripts
Familiarization with the interviews	Importing transcripts into NVivo software. Reading and rereading the transcripts and relevant interview notes.	Additional notes/memos.
Coding	Independent examination of each line of the transcript by two researchers.	Broad labeling/coding relevant phrases/sentences; memos; annotations.
Developing a working analytical framework	Coders discuss their codes and agree on common codes.	Coded as major/tree nodes and child nodes.
Applying the analytical framework	The working analytical frame is applied to the transcripts.	Iterative process of examination of transcripts and coding. Themes finalized.
Developing the framework matrix	Developing a framework matrix in NVivo; populating the matrix.	A framework matrix in NVivo with the cases (transcripts) as rows and codes/themes/nodes as columns. Additional column for notes, methodology.
Interpreting the data	Probe theoretical concepts a priori • Explanatory models of illness for service users and service providers • MRC framework for complex interventions as overarching theme –addressing feasibility of the model of care Probe research questions. • Pathways to care • Acceptability of task-sharing – prior to the development of the model of care and after piloting the model • Acceptability of the intervention – KIIs prior to the intervention and service providers after piloting the model A priori themes – coding additional themes that were found to be useful and adding to the interpretation of the data during the iterative coding process	• Interrogation of preliminary results • Final results

Ethical protocols

The study commenced once ethical approval was obtained. Approvals were granted by the University of KwaZulu-Natal ethical clearance numbers HSS0880/11 and BFC 587/16, and the Policy, Planning, Research, Monitoring and Evaluation division at the North West province Department of Health (Appendices 10, 11 and 12).

Research activities commenced once the relevant ethical approvals were granted for the study. A sub-district family physician facilitated contact with the PHC managers who were provided with proof of ethical approval and support. Engagement was face-to-face with key informants, managers and other participants at agreed dates and venues. All team members were introduced to the clinic management and staff. Research staff presented themselves to the operational managers at each visit, and additionally obtained verbal permission at each visit to use allocated venues for the research.

The researchers adhered to a standard operating guideline developed for the study for recruitment for each visit, and for each service user and service provider participant, explaining the study, providing an information sheet in a private space for participants to read and understand, and obtaining written consent before proceeding with recruitment and data collection. The information documents outlined details on confidentiality, voluntary participation, and the purpose and management of the research and data.

5.2 Results

Results are reported according to themes identified from each phase of the study. In Phase 1, clinical understanding of PND, possible pathways to care for PND and challenges regarding PND care were discussed, and are summarized according to themes and subthemes below.

Table 5.3: Themes

Key themes	Subthemes	Participants
Understanding PND	• Understanding PND in terms of causes • Clinical awareness of PND as a mental illness	Nurses; operational managers; HIV counsellors; participatory workshop
Challenges and barriers to counselling	• Sensitization to postpartum cultural practices • Language as a barrier • Paucity of resources	Nurses; operational managers; HIV counsellors; participatory workshop; key informants
Task-shared collaborative care	• Suitability of different cadres of health workers	Nurses; HIV counsellors; participatory workshop; key informants
	• Practical application of task-shared care for PND	Participatory workshop; key informants
Recommendations		All participants

5.2.1 Understanding PND

PND was commonly described in terms of causal factors (n=10), including adverse health and social factors including being HIV positive, traumatic events such as rape, unplanned or teenage pregnancy, lack of social support, and desertion by the partner.

"A person would be expecting and they question themselves, what am I going to do with this child? I am positive and things like that… there's no boyfriend, he has run away and I'm unemployed … and usually these things come up when, you see a client coming into the clinic

... *coming for ANC* [antenatal care]. *At the clinic, once the person has been tested, that's when they start…things like that would come up."* (FGD 2_Lay counsellors)

The poor mental health literacy surrounding PND was highlighted by some participants (n=3), who described PND in terms of severity, conflating depression with puerperal psychosis. This accentuated the need for improving perinatal mental health literacy among nurses and HIV counsellors, to promote appropriate and adequate care and avoid stigmatizing the patients and the disease.

"They present with psychotic symptoms just like mental health patients." (Nurse_3)

Even when recognized as a mood disorder, PND was still attributed exclusively to social issues such as unplanned pregnancy.

"It's a mood disorder but maternal depression is about issues related to pregnancy … they were not dealt with and they end up leading you to reject the baby or rejecting the pregnancy because of being depressed due to pregnancy." (Nurse_9)

As participants described the causes of PND in their context as rooted in social and economic adversity rather than biological factors, counselling was a preferred option rather than pharmacological intervention. Nevertheless, several barriers were specified with reference to counselling for PND.

5.2.2 Challenges and barriers to counselling

Challenges and barriers to counselling are reported as two key subthemes, possible cultural sensitivities that relate to accessing postnatal mental health care, and access to counselling in indigenous languages.

5.2.2.1 Postpartum cultural practices

Potential challenges to accessing postnatal mental health care were associated with cultural practices, including observing the traditional period of seclusion for women postpartum. There were mixed responses on whether it was culturally acceptable for new mothers to receive home visits for counselling from health workers, with a perceived shift towards acceptability of any postpartum health services, particularly if facility based, as these were for the benefit of the new mother.

"Where do they give birth? At the hospital, isn't it so? They do meet people at the hospital and they also come for three days check-up and they also get mixed with different kinds of patients so … ? What is so special with botsetsi [traditional confinement period]?" (FGD1_managers)

And

"According to attendance that we've got, botsetsi thing (sic) *is slowly fading out because after three days of delivery, there will be community health workers who will check the baby and the mother, but previously strangers were not allowed in their homes, but now there are people who will be visiting the mothers and people allow it."* (Nurse_7)

Cultural practices may also influence treatment pathways. One participant noted that, customarily, postpartum depression was addressed through traditional healing which was still somewhat prevalent. This participant advocated creating awareness around PND and encouraging supportive networks for women with PND. Building on the theme of awareness

and support, a participant suggested that some communities considered counselling a privilege reserved for the wealthy. The quotation below encapsulates the disenfranchisement and exclusion experienced by disadvantaged socio-economic groups (framed by the participant as an ethnic group) in relation to health services that they perceive as only available to economically privileged groups.

"We African people, when it comes to counselling, the disadvantage to the community is that we think counselling is only for privileged people." (Nurse_4)

5.2.2.2 Language as a barrier to counselling

The discourse relating to counselling revealed a further level of complexity, as language was also highlighted as a barrier. Poor accessibility of services was linked to a dearth of mental health professionals who are fluent in indigenous languages. Language was perceived to be a barrier if the counsellor and client were not able to understand each other. This issue is particularly pertinent when viewed in the context of a dire shortage of mental health counsellors who can communicate in the various indigenous languages in South Africa; this context is framed within a historical background which favoured English and Afrikaans as official languages in South Africa, to the exclusion of indigenous languages. This gap in mental health services was highlighted in all three phases.

"You can't expect an Afrikaans-speaking person to come and help me, a Xhosa-speaking person … I don't think we will understand each other because if you go help someone, you have to make sure that I will understand this person and they understood me". (FGD _Lay counsellors)

The absence of counselling services in indigenous languages was pivotal in the discussions pertaining to mental health resource constraints and the concept of task-sharing services for PND.

5.3 Support for task-sharing

Participants in all three phases were in favour of task-sharing to address perinatal mental health. The cadre of health worker who could be trained to deliver counselling for PND was discussed at length by all categories of participants across Phase 2. The opportunity to drive this process using the existing facility-based HIV counsellors was proposed by an HIV counsellor, who saw the opportunity to identify patients with possible PND during routine HIV pre/post-test counselling.

"What I think is that, it is easier when the person comes to me, and I start offering HIV/AIDS counselling to her. She will begin to tell me that 'I have got such and such a problem', and that's when we would start to address issues of concern right from the time when she is pregnant." (FGD 3_Lay counsellors)

The concept of task-shared care for PND was endorsed across the board and echoed in the strengthened collaborative care model for PND developed in Phase 2

5.4 Recommendations

5.4.1 Phase 1 Recommendations

Considering that Phase 1 was a preliminary investigation of limited scope and depth, and a relatively unexplored area of focus for participants, the recommendations from this phase were fairly general, with the formation of PND support groups and home visitation common themes.

5.4.4.1 Support and support groups

A number of participants (n= 6) proposed that women with PND require support, including support groups, due to the lack of emotional and social support which many women experience in the perinatal period, and the opportunity to equip women to deal with stressful issues.

"Socially, they do need support because some of them are depressed that there's nobody to help them after the baby is born, or during pregnancy, there's nobody who's supporting them, because they need social support. In terms of emotional support, they need someone to support them and maybe have support groups for them as pregnant women. We could also give them training in ways to deal with other life stressors." (FGD_Managers)

While stigma was not reported to be associated with either depression or counselling, a participant cautioned that counselling for conditions other than HIV should be in a separate room from rooms designated for HIV counselling, as the HIV-counselling room could have negative connotations due to the presence of needles and blood, and thereby distract the patient. These recommendations for support systems and for consideration of appropriate spaces for counselling were incorporated into the discussion in Phase 2.

5.5 Phase 2

Development of a draft collaborative care plan

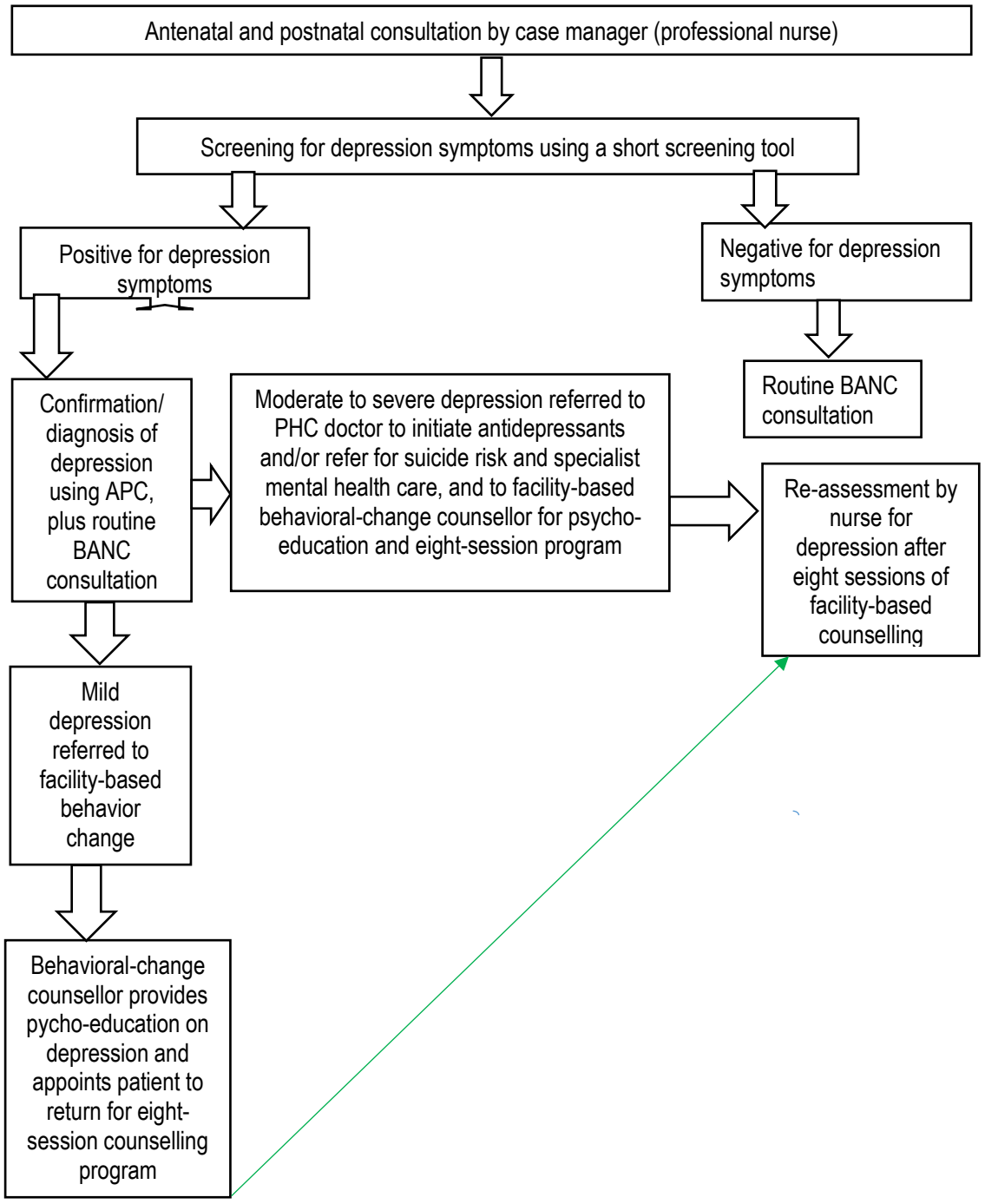
The results from the Phase 1 interviews were incorporated into the discussion by the research team in Phase 2 to guide the participatory workshop to focus discussion on task-sharing and pathways to care for PND. They addressed additional issues including: i) the need for refresher education and promoting awareness of PND for nurses, doctors and HIV

counsellors, ii) identification of appropriate cadres of health care providers to provide services for PND, and iii) training requirements for the identified cadres. Planning a detection, referral and treatment pathway using available resources for PND underpinned the discussion, including the need for a short, easy-to-use screening tool for PND, and a plan to commence the intervention as soon as feasible. A draft model to address PND emerged from the workshop. The model proposed that nurses be trained as case managers to use a brief screening tool to screen for PND, and in the absence of mental health guidelines in BANC, to confirm PND using the (formerly PC101) Adult Primary Care 101 (APC) guideline using the "*Stressed and Miserable*" and "*Depression and/or Anxiety*" in APC, and provide basic psycho-education, in addition to using the BANC guideline for routine maternity care.

Perinatal patients who screened negative for depression symptoms would be consulted as per usual care using BANC. In addition to the BANC care, patients with mild PND would be referred to a trained facility-based counsellor for psycho-education, while moderate-to-severe PND would be referred the primary care doctor for initiation of antidepressants/or specialist care and/or referral for suicide risk. Mild and moderate-to-severe PND would also be referred to the facility-based behaviour- change counsellor for the PRIME-SA manualized individual or group psychosocial counselling programme, currently (at the time of the study) used for chronic care patients. This decision was agreed upon by the health provider stakeholders and the research team as the results from the preceding study with perinatal service users (Kathree et al., 2014) indicated similar socio-emotional stressors as the chronic care patients in the PRIME cohort, and the content of the program was therefore considered suitable for PND counselling. The counselling format comprising an eight-session program delivered by non-specialist mental health counsellors trained to provide basic psychosocial counselling using problem-solving and behavioural-activation techniques, with patients re-evaluated for

depressive symptoms by the nurse to assess the need for onward referral after attending the counselling programme. The draft collaborative care plan for PND is depicted in Figure 5.

Figure 5: Draft collaborative care model for perinatal depression



5.6 Phase 3

Key informant interviews

Key informant interviews were conducted with a sub-set of five participatory workshop participants and an additional key informant, who collectively corroborated the Phase 2 decisions emanating from the participatory workshop. The recommendations of the key informants were used to refine the model (Figure 5). The purpose of the interviews was: i) confirmatory in relation to the participatory workshop, ii) to harness participants' specific expertise, and iii) for additional institutional perspective. Given the diverse backgrounds and roles of the key informants within the health system, the recommendations in this phase expanded on the workshop decisions, and mirrored key aspects of the plan, such as task-sharing, screening, adding perinatal mental health indicators and setting targets to report PND.

Significant points raised in the workshop were re-iterated in the key informant interviews, including: i) consensus that routine perinatal services offer multiple opportunities to address mental health issues, ii) screening for PND is absent, and iii) there is a need for a brief PND screening tool and screening targets for PND. Noteworthy threads that overlapped from the workshop and highlighted during the key informant interviews are outlined below, listed as challenges and barriers to care, and key recommendations.

5.7 Themes

5.7.1 Theme 1: Challenges and barriers to care for PND

Participants identified a number of challenges and barriers to identification and care for PND. These included an absence of protocols to identify and manage PND, the need for training in mental health care for PHC service providers and training in counselling, difficulty in

accessing specialist care given the shortage of mental health specialists, and language barriers.

In relation to the absence of protocols for identifying and managing PND, a clinician highlighted the absence of routine mental health assessments for perinatal patients.

" I don't see us looking at them in that … to say they are mental health clients, we only consider them to say they are ANCs [antenatal patients]*."* (KI2)

And

"... because it's not such a commonly perceived thing, it is not commonly asked or screened for." (KI4)

Continuing this theme, specialist mental health service providers indicated receiving few referrals for PND. *"Patients are only referred if* [there are] *complications during pregnancy or if the patient lost the baby."* (KI1)

Refresher training in initiation of psychotropic medication for primary care doctors who form an important referral resource at primary care level was proposed.

"The primary care doctors are trained in mental health but are not always confident in diagnosing and treating the ANC/PNC patients. They usually refer the patient to the psychologist to confirm the diagnosis and to recommend treatment, or will refer the patient to the hospital." (KI1)

With regard to the inaccessibility of psychological services, there was only one psychologist available to service the 16 PHC facilities. Patients were placed on a waiting list and thus not guaranteed consulting the psychologist in the near future.

"Specialist psychological services are [supposed to be] *available for ANC/PNC patients with depression at all PHC facilities. Unfortunately, these psychological services are rendered by only one psychologist and* [are] *not always accessible at each visit."* (KI1)

And

"The challenge is if the psychologist is giving us dates, but the client we have identified as having depression, the client is going home and maybe the problem is at home. Because she is not going there [psychologist] *directly".* (KI2)

Echoing the challenge of access to counselling services in indigenous languages, a key informant said:

"Psychological services are only available to patients in English/Afrikaans, not in their first language". (KI1)

Competing health priorities, including prevention of mother-to-child transmission of HIV (PMTCT) and the HIV and tuberculosis (TB) epidemics, were reiterated by key informants as a challenge, as these conditions were prioritized over others. The focus on these conditions was perceived as sensitizing health workers to target and manage these and other identified priority conditions in routine care almost exclusively, to the detriment of other conditions such as mental disorders.

"Mental health care/service is not a priority in health care at the moment. It seems that HIV and TB are priorities." (KI1)

While many challenges were outlined, participants also proposed recommendations to address these issues.

5.7.2 Theme 2: Key recommendations of key informants

Key recommendations from Phase 3 reiterated the crucial aspects of the model of care, including task-sharing, developing a PND protocol, screening, and adding indicators for PND. In terms of task-sharing, the collaborative care plan co-developed for PND was based on managing PND, primarily using non-specialist mental health providers, with the consulting nurse as case manager, supported by non-specialist mental health counsellors, primary care doctors and mental health specialists. The case manager would be responsible for screening, diagnosing and referring patients with PND for psychoeducation, counselling and pharmacotherapy, as well as monitoring and re-assessing patients with PND. Support for task-sharing was reiterated in the key informant interviews.

"Yes, a task-sharing approach will be feasible, especially because resources are limited." (KI1)

Additional training was recommended for cadres of health workers identified to provide counselling.

"The counsellors we have [are] *focussed on HIV testing. I believe they might be able to counsel patients but, because it is not done on an everyday basis, they might need some extra training or in-service training or mentoring and assistance."* (KI4)

Endorsing support for task-shared counselling, one participant used an example of a pilot study in the study site using mental health-trained facility-based HIV counsellors to provide psychosocial counselling for chronic care patients with depression as a beneficial skill for HIV counsellors.

"They [HIV counsellors] *feel* [it is] *worthwhile because previously they were only doing HIV/AIDS counselling, but now that they have been empowered with an advanced skill, they are in a position to see things from a broader perspective, so for every primary health care facility, if they can be exposed for the training..."* (KI6)

Being a relatively uncharted area for health providers, and in the context of a lack of clear guidelines and experience in managing perinatal mental health care, a participant proposed introducing protocols for PND.

"A specific policy/procedure to follow is needed as our nurses are not that familiar with mental health and it will serve as a guide and make them more confident in addressing mental health in ANC and PNC." (KI1)

The call for a PND protocol underscored the need for a structured approach to manage PND, including the requirement of a PND screening tool. The need to screen for PND was highlighted by health providers during the workshop and supported by the key informants. The rationale for screening was to prompt nurses to identify possible PND, as detecting and managing PND would be a new and additional task, not included in routine perinatal protocols. Screening was viewed as a valid option to detect priority conditions.

"Maybe the biggest one [challenge] *at this stage is the* [absence of a] *standardized screening tool….and then policy, to say if you screen and you have identified , do you need to treat on that level, then you can refer immediately because I would think that patient will need some counselling sessions."* (K14)

And

"If the nurses could have a screening tool, like the TB screening tool – they can tick – if there are more than two ticks… similarly for pregnant patients if they could have a screening tool the nurses can identify… the patient is depressed, then this is what we are supposed to do." (KI5)

The proposal for a brief screening tool for PND was linked to the need to add perinatal mental health indicators and to set perinatal mental health targets to encourage nurses to

identify and manage PND. At the time of the study, mental health indicators were absent from perinatal reporting, and the limited existing mental health indicators for chronic care did not differentiate between different types of mental disorders.

"The first step recommended would be to record mental health indicators in the antenatal register and then transfer to an electronic system when feasible." (KI3)

However, this participant cautioned that the volume and diversity of indicators could overwhelm the recording system, particularly when indicators are recorded on different systems, including physical registers and electronic systems, and should be linked to an existing system if possible.

"If that [perinatal mental health indicators] *could be linked up to an existing system … I don't imagine a new system should be created, we cannot deal with another system. There is an antenatal register, so it would have to start there … and then it would have to go into an electronic system."* (KI3)

PND indicators were associated with setting targets (i.e. data-driven performance indicators for PND) to encourage screening. Agreed targets for reporting screening, referral, and treatment for PND would need to be set by mental health, perinatal health and other district and provincial stakeholders. Fulfilling targets was viewed as mandatory, and therefore important for nurses to achieve.

"If we have targets, they are going to work because we have to reach those targets… it will push us to say those patients must be screened and, if not, there must be a reason why. It will be compulsory – it will be something we must report on". (KI2)

5.8. Discussion and Conclusion

Findings suggest an awareness of and consensus on the part of lay workers, clinicians and health management on the importance of identifying and treating PND. Results of the formative interviews in Phase 2 suggest that, while health providers have some knowledge about PND, both lay counsellors and nurses would benefit from training in identification of and care for patients with PND, as the condition may be viewed as normal rather than as a mental health condition. Key informants provided clear direction for practical application of the collaborative care model for PND and provided additional insights and recommendations. While perinatal care is a significant health focus, preventing neonatal and maternal morbidity and mortality are focal areas; however, mental health is not an explicit focus. The lack of emphasis on mental health care for this population is evident in the absence of mental health screening or mental health indicators for perinatal patients, although brief screening tools for PND have been validated in several sub-Saharan African countries (Marsay et al., 2017; Tsai et al., 2013; van Heyningen et al., 2018).

Perinatal patients are thus seldom referred or treated for depression in the context of this study, as evidenced by data from all three phases. This was attributed to four key factors: i) the lack of a short screening tool to identify PND; ii) the absence of data elements and mental indicators to assess mental health and depression in the BANC consultation checklist; iii) the absence of targets to screen for PND; and iv) the absence of health system data elements and indicators to report PND. The exclusion of CMDs such as depression, from perinatal care is a significant omission in the context of a high burden of PND. A lack of mental-health trained PHC service providers exacerbates a poorly resourced mental health care context (Baron et al., 2016; Lund et al., 2014; Petersen et al., 2015; Petersen et al., 2018), and while PND is already a neglected health care area with minimal identification, a lack of confidence to treat perinatal patients for mental health-related disorders on the part of some doctors may

magnify the issue.

The importance of prioritizing mental health care for perinatal patients was a theme that emerged in interviews and the workshop, where participants indicated that, contrary to this being a novel activity, the nurses who were identifying chronic care patients with depression using the APC guide were also consulting perinatal patients, and could therefore easily screen these patients for depression. This strategy was proposed as an interim solution in the current absence of indicators to screen for depression in BANC, with the caveat that a brief PND screening tool was necessary as a prompt for nurses to screen for depression. Interview and workshop participants mentioned the successes of data-driven health care, citing HIV and TB, suggesting that data-driven indicators were the route to achieve improved identification of perinatal mental health problems. Similarly, setting targets for screening for PND was proposed as a strategy to prompt nurses to screen for PND.

Previous findings based on formative interviews with service users (Kathree et al. 2014), together with these findings, suggest that PND can be addressed through a collaborative care model using a task-shared approach that utilizes existing resources and health care providers. The task-sharing approach is supported by evidence-based findings in diverse settings to support task-sharing to address CMDs, including PND. Singla, Raviola and Patel (2018) make a compelling argument to support the use of non-mental health specialists for psychosocial interventions for mental health care, arguing that the shortage of mental health specialists, limited access and low demand can be mitigated by a change of perceptions. Perceptions thus need to shift from viewing skilled mental health providers as the only health professionals who are trained in psychiatry, psychology or social work, so as to support task-sharing using non-specialist health providers.

5.9 Limitations

The initial sample of 10 nurses and four FGDs was limited to the four clinics out of a possible 16 clinics in the sub-district and therefore was not representative of all the health care providers in the sub-district. The participation of a range of service providers from additional clinics and the sub-district management in the participatory workshop, as well as key informants serves to mitigate this to some extent. Although we employed a participatory approach for the workshop with a range of service providers, we did not include service users as we had engaged service users separately in the formative phase. This may be a limitation in terms of service user acceptability of the draft collaborative care model. However, determining service user acceptability of the model was planned as a component of the evaluation of the collaborative care model.

Chapter summary

The historically biomedical focus on morbidity and mortality in pregnancy has had a natural trajectory into mainstream perinatal care due to high infant and maternal mortality rates in South Africa; however, the inadequacy of perinatal mental health care is a concern in the context of high depression rates and potential negative intergenerational impacts. This study suggests that leveraging existing PHC resources within a task-shared collaborative approach is acceptable, and is more likely to be scaled up as it espouses the efficient use of existing clinic resources rather than a separate intervention. The next step planned was to evaluate such a collaborative care model aligned with the existing clinic system, to evaluate proof of concept and feasibility.

CHAPTER 6

Sub-study 3: Feasibility and acceptability of collaborative care for perinatal depression in Dr Kenneth Kaunda District in South Africa: outcome and process evaluation

***An edited version planned for submission to African Journal of Primary Health Care & Family Medicine**

Background

PND is a disorder included in a group of perinatal mood and anxiety disorders (PAMDs) occurring in the antenatal and/or postnatal period. Untreated PND has prevailing and potentially harmful intergenerational effects. Risk factors for PND may be rooted in biological, psychological and/or socio-environmental factors, which may be exacerbated by high levels of stress and associated mental illnesses affecting women at a sensitive period (i.e. any time during pregnancy, birth and during the first year of their infant's life).

Antenatal depression is a predictor of postnatal depression and is strongly associated with adverse neonatal outcomes (Eastwood, Phung, & Barnett, 2011), including stunting (Wemakor & Mensah, 2016). Childcare is physically and emotionally demanding, and the additional burden of untreated PND is associated with a range of poor outcomes for affected women, their children and families (O'Hara & Wisner, 2014; Patel, Rahman, Jacob, & Hughes, 2004). Harmful effects of untreated PND may result in poor self-care, withdrawal, chronic mental illness and poor medication adherence for mothers (Stringer et al., 2014), and children may experience sub-optimal care and poor socio-emotional and cognitive development (Patel et al., 2004) . Evidence from South East Asia links PND with infant failure to thrive (Patel et al., 2004), particularly in the context of substandard maternal care, and poor socio-economic conditions, including poverty, poor sanitation and poor living conditions.

Long-term consequences of cognitive and socio-emotional deficits, rooted in the crucial foundational stages of childhood and adolescence (Kersten-Alvarez, 2012; Canadian Paediatric Society, 2004), potentially compromises optimal functioning and growth necessary for the advancement of good mental and physical health; which in turn helps promote collective social capital in communities and society. In South Africa, high unemployment

(STATSSA, 2016) and poverty levels converge to increase the social burden and provide multiple risk factors for mental illness, including elevated stress levels, food insecurity, reduced access to economic prospects, social networks and capital, as well as elevated obstetric risks. These macro-level social challenges present a significant risk for mental disorders as these social determinants influence mental health outcomes (Burgess, Jain, Petersen & Lund, 2020).

PND is widely acknowledged as a significant mental health condition that receives low priority. The South African mental health policy environment, which includes a Mental Health Care Act (The Government Gazette of South Africa, 2002), reinforced by a national mental health policy framework and strategic plan (MHPFSP) (National Mental Health Policy Framework and Strategic Plan 2013–2020, 2013), offers an enabling backdrop to support perinatal mental health care. Notwithstanding the MHPFSP support for the integration of mental health services into general health care, promotion of perinatal mental health care, and endorsement of task- sharing in mental health care, clear strategies to address PND are absent in clinical guidelines for perinatal care in PHC (McKenna, Abrahams, Marsay, Bass, & Honikman, nd), despite high prevalence rates.

The public health care context

Collaborative care models are health system- level interventions found to be effective for the detection and treatment of CMDs in primary health care settings (Araya, Alvarado, & Minoletti, 2009; Araya et al., 2003; Katon et al., 2010). This case management approach links patients and health providers, and may include both facility-based care with mental health teams (usually including highly qualified mental health professionals in HIC settings) (de Jong et al., 2009), as well as community components (Connelly, Baker-Ericzen, Hazen,

Landsverk, & Horwitz, 2010), and in LMIC, often includes elements of task-sharing (Fairall et al, 2018; Patel, Simon, Chowdhary, Kaaya, & Araya, 2009; Petersen et al., 2018; Van Ginneken et al., 2013).

Given the gap in addressing PND in public health settings in South Africa (Baron, et al., 2016; Hanlon et al., 2014; van Heyningen et al., 2016; Manikkam & Burns, 2012; Marsay et al., 2017; Ramchandani et al., 2009; Tsai et al., 2014), as well as the paucity of specialists available to treat PND in PHC settings, there is a need for research to assess the feasibility of utilizing task- shifting interventions in this context. Research on PND in South Africa has focused on prevalence, risk factors, effects and validation of screening instruments (Ramchandani et al., 2009; Rochat et al., 2011; van Heyningen et al., 2016; van Heyningen et al., 2018; Rochat et al., 2013), with sparse research or implementation of interventions for PND (Lund et al., 2014; Myers et al., 2019; Nyatsanza, Schneider, Davies, & Lund, 2016). Following the co-development of a collaborative care model with health care stakeholders to identify and manage PND, described in Chapter 5, the objective of this sub-study was to evaluate the feasibility and the potential of the co-located, task-shared collaborative care model, to reduce depressive symptoms in women with PND who were referred for counselling/other treatment as per the collaborative care model. The terms feasibility and piloting have been used interchangeably in public health research, and the definitions of the terms are somewhat ambiguous in relation to larger studies (Eldridge et al., 2016). Within the MRC framework (Craig et al., 2008) that guided this study (see Methodology), feasibility and piloting phases are included in a single category of studies recommended in relation to planning future larger studies and trials. Eldridge et al. (2016) suggest in their review that all studies done in preparation for larger studies be viewed as feasibility studies, with pilot studies as a subset. The features of feasibility studies have been expanded as a public health

concept to embody a number of factors integral to intervention delivery. These include: i) acceptability, which is evaluated as the reaction to the intervention by key players; ii) practicality, which examines whether the intervention can be delivered when resources are constrained;, iii) implementation, evaluated as the intervention being delivered as planned; iv) demand, evaluated as uptake of the intervention; v) limited-efficacy testing, evaluated using a convenience sample with limited statistical power; vi) adaptation, focusing on modifications of programme elements to suit a new context, as well as vii) the related element of expansion focusing on the potential success of an existing successful programme in a different context or population; and lastly viii) integration, which focusses on the system-level changes required to integrate a new programme/process into an existing programme (Bowen et al., 2009). This study will be reported in terms of acceptability and will include elements of demand and limited efficacy-testing.

The objective (Objective 4 explained in Chapter 3/Methodology) of this sub-study was to conduct a feasibility study to evaluate the potential of a task-shared collaborative care model for PND which includes strengthened identification and referral pathways to a co-located psychosocial intervention delivered by non-professional mental health workers at PHC level for reducing depressive symptoms at four months after baseline assessment, and to conduct a process evaluation to understand factors impacting on feasibility and acceptability of the collaborative care model. For the outcome and process evaluation of the feasibility study, data collection and analysis focused on evaluating the feasibility of the model (i.e. the collaborative care model that emerged as a product of Phase 2). Both quantitative (outcome evaluation) based on reduction of PHQ-9 scores, and qualitative (process evaluation) measures were used to achieve these objectives.

Methodology

Quantitative methods

Setting

The setting was a 24-hour service CHC, providing maternity services in the Matlosana sub-district, DKKD, North West province. The facility was also the pilot site for the PRIME intervention (Petersen et al., 2016), and was one of four clinics serving a catchment area of approximately 78419 people (STATSSA, 2012). In terms of the national perinatal health information indicators, during the study period the pilot facility reported the four mandated perinatal health indicators:, i.e. i) the delivery- in- facility rate for women over 18 years old (73.4%); ii) antenatal first visit rate before 20 weeks (61.4 %); iii) antenatal visits coverage rate (90.5%); and iv) postnatal visit within six days rate (66.2%), highlighting a conspicuous absence of mental health indicators for this PHC population. Specialist mental health care was available by appointment with the sub-district psychologist, as well as referral to secondary and tertiary (in-patient) levels of mental health care.

Description of the research study

As the Phase 2 analysis indicated a need for strengthened referral pathways and refresher training for nurses to screen, identify, and manage perinatal patients with depression, a 2-step identification process for PND was agreed upon during the co-development of the collaborative care model, i.e. brief screening for PND, confirmation of diagnosis where indicated, and co-located collaborative care for PND. The 2-item Whooley screening tool (Marsay, Manderson & Subramoney, 2017) (Appendix 14) was introduced at the request of the health providers in the absence of a mandated screening tool. The screening tool was used to ask patients two questions i.e. a) during the past month have you been feeling down, depressed or hopeless? and b) during the past month did you feel you have little interest or

pleasure in doing things? An affirmative response to either question was considered a positive screen. The version of the tool validated by Marsay et al. included a third question asking if the patient wanted help for her condition. This question was omitted in favour of a clinical diagnosis using the (former) PC101 (now APC) guideline in the event of a positive response to either question.

Accordingly, two members of the research team, the investigator and the clinically trained (psychologist) site coordinator provided training to nurses (n=6) at the designated CHC to use the brief screening tool as a first step in the identification of PND process.

Additionally, the research team provided refresher training to nurses (n=6) at the designated CHC, in the use of the APC guideline to diagnose and manage/refer patients who screened positive for PND. The options to manage patients diagnosed with PND were a) psychoeducation during the consultation, b) referral for psychoeducation and/or counselling for PND to the co-located counsellor who was trained to provide this service, and/or c) referral for specialist care. In all cases, whether patients were diagnosed with PND or not, the BANC guideline was also administered as per usual care.

Counselling Intervention description

With antecedents dating to an earlier counselling intervention in KwaZulu-Natal (Petersen, Hancock, Bhana & Govender, 2013; Petersen et al., 2014), the eight-session depression counselling intervention was adapted for the PRIME-SA study to suit the needs of the target chronic care population in DKKD (Selohilwe et al., 2019). The introductory psychoeducation session and final closure session supported the six core sessions which addressed the depression triggers. These included interpersonal conflict (including partner infidelity); grief

and bereavement; experienced stigma, social isolation; perceived stigma and poverty. An optional ninth session addressing adherence to chronic medication was added for patients who required adherence counselling as well. This counselling intervention was considered appropriate to use for perinatal patients as the formative study in phase 1 indicated that the triggers for depression were similar for both the perinatal and the chronic care patients. Participants were given the option of joining a group for counselling sessions or attending individual counselling sessions.

Following the training, a non-randomly assigned comparison group cohort design was used to assess changes in symptom severity for screen-positive patients who were identified and referred for PND care by nurse clinicians, compared to patients who were not detected or referred for treatment for PND by the clinician, although they screened positive on the PHQ-9, which was independently administered by mental health practitioners within the research team. A baseline interview was conducted by the research team after screening for depression, followed by a follow-up assessment four months later, the time-point at which the optimal effect of treatment is expected to occur. The same baseline and follow-up questionnaire was also administered to participants in the comparison arm.

Given the pragmatic setting of the study, random allocation of participants was not feasible. Reasons included: i) the real-world health care setting, which did not allow for randomization, as the study design dictated that the selection of participants and timing of the intervention was reliant on the identification, diagnosis and referral of the patient by the consulting clinician (usually the nurse) for allocation to the intervention arm, as well as uptake of the counselling intervention which was voluntarily undertaken by the patients/participants, and was therefore not within the control of the investigator, and ii)

ethical considerations related to the rollout of the intervention during routine care, where potentially effective treatment could not be withheld.

3.6.2 Phase 3 –Quantitative sampling

Sampling strategy

Purposive sampling was used to select participants. While more commonly associated with the qualitative paradigm, this sampling technique was appropriate as the study design required participants who shared a particular characteristic (i.e. perinatal patients). This form of non-probability sampling is useful for studies focused on specific populations and which do not aim to generate results that are generalizable to the general population (Etikan et al., 2016).

Criteria for selection

Conditions for eligibility to participate in the study included adult women aged 18 and older, able to consent and willing to participate in the study, being either pregnant or postnatal (6-72 weeks post-delivery), able to speak Setswana or English, attending perinatal PHC services at a 24-hour community health centre in the Matlosana sub-district, and either referred for PND treatment by the clinician (for allocation to the intervention arm), or a score of ≥ 10 on the PHQ-9 administered by a research assistant (for allocation to the comparison arm).

Quantitative research instruments

A survey questionnaire (Appendix 15) including demographic information, depression, alcohol use, stigma, functioning, social support and interpersonal violence scales was used. The PHQ-9 depression screen was translated from English to Setswana by a bilingual Setswana/English-speaking clinician psychologist and back-translated by a second

Setswana/English-speaking clinician psychologist (Bhana, Rathod, Selohilwe, Kathree & Petersen, 2015) for clinical accuracy and meaningful translation. The survey questionnaire was translated from English to Setswana by a mid-level, fluently bilingual Setswana/English-speaking psychological counsellor with a four-year Bachelor degree in psychology, supervised by the clinician psychologist, with back- translations to confirm meaningful translation.

Patient Health Questionnaire 9 **(Appendix 13)**

The PHQ-9 is a brief diagnostic and severity measure for depression used in both research and clinical settings for PND (Gjerdingen & Yawn, 2007; Santos et al., 2016). It is a nine-item questionnaire with a cut-off measure of 10 points indicating possible depression. Items are derived from DSM-IV criteria for determining current episode of depression, and current problems experienced within the past two-week period are rated by the participants on a scale of 0-3. The primary outcome measure was reduction of depression symptoms measured using the PHQ-9.

Reliability and validity of the PHQ-9

The PHQ-9 has been validated in South Africa in a predominantly Setswana-speaking chronic care population (Bhana, Rathod, Selohilwe, Kathree, & Petersen, 2015) attending PHC services in the same physical research context as this study. As both populations sampled were predominantly Setswana first-language speakers, we used the Setswana version of the instrument that was used in the local validation study (Bhana et al., 2015) for the participants who indicated a preference to respond in Setswana. The PHQ-9 has also been validated in South Africa among patients undergoing routine HIV counselling and testing, demonstrating ease of administration and utility in local PHC setting (Cholera et al., 2014). In a perinatal setting, a validation of the PHQ-9 using the Structured Clinical Interview for

DSM-IV (SCID II) diagnostic categories reported sensitivity and specificity rates of 85 and 84 percent, respectively, using a PHQ-9 score cutoff of 10 on a sample of pregnant women (Sidebottom, Harrison, Godecker, & Kim, 2012). The sensitivity and specificity rates are comparable to other studies in perinatal populations (Gilbody, Richards, Brealey, & Hewitt, 2007; Gjerdingen, Crow, McGovern, Miner, & Center, 2009; Kroenke, Spitzer, & Williams, 2001). Positioned within a multidimensional risk-screening interview, the authors report that the PHQ-9 effectively identified pregnant women who met criteria for current depression (Sidebottom et al., 2012), and that the PHQ-9 also identified women with sub-diagnostic symptom levels who may benefit from interventions to alleviate their distress and improve pregnancy outcomes.

Process indicators

Three indicators were used to track the collaborative care process. These included the two-item Whooley screening tool (Marsay et al., 2017 (Appendix 14), a referral form used by the clinician to refer patients for mental health care (Appendix 16), and a log to document the counselling sessions attended. The Whooley screening tool which consisted of two questions which were also included in the *Depression and Anxiety: Diagnosis* section of the Adult Primary Care (APC) guideline, was provided to the facilities by the research team as this was a new tool introduced during the research process, and was not in use within the health care context. The tool was not translated into Setswana from English as it was intended for use by clinicians who were asking the same questions provided in English in the APC guideline. The referral form was a already in use at the facility, having been introduced previously by the PRIME chronic care study, and the counsellor log was used by the counsellor for record keeping purposes for both the research and the clinical records for the facility (tracking patients within the collaborative care model).

2-Item Whooley screening tool (Appendix 14)

The brief 2-item Whooley screening tool was adapted from the 3-item tool validated in South Africa (Marsay et al., 2017) and asked the following two questions:

- During the past month have you been feeling down, depressed or hopeless?
- During the past month did you feel you have little interest or pleasure in doing things?

The third question asking if the person wanted to be helped for either of the affirmative responses was omitted in favour of a clinical diagnostic process to determine if a referral was required.

Quantitative data collection

Data collection commenced on receipt of ethical approval. A research assistant who was a locally based, mid-level psychological counsellor fluent in English and Setswana was trained to recruit participants using the information and consent document in either English or Setswana. The research assistant was also trained to use the baseline and follow-up questionnaire, with additional training by the clinician psychologist on using the PHQ-9. A standardised operational procedure for recruitment was used. Daily information sessions were conducted by the research assistant in the clinic waiting room for perinatal patients to allow opportunities for potential participants to volunteer for the study.

Patients in the antenatal waiting room and those waiting to consult for postnatal care or infant vaccinations and care were informed that volunteers were required for a research study, and were invited to approach the research assistant if they were interested in knowing more. Women who volunteered were told that an independent research study was researching mental health care services in DKKD, and informed written consent was obtained from interested participants. All consenting women exiting the perinatal consultation (antenatal

and postnatal) were screened for PND using the PHQ-9 in either Setswana or English. Participants were also asked by the research assistant if they had been diagnosed with depression by the clinician. Patients who indicated that they were diagnosed with depression by the professional nurse practitioner and who were referred within the collaborative care model were enrolled into the intervention arm (n=31) regardless of PHQ-9 score, as they were clinically diagnosed with PND during the consultation.

Women who indicated that they were not diagnosed by the PN but who scored ≥10 on the PHQ-9 (administered by the mid-level psychological counsellor) were enrolled into the comparison arm. One participant in the control arm (n=24) was re-assigned to the intervention arm after a subsequent diagnosis of PND by the clinician, resulting in a final total of 23 participants in the control arm. Data collected for the participant for the control arm were not used and the only data that were analyzed for this participant were data collected after she was reassigned to the intervention group. A follow-up interview using the same questionnaire (Appendix 15) was administered to participants four months after the baseline interview. A mobile cellphone was used by the trained research assistant to capture the data in private spaces at the facility and at some participants' homes, and data were uploaded onto a secure server in real-time. At both interviews, participants received a R50 (approximately USD $3) supermarket voucher to acknowledge appreciation of their time.

Data collection-process indicators

To ascertain whether patients were screened using the brief 2-question Whooley screening tool, copies of the screening tool were placed in each consulting room. Completed copies were placed by the clinician in a dedicated box in the room and were collected at the end of each day. Referral forms (Appendix 16) were also provided in each room to track the number of patients referred for PND treatment within the collaborative care model. The nurse

clinician was asked to complete the form indicating the mental health condition/s the patient was referred for, and cadre of health provider to whom the patient was referred, and placed in the dedicated box. However, forms were sometimes also handed directly to the patients and were therefore collected either from the patient at their first contact with the counsellor, or daily from the dedicated box in each consulting room. Counsellor records were used to link the patients who were referred for counselling and who were assigned to the study to ascertain the number of sessions attended. Counsellor records were also used to ascertain the number of patients who were referred and who took up counselling services independently of the research process, i.e. those not assigned to the study, but who were routinely identified and referred, in order to gauge the demand and implementation of the strengthened collaborative care model on the part of service providers. Data were collected by the facility-based study counsellors (n=2) who provided the counselling services, and stored securely at the project offices under lock and key. Data were collated and analyzed after the 4-month follow-up period.

Quantitative data analysis

The primary outcome measure was reduction on PHQ-9 scores defined as at least 50 percent reduction at the follow-up at four months from baseline, with remission and improvement defined as a PHQ-9 score ≤ 5 (Huijbregts et al., 2013) used as measures of clinical significance in treatment trials. For statistical analysis of reduction in depression scores, nine participants were excluded out of a total of 31 clinically diagnosed participants in the intervention arm, as they did not meet the criteria for depression at baseline using the PHQ-9 assessment (i.e. PHQ-9 score of ≥10). Statistical analysis was conducted for the remaining 22 participants in the intervention arm and 23 participants in the comparison arm. Data were analysed using STATA quantitative analysis software. We used non-parametric tests (i.e. Mann-Whitney U test for continuous measures, and Exact Fisher's test) to compare symptom

severity between groups at the four-month follow-up visit.

Process data analysis

The process data which documented some procedural and tracking information were analysed quantitatively using descriptive statistics for additional perspectives on feasibility such as uptake/demand and implementation -as well as acceptability of the strengthened collaborative care model for PND.

Qualitative methods

For the qualitative process evaluation interviews in phase 3, individual semi-structured interviews were conducted at the end of the four-month follow-up period with both service users and service providers who participated in the collaborative care model. This was done to elicit their experiences of the collaborative care model exploring elements of feasibility, as well as acceptability.

Qualitative sampling and instruments: Service users

Purposive sampling was used for both service users and service providers. The focused aim of this component, which was qualitative evaluation of the collaborative care model for PND, necessitated a specific and narrowly defined sample.

Criteria for inclusion

Participants were selected on the basis of uptake of the counselling intervention and the dosage received.

Sample

Five participants, who were given a referral by the nurse using the strengthened referral pathways for the co-located psychosocial counselling intervention and who attended either

one session or more sessions were recruited. We were unable to locate or recruit participant who did and did not take up the service for various reasons including unwillingness to be interviewed or incorrect contact details on file.

Instruments

A semi-structured interview guide (Appendix 17) was developed for service users, that asked about their experiences of the referral system, and whether they perceived the intervention to have helped them or not. In addition, they were asked for their suggestions on what worked well, and recommendations to improve on aspects that did not work well in their assessment.

Qualitative sampling and instruments: Service providers

Criterion for inclusion

The inclusion criterion was the provision of services at any level of the collaborative care model for PND.

Sample

Nurses (n=7) and behaviour-change counsellors (n=1), who provided care in terms of the collaborative care model for PND, were recruited. Nurses with both high and low rates of referral were included.

Instruments

A semi-structured interview guide (Appendix 18) was used to ascertain service providers' experiences of the referral system, and whether they perceived the intervention to have helped their patients or not. They were also asked for their suggestions on what worked well and how to improve on aspects that did not work well in their estimation.

Qualitative data collection: Service users

Informed consent procedures were followed, and the voluntary nature of the participation was explained. Qualitative semi-structured interviews were administered to service users in either English or Setswana (Appendix 17). Participants were asked about their experiences in being identified, referred and treated for symptoms of depression. Questions related to whether they were informed about their diagnosis of PND, what if any information they were given about the illness and the referral, their experiences of the counselling process, what was helpful or not useful about the counselling, and recommendations to improve the counselling programme. Interview schedules were translated into Setswana from English by a mid-level mental health practitioner and were administered in the participants' preferred language of either Setswana or English. Service users who utilized the psychosocial counselling service were approached either telephonically or at a personal appointment by a fieldworker who explained the evaluation component of the study; the fieldworker recruited participants following informed consent procedures and reiterated the voluntary basis of participation. Interviews were conducted by appointment with participants either at a private space at the clinic or at the participant's home. Interviews were audio-taped and translated, where appropriate, into English. Participants received a R50 (USD$3) supermarket voucher to acknowledge their time.

Qualitative data collection: Service providers

Eight service providers who provided services within the collaborative care model for PND were also interviewed. Nurses were asked about their experience of identifying and referring perinatal patients with depression; they were also asked for their views on aspects of the process that worked and those that did not, as well as suggestions to improve the service (Appendix 18). A behaviour-change counsellor was also interviewed about the referral

experience, intervention process and view on aspects that worked or did not work, as well as suggestions to improve the process (Appendix 19). The voluntary nature of participation was emphasized to the participants and interviews were audio-taped following informed consent procedures (Appendix 20).

Qualitative data analysis

In Phase 3 we used the framework analysis method (described in Chapter 5) and combined the service user and service provider data within a single framework, teasing out common themes as well as reporting themes specific to the category of participant. The framework process is outlined in Table 6.1 *Triangulation* was achieved using interviews with three different sources (i.e. different categories of participants), i.e. nurse who are an essential component of the PHC system, an externally funded non-professional mental health counsellor employed by the study to fulfil the role of co-located task-shared mental health care, and perinatal service users who participated in the study.

Table 6.1: Framework process for qualitative data analysis

Step	Procedure	Output
Transcription	Audio-recordings were independently translated where applicable and independently transcribed verbatim.	• Service user transcripts • Service provider transcripts
Familiarization with the interviews	Importing transcripts into NVivo software. Reading and rereading the transcripts and relevant interview notes.	Additional notes/memos.
Coding	Independent examination of each line of the transcript	Broad labeling/coding relevant phrases/sentences; memos; annotations.
Developing a working analytical framework	Common codes finalized.	Coded as major/tree nodes and child nodes.
Applying the analytical framework	The working analytical frame is applied to the transcripts.	Iterative process of examination of transcripts and coding. Themes finalized.
Developing the framework matrix	Developing a framework matrix in NVivo; populating the matrix.	A framework matrix in NVivo with the cases (transcripts) as rows and codes/themes/nodes as columns. Additional column for notes, methodology.
Interpreting the data	Probe theoretical concepts a priori and emergent • MRC framework for complex interventions as overarching theme –Step 2 addressing feasibility of the model of care Probe research questions. • Feasibility of the intervention – service providers and service users after piloting the model Emergent themes – coding additional themes that were found to be useful and adding to the interpretation of the data during the iterative coding process	• Interrogation of preliminary results • Final results

Data management

All qualitative and process study data are securely stored on a password-protected computer and on an external hard drive, and hard copies of data are stored in a locked facility at the Centre for Rural Health, School of Nursing and Public health, Howard College Campus,

University of KwaZulu-Natal, Durban, South Africa. Both of these are accessible only to the primary researcher and the supervisor. These include audio-recordings, anonymized transcripts and anonymized process data. Hard copies of recordings will be deleted on completion of the Doctoral thesis and transcripts will be stored securely for 5 years. The anonymized quantitative data (perinatal cohort questionnaire) pertaining to the feasibility study is stored on an access-controlled (password- protected) repository allocated to the PRIME project at the University of Cape Town (primary recipient of the PRIME grant), accessible to the primary researcher and the PRIME project data manager. All data were anonymized and securely stored to protect confidentiality and unauthorized access.

Ethical protocols

The research team adhered to ethical protocols at every step of the research. Ethical approval was obtained for data collection from the University of KwaZulu-Natal through ethical clearance numbers HSS0880/11 and BFC 587/16, and the Policy, Planning, Research, Monitoring and Evaluation division at the North West province Department of Health (Appendices 5;15; 6).

Research activities commenced once the relevant ethical approvals were granted for the study. A sub-district family physician facilitated contact with the PHC managers who were provided with proof of ethical approval and support. Engagement was face-to-face with key informants, managers and other participants at agreed dates and venues. All team members were introduced to the clinic management and staff. Research staff presented themselves to the operational managers at each visit, and additionally obtained verbal permission at each visit to use allocated venues for the research.

The researchers adhered to a standard operating guideline developed for the study for recruitment for each visit, and for each service user and service provider participant, explaining the study, providing an information sheet in a private space for participants to read and understand, and obtaining written consent before proceeding with recruitment and data collection. The information documents outlined details on confidentiality, voluntary participation, and the purpose and management of the research and data. Service users were given a R50 (USD$3) supermarket voucher at each interview, to acknowledge our appreciation of their time.

Results

Of the 31 participants diagnosed with PND by the nurse, one was referred to the hospital for specialist care and did not attend any facility-based counselling for PND. The other 30 were referred to the behaviour change counsellor and attended at least one session. For statistical evaluation, nine participants were excluded on the basis that they scored <10 on the PHQ-9 which was used as the main outcome score. Calculated as a 29 percent false positive rate for a diagnosis of PND, this rate is marginally lower than the 36 percent false positive rate for diagnosis of depression by nurses in the PRIME chronic care cohort, which included nurses and patients at the same CHC (Petersen et al., 2019). Sample characteristics are reported in Table 6.2. Qualitative results are reported in terms of the feasibility criteria recommended by Eldridge et al. (2016) and Bowen et al. (2009) and quantitative results are reported in terms of efficacy, with limited statistical power.

Table 6.2: Sample characteristics at baseline

Demographic characteristics	N=22	%
Perinatal status		
Pregnant	20	90.9
Postnatal	2	9.1
Marital status		
Single	20	90.9
Partner	2	9.1
Other children	9	40.9
Age range		
≤25	12	54.54
26-38	10	45.45
Education		
Less than primary school	3	13.63
Primary school and above	19	86.36
Employment		
Unemployed	22	100
Food insecure		
Yes	10	45.45
No	12	54.54
History of abuse		
Ever been emotionally abused	9	40.9
Ever been physically abused	13	59.09
Ever been sexually abused	5	22.72

Quantitative results

Table 6.3: Primary outcome for depression

Primary Outcome for Depression* at Baseline and Four Month Follow-up						
	Intervention		Control		z-score	*p*
	Baseline n=22	Follow-up n=21	Baseline n=23	Follow-up n=19		
PHQ-9	14.3 (2.9)	4.3(4.5)	13.0 (3)	7.9 (3.3)	3.329	.009

*Mann-Whitney U test

Table 6.2 shows the baseline and four-month post-intervention change scores on PHQ-9. The PHQ-9 change scores in the intervention group declined significantly by 10 points from baseline and at 4-month follow-up. According to Kroenke et al (2002), this is indicative of a 50% reduction or more in PHQ-9 scores as well as suggesting clinically significant remission in PHQ- 9 scores (score <5). While these results are encouraging and would be considered clinically significant in a larger sample, they should be interpreted with caution in this study due to the small sample size.

6.2 Feasibility and acceptability

Feasibility and acceptability are reported in terms of process indicators, as well as qualitative results which report on themes suggesting acceptability, practicality, and demand. The study took place within a pragmatic setting during routine services, and process indicators collected

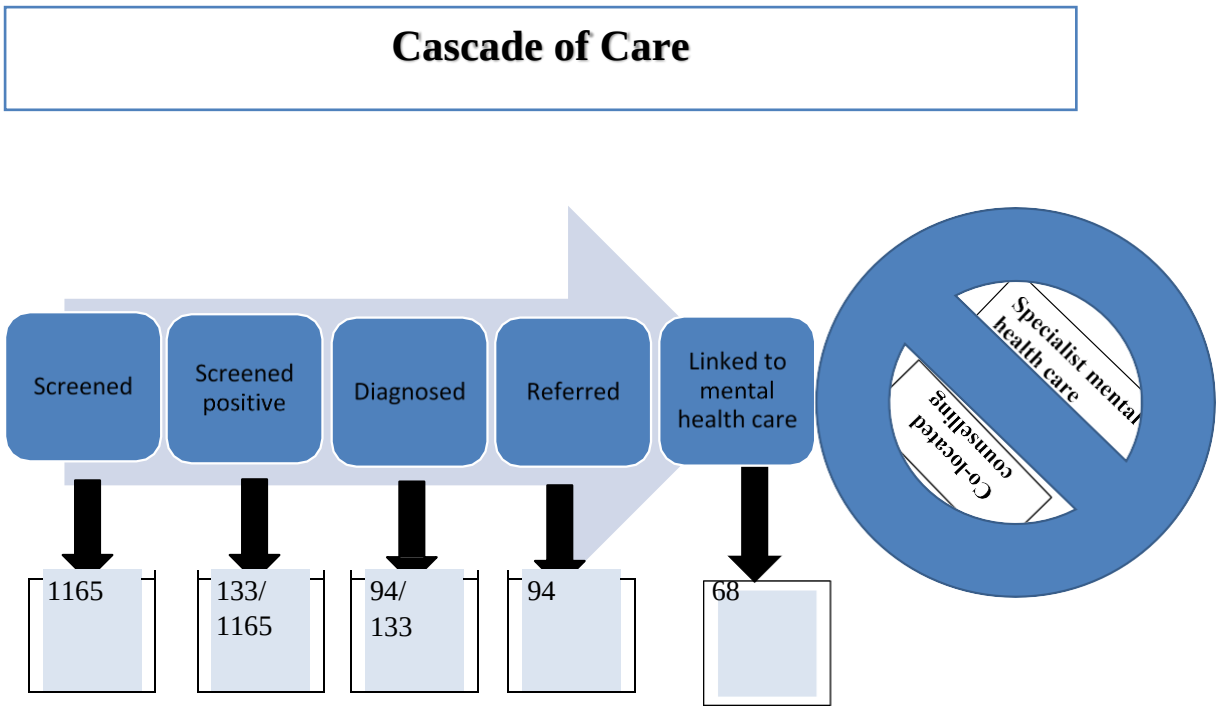
as part of the research process provide some insight into uptake as well as acceptability of the screening tool. Accurate estimation of the screening is difficult given that the total perinatal headcount for the period is uncertain. While antenatal headcounts were reported, postnatal headcounts are unclear, as only the 'Mother postnatal visit within six days' indicator was available, as per the nationally mandated perinatal indicators.

Additional process indicators that were instituted within the study to track the number of people screened and referred (explained in more detail in the Methodology section pertaining to phase 3) provided some indication of the processes followed, although these were not necessarily wholly accurate, as they were dependant on nurses accurately recording the information using the agreed forms. Furthermore, a review across data sources indicated the possibility that a larger number of women were screened using the Whooley than the physical reconciliation of forms collected indicated. The counselling records kept by the counsellor also indicated the attendance of perinatal patients for whom no referral forms could be traced. These discrepancies may be attributed to the following possibilities-a) research field notes indicated that one particular nurse preferred adding the Whooley screening forms to the patients records which were not available to the study and this could possibly apply to the referral form as well, and b) some patients might have been referred within the collaborative care model without the use of the referral form as this was a tracking document instituted by the study and was not a mandated referral form within the health system.

Available process records (physical copies of forms) indicate that 1165 perinatal patients were screened using the brief Whooley screening tool over a 12-month period. Of the 1165 women screened, 683 screens were conducted at the first visit either before or after 20 weeks, with the balance including women attending postnatal care, routine infant care appointments and chronic care.

Of the total number screened, 1025 responded negatively to both questions, seven questionnaires did not indicate affirmative or negative responses, 58 responded affirmatively to one question and 75 responded affirmatively to both questions on the brief Whooley screening tool. Process records indicate that one woman was referred to the hospital for specialist mental health care. While the proforma referral forms did provide some indication of the number of people referred for services or given psychoeducation, we were unable to collect data on whether nurses did consult the APC guideline to diagnose and refer patients who answered affirmatively to either question as this clinical process was not recorded.

Figure 6: Depiction of cascade of care



Although groups counselling was the preferred option, the formation of groups proved difficult logistically as counselling sessions were scheduled to coincide with participants' clinic consultation dates in order to minimize costs and inconvenience to them. Thirty study participants who were allocated to the intervention group

attended the co-located counselling service and received individual counselling. Given the real- world study context, parallel to the study, nurses continued screening and referring patients for PND (n=64) counselling, of whom 37 women external to the study also attended PRIME counselling services at this facility. In total 67 women took up counselling and received facility-based mental health care, and one woman was referred to specialist care. The total number who received facility-based counselling within the strengthened collaborative care model equated to 71 percent uptake based on the total number who were referred (see Table 6.3).

Table 6.3: Process indicators

Process indicators						
Total screened on brief Whooley	Total screened positive on brief Whooley	Of those screened positive, total referred within the collaborative care plan (using proforma referral form)	Of those referred, number enrolled in the cohort study	Counselling uptake of participants enrolled in the study	Counselling uptake independently of the study	Total Counselling Uptake
n= 1165	133 (11.4%)	n= 94 *(70.6%)	n=31 (33%)	n=30	n= 37 (39%)	n=67** (71%)

Counselling uptake by number of sessions within the study: n=31			
0 sessions	1 session	2-5 sessions	5-8 sessions
1	3	12	15

*Based on denominator (n=113) screened positive on the brief Whooley screening tool
**Based on denominator (n=94) of number referred to co-located counselling service

6.2.1 Qualitative results

The qualitative results are reported in terms of enabling factors, challenges, recommendations and feasibility.

6.2.1.1 Theme 1: Enabling factors

Both service users and service providers expressed positive views on the intervention. Service users did so in terms of the impact of the counselling intervention on their symptoms and/or functioning, while service providers articulated their experiences of the collaborative care plan in practice.

Service user perspectives

Positive counselling experience

All five service users interviewed who attended counselling reported a positive experience at their first contact with the counsellor and reported experiencing the counselling process as a helpful experience. This initial session provides psycho-education on depression, so is helpful for patients to understand depression and the importance of receiving treatment.

"It was really helpful because I could at least talk to someone and share my problems with them. I was feeling a whole [(lot]) better after the first session; Sister X [(counsellor]) really helped me." (P1_Service user)

The subset of five participants who attended counselling also reported feeling that the counselling helped them. In response to the question on whether they would recommend counselling to others, all the participants said they would recommend counselling because they experienced an improvement in their symptoms and in dealing with their stressors after counselling. This was expressed as confidence in the counsellor.

" *She [(counsellor]) really offered me great advice and I stopped stressing*." (P3_Service user)

And

"*I would tell them that the counsellor really helped me with my problems and she [(counsellor]) helps a lot of people*." (P2_Service user)

This was expressed as confidence in the counsellor. The integration of the counsellor into the collaborative care plan encouraged patients to view the counsellor as a competent and trusted member of the clinic team, with patients reporting that they felt issues of confidentiality were adequately addressed, which engendered trust in the counselling relationship.

"Talking to a professional helps a lot, and one doesn't need to be worried about their secrets being blabbed around the community." (P4_Service user)

Service provider perspectives

Positive referral experiences

Within the study sample, one person was referred to the doctor, but none of the nurses interviewed had referred patients to the doctor, and some nurses had referred patients external to the study participants to psychologists within the collaborative care model. Positive referral experiences on the part of nurses were linked to the availability of a behaviour change counsellor on site. The accessibility of a mental health- focused counsellor was reported to ease the referral process and encouraged nurses to assess for PND, as they were assured that patients they took the time and effort to identify with PND would receive immediate attention.

"*We are now aware and more keen to screen and refer for depression*." (P6_Nurse)

Based at the sub-district office and serving 16 PHC facilities, it was difficult for the PHC psychologist to attend to the referrals on demand, as patients were consulted by appointment.

Some nurses eschewed this process and referred directly to the hospital, which was perceived to be a quicker route because it was considered better resourced in terms of psychologists and intern psychologists, and patients were considered more likely to be seen promptly. This highlights the issue of resource constraints in mental health care and reinforces the need for a co-located task- sharing counselling service, as per the collaborative care plan.

"With the psychologist, it is not so difficult but you must book; you can't phone now and they are able to see the client now. You must schedule a time when she is available." (P8_Nurse)

And

"I refer the patient to hospital, knowing in the hospital the psychologists are there, unlike this sub-district." (P2-Nurse)

Acceptability

In contrast, the success of referrals was attributed to the dedication of the on-site counsellor.

"The referral system works best when we are having a counsellor. With our facility, patients with depression did come for follow up because she (counsellor) took time to follow clients." (P9-Nurse)

The value of a facility-based mental health- trained counsellor to manage mental health services was reiterated in their responses to the pressures of their workload, including limited time to attend to large patient volumes.

"Unlike us, they (counsellors) have the time to sit down with the patients and deal with the main causes of depression." (P7_Nurse)

Six out of the seven nurses interviewed welcomed the presence and skills of the counsellor as a legitimate and competent mental health service provider who eased their (nurses') mental health workload.

"They (counsellors) have more time and have received specialized training." (P10_Nurse)

6.2.1.2 Integration within the clinic

Service provider perspectives

Reponses from the nurses interviewed suggests that the counsellor was well integrated into the clinic functioning, as suggested by the observations and positive views expressed on the role played by the counsellor. In the first instance, it was observed that the referral process put in place was embraced, with the nurses routinely using the referral form to the counsellor, with each consulting room being equipped with the forms that were replenished by the counsellor on a daily basis.

"The day nurses are the most referring nurses. Even the night shift or during the weekend, they do refer and they keep them in the envelopes, and on Monday, I will check on the envelopes." (PC2_Counsellor)

Secondly, the education and awareness talks on PND, delivered by the counsellor to the patients in the patient waiting area, were viewed positively. One nurse indicated that this encouraged patients to discuss their depressive symptoms with the nurses.

"I think, as nurses, we are now more aware of having to screen and refer, and the health talks helps because some patients can report their symptoms relating to the stories read." (P7_Nurse)

Thirdly, the mere presence of the counsellor was reported to make nurses more aware of mental health issues, including PND, as the counsellor reminded nurses to refer patients. Including the counsellor in the weekly clinic staff meetings was also perceived as helpful for creating awareness, as it was a forum to reiterate the importance of screening for PND, and provide feedback on patients and on the screening and referral processes.

"She would also motivate us to keep on screening and referring for mental health issues."
(P10_Nurse)

And

"We would even communicate to say, 'Look, did so and so come to see you … you need to call the person to make an appointment', then they (counsellor) would come and talk about the challenges that they found". (P8_Nurse)

Fourthly, having a facility- based counsellor encouraged them to refer as they knew that the patient was likely to be seen immediately rather than having to wait for a long period to see a specialist or the doctor.

"I feel like [having] the counsellor makes things easier because they can see the patient promptly, whereas with the doctor, they would have to make an appointment."
(P7_Nurse)

Fifthly, being able to observe positive changes in the patients, or being given feedback on patients referred, acknowledged the important clinical role of the nurses and encouraged nurses to refer patients for PND. Nurses were thus able to view the benefits of the screening and counselling programme, validating the use of the screening tool, the presence and contribution of the counsellor and, most importantly for nurses, validating the additional task of detection and referral for PND.

"The changes/improvements are also noticeable in the moods and the way the patient handles themselves."(P8_Nurse)

Sixthly, the participants had a positive view of having the sub-district social worker work with the counsellor in the collaborative care model, to assist with and follow -up patients who required help related to social services.

"She (social worker) is very cooperative, she even does the home visits … some of them are being referred, maybe for adherence … that patient she will tell you, 'I don't have food at home' or 'I am not working', like all those things." (P13_Nurse)

Finally, the integration process, including the screening, was not viewed as an additional work burden, with the process viewed as a benefit to patients rather than a burden to nurses.
"As far as the load, I would not say it has added. In a day when we see perinatal clients, there are a lot of things that you need to be aware of. You would not say actually it is added; in most of the cases when you screen a client, you don't screen outside the process. So you would not say it is added, but as far as improvement, it has really improved the identification and diagnosis of someone who might be depressed and who needs support or counselling." (P8_Nurse)

6.2.1.3 Theme 2: Challenges

Service user perspectives

Barriers to completing counselling

Despite scheduling counselling appointments to coincide with patients' monthly appointments, and telephonic and electronic text reminders for their appointments, three out of 22 participants only attended the first counselling session, and 12 participants completed fewer than five sessions. Reasons offered for not taking up or not completing the recommended eight counselling sessions included feeling better, being tired and not wanting to travel to the clinic and moving away to another town.

"I was feeling better and the thought of coming to the clinic every week was also tiring. I was starting to get big with my pregnancy and got tired easily". (P1_Service user)

Service provider perspectives

Emotional burden

Both nurses and the counsellor reported feeling emotionally taxed when dealing with stressors reported by patients, underscoring the emotional burden associated with this type of work.

"It is not easy listening to other people's problems and sometimes it gets too much for me, because I end up feeling helpless." (P7_Nurse)

Compounding the taxing nature of the work, patient expectations and requests for practical assistance with food or money were reported to be stressful for the nurses and counsellor, who were expected to render practical assistance that fell within ambit of social services.

"They are saying they are also affected after asking patients questions and not being able to assist patient financially or physically." (P9_Nurse)

And

"When you ask them about depression, sometimes they want immediate help and sometimes their depression is caused by the lack of finances. So, they will ask you to write them SASSA (South African Social Security Agency) forms, or give them food parcels, and it's very difficult to get those things." (P11_Nurse)

Integration challenges

Long patient queues and/ or pressure from managers to speed up consultations were cited by some nurses (n=4) as challenges to providing longer, intensive consultations to perinatal patients regarding mental health issues. Combined with the very specific standard operating procedure for consultation with perinatal patients, consulting clinicians reported feeling pressured to rush through consultations, leaving little time to address perinatal common mental disorders.

"The main thing would be chasing the line, especially with perinatal patients, because a lot of things have to be done with each and every single patient, and there is not enough time for other things (mental health)." (P7_Nurse)

Reactions to using two different guidelines during perinatal consultations were mixed, with one nurse indicating that it was not additional work, while two others articulated that having to use APC for mental health as an additional clinical guideline in conjunction with the BANC guidelines was time consuming. The issue of contention was not the use of the BANC standard tool, in which nurses are trained but which does not contain guidelines to detect PND; it was APC which is geared towards chronic care, but which contains specific guidelines on diagnosing PND, and which the relevant nurses described as time consuming.

"Although easy and straight forward, PC101 (now APC) is very time consuming, the paging through is tiring." (P6_Nurse)

6.2.1.4 Theme 3: Recommendations

Service provider recommendations

Four nurses raised refresher training and other training- related issues related to APC as factors to be considered for sustainability and to assist them. Four nurses also indicated that more counsellors were required on a full-time basis to serve patients after hours, and two nurses indicated that social workers and psychologists needed to be readily available as well.

"They are very much useful; they are needed to work more hours, sometimes a patient comes after 4pm in the afternoon and there is no counsellor at that time." (P11_Nurse).

Of the 30 women who took up the counselling service, 15 completed fewer than five sessions, with one participant who stopped attending, indicating that she felt better. Echoing

the possibility that patients might benefit from fewer sessions, the counsellor suggested that fewer, more relevant counselling sessions could be beneficial, as differing patient needs meant that not all patients required all eight sessions or the optional ninth session on adherence for chronic medication.

"Maybe we can concentrate on what are the sessions that need to be done for particular patients. Some of the patients don't need all nine sessions." (PC2_Counsellor)

6.3 Theme 4: Feasibility

Both the counsellor and the nurses provided insights into the practicality of the collaborative care model. The counsellor had prior experience in counselling for depression on the chronic care platform, but not in PND. Given that the same counselling manual was used for both PND and chronic care patients who were being counselled at the same facility concurrently, the counsellor was able to provide her perspective on counselling for PND.

"It was quite an experience working with PNC and ANC; I actually learnt a lot. I was not working with PNC and ANC patients before … Unlike other women, pregnant women, they end up not loving their child because of the anger, for being rejected because of the baby, some of them end up hating the baby before birth …… because [(with] the PNC and ANC, it also includes the child." (PC2_Counsellor)

Echoing the results of the formative interviews with service users, the counsellor observed that the most common problem for perinatally depressed patients was rejection of the woman and/or the child by the partner and the accompanying lack of support during and after the pregnancy. This differed from the interpersonal conflicts usually experienced by chronic care patients; thus while most of the sessions were appropriate for both categories, her recommendation was that the issue of partner rejection could be reflected in a more

appropriate vignette on interpersonal conflict for PND. The counsellor also reflected that perinatal patients were more comfortable with individual sessions.

"I think they have different needs. Most of the ANC and PNC patients … they are depressed, and sometimes the father does not want the baby or does not have anything to do with the baby… For the PNC, it is almost the same. It is different to the chronic patients;, most of them are depressed because of poverty. From PNC and ANC, they are also depressed, most of them have relationship problems … I think there should be something extra for PNC and ANC. Not to say that the sessions we had are not relevant, they are, because we have interpersonal conflict and poverty…. some of them are depressed because when you find out that you are pregnant and you test for HIV and you are positive…" (PC2_Counsellor).

Discussion

Despite the small sample, this study augments the limited research base on task-shared collaborative care for PND in South Africa in PHC, (Honikman et al., 2012; Munodawafa, Mall, Lund, & Schneider, 2018; Nyatsanza et al., 2016), and adds to the literature in LMIC supporting the feasibility of task-sharing to treat PND (Atif et al., 2017; Khan et al., 2019; Nyatsanza et al., 2016; Sikander et al., 2019; Verdeli, 2003). While PHC and community contexts may differ across LMIC contexts, elements of task-sharing models and resources may be transferable or adaptable. In this study, the quantitative and qualitative results converge to validate the concept of task- sharing for PND within a collaborative care model, supported by reported references (process evaluation interviews) to the clinically significant improvement in PND symptoms and endorsement for task-sharing on the part of service providers and recipients of care.

Process indicators suggest that screening and referral for PND were adopted to some degree, and the qualitative data indicated that the counsellors and counselling services were well received by both service users and service providers. However, there were elements of the model that were reported by service providers as challenging. Dealing with patients who raised poverty- related issues was reported as stressful. In contexts where poverty is prevalent for people attending PHC, unemployment, difficulty accessing social services and food insecurity are significant stressors causing depressive symptoms; consequently, feeling helpless to assist patients with hunger and lack of food in the home can be distressing to service providers. The emotional burden of mental health- related work is an important factor to consider in terms of emotional support to the service provider to avoid burnout. It is possible that clinicians may avoid addressing PND in order to avoid feeling helpless to address the patients' distress. Practitioner fatigue and distress related to managing the social challenges facing their patients is an acknowledged limitation in health systems driven by vertical programming that promotes a curative disease focus, which consequently limits opportunities to address comprehensive and appropriate psychosocial mental health promotion and treatment interventions to address the negative impacts of the socio-economic and political contexts (Burgess et al., 2020).

These issues need to be appropriately addressed in order for service providers to be able to provide optimal care and to function daily in their work situation. This requires action on a macro-level including political will and support to address the socio-economic challenges that impact on mental health, and at a meso level, provision of accessible support services to service providers and adequate supervision to assist with dealing with traumatic issues that arise in counselling.

In this study, the availability of mental health counsellors provided a viable alternative to referrals to doctors and psychologists, as they were a readily available resource who could provide immediate counselling services. In this facility, previous positive experiences with the behaviour change counsellors may have influenced this perception and promoted buy-in for the counsellors, who were a somewhat established component in the system. This, in combination with logistical issues such as limited hours of service and absence of continuity with doctors, encouraged nurses to refer to counsellors in preference to doctors. The counsellors were viewed as being proactive and involved in ensuring that patients were not lost and were encouraged to return for treatment. Notwithstanding some resistance from nurses to refer patients upwardly for specialist mental health care, it is unclear whether the success of the on-site counsellor was a factor that impacted negatively on upward referrals for medical and specialist treatment, or whether other factors impacted on the (lack of) upward referrals.

The supportive role of the social worker was reported to be a great help to the counsellor, as she was able to assist with social issues impacting on the depressive episode that could not be addressed through counselling. This is a significant resource in low-income settings, where issues associated with poverty, access to welfare and obtaining official documentation are common difficulties that cause anxiety and distress for marginalized populations. When these difficulties impact on mental health, sufferers may feel overwhelmed by their social problems, which may exacerbate or lead to depression.

In terms of the aim of the study to evaluate the feasibility and potential effectiveness of a task-shared collaborative care plan for PND, the study examined: i) acceptability, which is evaluated as the reaction to the intervention by key players and reported as the qualitative component; ii) practicality, that is delivery of the intervention in the context of resource

constraints; iii) delivery of the implementation as planned; and iv) uptake of the intervention and limited-efficacy testing, evaluated using a convenience sample with limited statistical power.

In relation to the potential of the task- shared collaborative model to improve patient depressive symptoms, the results suggest that an intervention for PND delivered by a non-mental health worker delivered intervention for PND has the potential to significantly reduce depressive symptoms. In relation to feasibility, with regard to acceptability, triangulation of data suggests a general concordance in service provider and service user perspectives in relation to positive experiences of the facility-based counselling component of the model. Six out of the seven nurses reported having confidence in the competence of the counsellor and stressed the usefulness of having a dedicated counsellor available for depression counselling. These nurses, cited the urgency of referrals as a significant factor in referring to the counsellor rather than doctors or specialist care, which would require the patient to have to be put on a waiting list or travel to other facilities, thus highlighting the benefit of facility-based PHC depression counselling (Bantjes, Kagee, & Young, 2016; Weissman et al., 2014).

The qualitative data indicated that service users viewed the counsellor in a positive light, perceiving her to be competent and trustworthy, and accepting her as a health professional. This highlights the importance of ensuring these qualities when using lay counsellors within a task- sharing approach (Singla et al., 2017; Singla et al., 2018). Nurses reported positive feedback from the counsellors and patients regarding the counselling programme. The process was generally described by both service providers and patients as being beneficial for patients suggesting acceptability of the model.

As with integrating any new process into an existing programme, systemic level changes are required to support the integration of mental health, a relatively new process within health systems (Bowen et al. 2009). Results of this study suggest that the incorporation of the strengthened collaborative care model into routine perinatal services demonstrates the need for systemic level changes. Data elements on screening, referrals and treatment for PND prior to the study were therefore not available as these were not routine activities, and neither were they reported as such. The absence of a screening tool, routine detection for PND and absence of health system data elements and indicators for reporting screening and referrals for PND were all highlighted during the service user engagement phase, and necessitated the introduction of a brief screening tool and a referral form to facilitate mental health referrals. From the study data, we can surmise that use of the referral form for PND referrals suggests some degree of integration of mental health detection and management compared to the absence of focus on mental health reported during the formative studies and the process of developing the collaborative care model in phase 2. Meaningful comparison is also constrained by the absence of data on treatment initiated for PND prior to the study, for the reasons mentioned previously i.e. absence of indicators to report mental health data for perinatal patients. Nevertheless, using the formative data for contextual reference, and bearing in mind the absence of mental health indicators for this population, the data from the process evaluation interviews with nurses indicated that the proximity of the co-located counselling service and the assurance of (mostly) immediate assistance from the facility-based counsellor for patients referred for PND, prompted increased referrals to the counsellor instead of to specialist care.

While screening and referral to lay counsellors emerged as both acceptable and feasible, there was reluctance to refer upwards to doctors and specialists. This was because of the delays in care attributed to sessional work, as well as waiting lists. Having a facility-based counsellor

encouraged nurses to assess for PND, as they were more confident that the patient would be helped timeously. These factors are also suggestive of practicality, which is focussed on the extent to which the intervention can be delivered within the resource constraints of the system, while process indicators showing screening, referral and uptake both within the study and external to the study as part of routine perinatal care, as well as the positive responses to the waiting room PND awareness talks by both patients and nurses, refers to the concept of demand.

The inclusion of the social worker within the collaborative care model to assist patients with social issues, and the adoption by nurses of screening for PND as a routine activity, illustrates the adaptation and expansion elements of feasibility, which respectively focus on modifying elements of the programme to suit a new context and the potential to transfer an existing successful intervention to a new population or context (Bowen et al., 2009). In addition, the results of the quasi-experimental cohort design met the limited efficacy testing focus for feasibility. The eighth concept of implementation in feasibility studies "concerns the extent, likelihood, and manner in which an intervention can be fully implemented as planned and proposed, often in an uncontrolled design" (Bowen et. al., 2009, p. 3). Although the study met elements of the feasibility criteria, an efficacy study is recommended, with appropriate adjustments to the maternity clinical guideline, and training, supervision and implementation protocols to provide support to facility-based behaviour-change counsellors.

With reference to efficacy, studies suggest that the adequate dosage of psychotherapeutic treatment is between five and eight sessions (Forde et al., 2005; Selohilwe, Bhana, Garman & Petersen, 2019). Uptake of the counselling intervention in this study indicated that dosage varied with half the number of the participants receiving between five and eight sessions. Of these only three people completed eight sessions, and five people completed seven sessions.

However, those who received fewer than five sessions reported improvement in depressive symptoms, suggesting that they found the counselling beneficial, an assumption supported in Sorsdahl et al. (2015) and Myers et al. (2018). Furthermore, there was a marked improvement overall across the intervention group in scores for depression using PHQ9, suggesting that psycho-education on PND and counselling within a collaborative task-sharing approach can be helpful for PND.

Limitations

Although this study shows promising results indicating clinical and statistical improvement in depression and functioning scores, as well as acceptability of the collaborative task-sharing model for PND, the small sample size is a limitation and excludes the possibility of additional analysis. When the study was conceptualized, a sample size of 124 participants was calculated based on power calculations to estimate a 5-point reduction in depressive symptoms on the PHQ9. However the resource constraints, i.e. the absence of mental health trained counsellors at the four selected facilities starkly illustrates the systemic and contextual challenges faced. While negotiations between the project and the sub-district were ongoing to provide technical support to train and supervise HIV counsellors at these facilities in mental health counselling, delays in the process necessitated the retention of project employed counsellors at one facility in order to continue services to chronic care patients, and extend services to perinatal patients. The study was therefore limited to one facility instead of the four facilities planned and, as a result the sample was limited to a low number of repeat perinatal attendees in a single clinic.

Although the intervention group did show a clinically and statistically significant reduction of more than five points in PHQ9 scores, the small sample limited meaningful statistical inferences. The differences between the intervention and control group in terms of marital status and age are also potentially confounding factors when assessing outcomes.

We also acknowledge the possibility of bias in the sample of service providers, as the study site was previously used for the PRIME-SA pilot and cohort studies, and some nurses were already familiar with the concept of collaborative care and task-sharing for depression. As a result, some nurses might have been more receptive to transferring this care package to the maternal and child health platform, as there were strong elements of familiarity in the collaborative care model. Therefore some nurses may have felt more confident in participating in the collaborative care model, contributing to the acceptability of the plan.

Elements of the collaborative care plan that might not have been followed as per the protocol include the possibility that some nurses might not have used the APC guideline to confirm PND diagnosis after screening with the brief Whooley screening tool, as they indicated that they considered APC onerous to use, particularly in conjunction with BANC. Further, there was little evidence of upward referral for specialist care within the study, with just one person referred for tertiary care. This raises the possibility that patients with severe PND, who might have benefited from specialist care as well, might not have been referred. This could be attributed to the convenience of an on-site counsellor on-site, and the reported reluctance to refer patients to doctors and psychologists due to delayed treatment. This may also be a limitation related to the small sample (n=31), and insufficient data to ascertain whether there were other referrals to specialist care of women who were not allocated into the study. In mitigation however, the dearth of upward referrals for specialist care could also indicate that

a significant number of patients with PND can be managed successfully by non- specialist mental health- trained health providers, easing the burden of specialists who could better serve patients with severe PMDs and provide supervision for the non-specialist counsellors.

Recommendations for intervention

Due to delays in formalizing the scope of practice for the proposed cadre of worker (, i.e. existing HIV counsellors), the study utilized two PRIME- trained, experienced counsellors based at the CHC, supervised by the study psychologist. Counsellors, training and supervision were therefore well established. Future expansion of services will need to consider the sustainability of training and supervision for HIV counsellors or any other selected cadre of health worker.

Recommendations for future research

Future research should include PND detection and treatment guidelines, integrated into the BANC maternity guidelines, and the addition of mental health indicators to the existing perinatal indicators.

Conclusion

Notwithstanding the limitations associated with integrating mental health into PHC in LMIC using sustainable methods to identify context-appropriate interventions with proven efficacy, feasibility and sustainability, access to appropriate care for PND is a human rights issue encompassing women and children's rights to optimal health care. The potential long-term effects of PND on maternal and child health are indicative of the imperative to treat PND to promote optimal maternal and child mental health and development. This study suggests that leveraging existing PHC resources within a task-shared collaborative approach is acceptable and is more likely to be scaled up, as it espouses thrifty use of existing clinic resources rather

than a separate intervention. However, factors associated with efficacy and scalability require research into refining an intervention model in terms of appropriate content, training, supervision and support. The emphasis of this study was to assess feasibility of a collaborative care model for PND; we have presented this preliminary data to demonstrate the potential for a future study focused on evaluating such a collaborative care model, with the detection and management of PND integrated into the BANC guidelines. In addition, this would require appropriate training and support for the relevant health worker cadres, strengthening the upward referral pathways and inclusion of mental health indicators and targets.

CHAPTER 7

Discussion and Conclusions

Contribution of the study to addressing PND in South Africa and other LMIC

This study has added new lessons on integrating care for PND in in South Africa, where focused PND care is conspicuously absent at both facility and community levels, although both offer opportune platforms to screen for PND. The contributions of the study are framed within the first two steps of the MRC framework (Craig et al., 2008, 2013), which was used as an overarching guide for the development and evaluation of this study.

7.1 Contribution of evidence in terms of Step 1 of MRC framework: Development

The MRC guidance suggests identifying the relevant existing evidence base pertaining to the intervention, as well as a theoretical understanding of potential change processes, supported by new primary evidence such as key interviews with stakeholders who are likely to be involved in the intervention, either as recipients of the intervention or delivery agents. The contributions of this study towards the first step in the MRC framework are documented in Chapters 4 and 5. Chapter 4 is an adapted version of a peer reviewed, published article which describes the formative study investigating service user perceptions and understanding of PND, pathways to care for PND, service user recommendations to address PND, as well as attitudes towards task-sharing (i.e. receiving mental health care from non-specialist mental health practitioners).

Considering the mental health treatment gap and parallel use of traditional and non-medical care for depression and other mental illnesses (Seedat et al., 2009), this stage of the investigation was guided by the theory of cultural and explanatory models of illness (Aidoo, 2001; Gidron, 2013; Kleinman et al., 1978; Laws, 2016) in order to investigate how people affected by PND experienced and rationalised or explained the illness, particularly in terms of

causation. The study also investigated the treatment options for PND as perceived by women using PHC services, their recommendations for the preferred type of treatment they perceived to be helpful for PND, and the acceptability of services both at community and facility levels delivered by non-professional mental health practitioners.

This process was an important first step in the initial (formative) phase of the study, which was guided overall by the step 1 of the MRC framework (detailed in Chapters 1 and 4). In order for health services to be culturally and generally acceptable to the populations they serve, consumer/service user engagement is a key activity. The service user engagement was thus a crucial effort to include key stakeholder perspectives and to ascertain buy-in, particularly as service users in South Africa generally have limited agency to convey their perspectives and service needs. The process was also useful to inform the next steps, including alignment with the service provider recommendations and the content, choice and delivery of the intervention.

7.1.1 Contribution towards developing an integrated model of care for PND at facility level

Also falling within the ambit of Step 1of the MRC framework, the sub-study reported as Phase 2 in Chapter 5 in this thesis, details the extensive engagement with service providers at three different stages to investigate service provider perspectives, including clinical awareness of PND and pathways to care, attitudes towards task-sharing for PND care, and recommendations to promote PND care. The low level of clinical knowledge regarding PND on the part of service providers was indicative of the absence of focus on PND within the health system. This work, together with the service user interviews, contributed towards the second stage of service provider engagement, to co-develop an integrated model of care

for facilitating PND detection and treatment with frontline service providers and sub-district managers. The third stage in service provider participation was to engage key informants to ratify the collaborative care model for PND and provide additional institutional perspectives.

Given the acknowledged mental health treatment gap for PND in South Africa, the first phase of this study has reiterated the service gaps at PHC level in South Africa, as reported in a situational analysis of maternal mental health in South Africa commissioned by the PRIME project and reported by Baron et al. (2016). Furthermore, the recommendations that resulted from the service user and service provider engagement in the first phase guided the development of a culturally and contextually appropriate collaborative care model for PND that included a co-located psychosocial counselling intervention in a South African PHC setting. The PRIME maternal mental health situational analysis and extensive research of literature suggests few similar models of collaborative care for maternal mental health using task-shared co-located psychosocial counselling at PHC level in South Africa. Available models identified included the use of co-located specialist counselling services (Honikman et al., 2012) as well as task sharing of counselling with community health workers (Lund et al., 2014, Munodawafa et al., 2017) at facility and community levels. These studies feature some common elements with the current study including detection of PND and referral to/ counselling delivered by non-specialist mental health counsellors.

Delivery of psychological interventions for PND using manual-based methods is also common to these and other models that use non-specialist counsellors (Davies & Lund, 2017). Considering the dearth of human and other PHC resources, the approach used in this study sought to strengthen existing pathways of perinatal mental health care to support integrated counselling originally developed for a different (chronic care) PHC stream, and in this way maximise the use of existing mental health resources to cover the service gap for

PND. This was achieved using a common manualised approach to successfully address depression across the different streams of service. Crucially, this approach and delivery method, i.e. non-specialist led manualised counselling, also lends itself to adaptation to local languages, with the potential for broad reach as has been demonstrated in the MhINT scale up using the Isizulu adapted version in the Amajuba district in KwaZulu-Natal (Petersen, van Rensburg, Gigaba, Luvuno & Fairall, in press) . The availability of counselling in local languages cannot be over-stated given that this gap was highlighted in the interviews with service providers reported in Chapter 5.

The publication which emerged from phase one has contributed to the literature on service user perspectives and recommendations for PHC-based PND care in South Africa. The data was utilized practically in conjunction with the service provider engagement to inform the identification of a suitable counselling intervention which was a key component of the collaborative care model. The combined data from the first and second phases also contributed to the development of a strengthened collaborative care model for PND. The method and process are reported in sub-study 2 and contribute to the emerging literature on the process of developing integrated, collaborative care for PND at PHC level in South Africa. Sub-study 3 reported the evaluation of the collaborative care model adding to the incipient evidence base on the feasibility and acceptability of task-shared models of care for PND in South Africa (Davies & Lund, 2017; Honikman et al., 2012; Munodawafa, Mall, Lund, & Schneider, 2018; Selohilwe et al., 2019; Sorsdahl, et al., 2015a; Sorsdahl, et al., 2015b), and to the emergent body of evidence for collaborative, integrated task-shared care for PND in LMIC (Davies & Lund, 2017).

7.2 Contribution of evidence in terms of Step 2 of MRC framework: Assessing feasibility.

The MRC guidance for the feasibility stage describes feasibility as a vital stage for the purpose of testing procedures, estimating recruitment and retention rates and calculating sample sizes, cautious estimation of effect sizes, and use of quantitative and qualitative methods to understand the results, including barriers to uptake and response rates. However, this study did not focus on estimating recruitment sample and effect size, as the objective was to establish feasibility rather than establishing parameters for a larger trial. The purpose of this fundamental activity i.e. feasibility, is to understand the mechanisms that promote success and failure of an intervention to provide understanding to assist implementation. It is crucial in identifying weaknesses and factors that indicate whether continuing the research on a larger scale is warranted, or whether to avoid resource wastage and fruitless endeavour. This process may require refinement through a series of studies prior to full-scale evaluation (Craig et al., 2008).

Feasibility and piloting are terms that are commonly used interchangeably, including in the MRC guidance, which includes feasibility studies and pilot studies in a single category of preparatory studies for larger trials (Craig et al., 2008; Leon et al., 2011; Moore et al., 2015). Other researchers differ and provide recommendations and criteria to define each term (Bowen et al., 2009; Eldridge et al., 2016; Orsmond & Cohn, 2015). This study meets the criteria for feasibility studies defined by Bowen et al. (2009), who describe feasibility as being used to assess whether an intervention is suitable for further testing and adaptation for relevance and sustainability.

The third sub-study (Chapter 6) reports how the intervention met the criteria for feasibility, as described by Bowen et al. (2009), which is established by examining aspects such as:

i) *Acceptability: This is assessed as the reaction to the intervention by key participants.* In this sub-study, acceptability was advanced through service provider collaboration in the development of the intervention, exploring acceptability from service users exposed to the intervention, as well as service provider satisfaction with the model. Additionally, process data showing the detection, referral and uptake of the intervention during routine perinatal care in the pragmatic clinic setting, demonstrates uptake of the model on the part of service providers and uptake of counselling by service users independently of those enrolled into the cohort study. Details of the uptake of the counselling during routine services independent of the research study, are presented in Table 6.2, Chapter 6.

ii) *Practicality: This is studied by the delivery of the intervention in the context of resource constraints*. In this study, this was supported by the process data indicating uptake and delivery of the intervention within the constraints of the real-world setting of the clinic. In the absence of doctors and mental health specialists, the use of available personnel (i.e. nurses as case managers), and the expansion of the existing counselling service provided to chronic care patients by non-professional mental health counsellors, to include women with PND, demonstrates that the PND collaborative care model is feasible within the constraints of available PHC facility resources.

iii) *Implementation: This is assessed as the delivery of the intervention as planned*. This is described in Chapter 6 which details the phase 3 sub-study. The process data

collected alongside the cohort study, indicates that a proportion of patients screened for PND, and who were assessed and referred for counselling for PND, did use the counselling services. Process evaluations with the nurse case managers and the counsellors detail the aspects of the model that worked and those that posed challenges. One notable aspect of the model that posed a challenge was the process of upward referral for PND to doctors and the psychologist servicing PHCs. The process evaluation interviews with nurses suggested that some nurses preferred referring patients to the facility-based counsellors rather than the doctors or sub-district psychologist. This was supported by process data which indicated that 30 out of 31 study participants were referred to the facility counsellor, with just one participant referred for tertiary care.

This suggests that the upward referral for the specialist care component of the collaborative care model may not have worked as intended. There was demonstrable resistance to this from some nurses, who acknowledged their preference for referring patients to the facility-based counsellor or the psychologists based at the district hospital, in order to mitigate the delay in treatment associated with referrals to the PHC doctors or psychologist. This poses a limitation in terms of patients accessing specialist mental health care for PND or other perinatal mental health conditions at PHC level, and potentially could delay specialist mental health treatment for patients in need of specialist intervention. Strengthening this component of the model is crucial to ensure that a future collaborative care model for PND is able to serve perinatal women who require specialist mental health care. Thus, while the majority of patients would be adequately served by a non-professional mental health counsellor, thus alleviating the burden on specialists, every effort should be made to

ensure that those who do require specialist care are referred and receive the necessary care.

iv) *Demand: This is estimated as intervention uptake*. The process data showing the uptake of the intervention by both the service providers who assessed and referred patients, and service users who were referred for the psychosocial counselling was in sync with local and international evidence. This data is explained in Chapter 6, Table 6.2. which details among other information, the number of counselling sessions that research participants attended. Dosage varied widely with half the number of participants receiving fewer than five counselling sessions. Reasons provided for non-attendance included tiredness and the inconvenience of travelling to the clinic, but also positive experiences such as feeling better and therefore not needing the service.

v) *Limited-efficacy testing:* This was gauged using a convenience sample with limited statistical power. In this study, a non-randomly assigned comparison group cohort design was used to recruit a purposive sample, using a comparison group who screened positive for PND but were not referred for psychosocial services, to compare outcomes with a group that screened positive for PND and received the intervention. Although the sample was smaller than the recommended calculation to detect an effect size, the results of the quantitative data analysis explained in Table 6.1 in Chapter 6 did indicate a clinically significant reduction of more than five points on the PHQ-9 in the intervention participants' depression scores compared to the control cohort. However, the results should be interpreted with caution due to the limited sample size (see limitations section).

vi) *Adaptation; The focus of this aspect is on modifications of program elements to suit a new context.* In this study, adaptation is demonstrated by evidence reported in the second sub-study reported in Chapter 5 showing the service provider and research team's collaborative effort to adapt an existing collaborative care model for chronic care patients with comorbid CMDs, to suit integration into the perinatal stream. In the absence of diagnostic guidelines for PND in the existing BANC maternal care guideline, the adaptation included brief screening for PND which was a new activity, and the use of a chronic care guideline to diagnose PND. Recommended improvements for feasibility and acceptability are outlined in Chapter 6 which reports the process evaluations with service providers and service users. The results from this component of the study indicate the need to adapt the existing BANC maternal care guideline to include to strengthen referral pathways for care, screening/assessment, diagnostic instructions and reporting PND.

vii) *The related element of expansion: This aspect focuses on the potential success of an existing successful program in a different context or population*. In this study, this is supported by the outcome evaluation showing the potential mental health benefits for depressed perinatal patients receiving the counselling intervention that was originally developed for chronic care patients.

viii) Lastly, *integration: This was assessed based on the required system-level changes to accommodate/ incorporate new programs and or processes into existing programs*. These changes were assessed through the process evaluations with service providers, which yielded valuable information on the elements of the model that required system level refinements. While some elements of the model such as brief screening, diagnosis and referral proved workable, for sustainability, there is a need for these

elements to be incorporated into mandated structured guidelines for screening, assessment, referral and management of PND. Further, while the use of the project-employed facility-based counsellor emerged as acceptable and helpful to reducing depressive symptoms in patients referred, human resources in the form of trained counsellors to provide co-located counselling services, mental health specialists to provide regular supervision and support for the counsellors would need to sourced within the system to ensure sustainability. These recommendations emanate from the phase 2 sub-study with service providers reported in Chapter 5.

In summary, the phase 3 sub-study detailing the feasibility study provides evidence that an adapted collaborative, co-located task-shared model developed for patients with chronic conditions using existing resources and services is feasible for service users with PND. In the context of scarce mental health resources at PHC level, the feasibility and acceptability of adapting an existing counselling service for depression is a valuable finding. This supports the shift from vertical to integrated care, with the associated advantages including utilization of existing human resources, efficiency and holistic, person-centred care (Mugisha et al., 2017). The study also demonstrated how screening and treatment for PND can be operationalized under real-world conditions at PHC level, and outlines the challenges and limitations associated with inclusion of this service in the absence of dedicated guidelines for screening or management for PND in routine care. This sub-study also contributes to the literature and evidence base for the use of non-mental health professionals to deliver counselling services for PND (Atif et al., 2017; Sikander et al., 2019; Singla et al., 2014). This mechanism devolves mental health care from a specialist-orientated mental health model of care, which is expensive and is scarce at PHC level, to a more accessible model using widely available non-specialist mental health workers (Petersen, Fairall, Egbe, & Bhana, 2014; Rahman et al., 2013; Singla et al., 2017; Singla et al. 2018; Weobong et al., 2017).

7.3 Policy implications and sustainability

Despite PND being a commonly encountered obstetric complication (O'Hara & Wisner, 2014), the absence of protocols and training to detect, manage and refer patients with PND discourages its identification and treatment, as the condition is not sufficiently acknowledged in public health care. At a governance level, commitment to perinatal mental health care is a function of both the mental health policy landscape, which has historically been neglected (Lund, Kleintjes, Kakuma, & Flisher, 2010; Lund et al., 2012), and the perinatal health sector in South Africa, which has been focused on addressing physical morbidity and maternal and child mortality. Both the mental health and maternal health sectors need to acknowledge their joint roles in addressing maternal mental health in the vulnerable perinatal population.

The lack of attention from both mental and maternal health sectors in terms of addressing perinatal CMDs was apparent in this study, evidenced by the absence of both routine screening and detection of PND in the maternity clinical guidelines reported in the situational analysis conducted by the PRIME project in which this study was nested (Baron et al., 2016). The data from the first phase of this study was used to engage service providers to address the service gap. This gap was addressed in this study through: i) the introduction of a brief screening tool, as requested by service providers; ii) in the absence of guidelines to manage PND in BANC, the interim use of existing chronic care guidelines to assist service providers to assess and manage PND; and iii) the use of existing referral pathways to non-specialist, facility-based psychosocial counselling for depression in chronic care patients, as well as referral pathways to PHC doctors and mental health specialists at district level.

The outcome and process evaluation results (sub-study3-phase 3) showing the feasibility and acceptability of the collaborative care model developed during sub-study2-phase 2

demonstrate the potential for this model of care for PND within resource constraints. Further research based on a refined model that considers the recommendations of the key stakeholders is a logical next step, aligning with the MRC guidelines which advise that evaluation of feasibility sometimes requires several iterations of refinement (Craig et al., 2013). Flexibility in the use of available resources at PHC level for PND counselling is encouraged. A notable example demonstrating the flexibility in use of different cadres has been implemented in the KwaZulu-Natal province, in the Mental health integration Project (MhINT), which in collaboration with the DoH in KwaZulu-Natal and Mpumalanga, has trained existing HIV counsellors, enrolled nurses and health promoters to deliver the PRIME psychosocial counselling intervention (Petersen et al., in press). Crucially, due consideration should be given to the service provider recommendations for adaptations to the detection tools for ease of use and inclusion in the BANC guideline, and for the inclusion of perinatal mental health indicators.

Assessing appropriate resources required, and estimating the potential costs, are essential for implementation (Chisholm et al., 2016); and future research should ideally address this issue. However, this requires clarity on the cadres of health care workers required for this type of care. Training, support and supervision of service providers involved in task-sharing is also an important factor to consider for future research on the potential sustainability of the intervention (Mendenhall et al., 2014; Munodawafa et al., 2017; Petersen et al., 2014; Singla et al., 2018). This is a critical juncture for the South African PHC system, particularly in terms of the acknowledged need for task-sharing, as mooted in the NMHPF which espouses guidelines for task-sharing for perinatal mental health (*National Mental Health Policy Framework and Strategic plan 2013-2020*, 2013). Therefore, it is also crucial to acknowledge that the dire shortage of mental health specialists impacts not only on specialist mental health

treatment, but also on specialist supervision resources for generalist and lower level workers, to whom mental health care tasks are devolved. The absence of training and supervision resources for non-professional mental health workers is an important component that poses potential barriers to the scaling up of lay counselling services, as this is traditionally considered the domain of mental health specialists. In resource constrained settings where task-sharing models are mooted, it is crucial to consider the diversification of roles for mental health specialists who might lack administrative, advocacy, community engagement, management, leadership and supervision skills and experience necessary to train, lead and supervise non-specialist mental health workers due to the emphasis placed on clinical expertise to the detriment of PHC and community focused care (Rwafa-Madzvamutse, Lidia, Gureje, Mangezi & Jack, 2020). Capacity building in leadership and management training which encompasses these components should be included in psychiatric training, particularly for early career mental health specialists, and in externally funded capacity building programmes, whilst developing/utilising cost effective, sustainable approaches to deliver such training (Rwafa-Madzvamutse et al., 2020).

A critical mass of personnel resources, including mental health specialists and generalists, is required within the health system to propel the innovative change in direction to task-sharing for depression treatment at PHC level, including PND treatment. However, it requires a shift in orientation and buy-in on the part of these mental health specialists within the health system, in order to diversify their roles to include supervision and support for non-specialist mental health counsellors (Kemp et al., 2019). Mechanisms need to be instituted to ensure that appropriate trainers and supervisors are identified, whether these are generalists, peer-led or specialised, to be trained and in turn to train and supervise others to promote and sustain the task-shared model of care for mental health. In scarce resource contexts, mental

health specialists tend to be very limited, and may not necessarily have the time or expertise to provide supervision to generalists such as nurses or doctors in task shared mental health care. Yet these specialists are the most appropriately skilled resources to supervise task shared mental health care. A further consideration is that mental health professionals may not necessarily know how to supervise, and may need to be taught this skill, preferably during pre-service training. This is a long-term solution. In the more immediate context, creative, context-specific solutions to utilise specialist supervision are needed (Kemp et al., 2019). Ongoing, effective training, supervision and mentorship have been identified as crucial to ensure that generalist health workers adopt and deliver evidence-based treatments with fidelity, and while ongoing supportive supervision is linked to better emotional support for mental health workers and generalists, and lower risk of burnout, the scarcity of specialists suggests the use of digital platforms, regular supervision calls, the use of relatively cheaper communications forums such as "WhatsApp" groups, and standardised competency measures may be practical solutions to the face to face models (Kemp et al., 2019; Singla et al., 2014).

A shift towards a task sharing approach, however, requires focused efforts at a policy and at practice level. While laudable strides have been made with regard to formulating policy guidelines for mental health, particularly as contained in the NMHPF which in recognition of the high comorbidity between mental ill health and other diseases, as well as the links between poor mental health and adversity including poverty and violence, espouses guidelines for task-sharing for perinatal mental health (*National Mental Health Policy Framework and Strategic plan 2013-2020*, 2013), it is not clear to what extent the objectives of the plan have been realised with reference to maternal mental health as there is still an absence of routine data elements and indicators for maternal mental health. Mental health needs to be included in the maternal health guidelines, which requires policy changes to the

maternal health guidelines. In particular, mental health data elements for screening for PND need to be included into BANC and refresher courses/additional training in PND care for health providers instituted. Further, the human resources responsible for health policy need to review job descriptions and core competencies of mental health practitioners to ensure diversification of roles to support task-sharing. Training, support and supervision of lay counsellors for depression counselling, including PND counselling should be included. Realignment of pre-service training and appraisal systems to support these changes would also be needed.

It should be noted that at the time of reporting this study, notwithstanding the absence of a nationally sanctioned dedicated program to address PND, the PMHP reported a change in June 2019, to the maternity care stationery in the Western Cape province. This now includes a brief three-item screening tool for PND to be administered, with the caveat for screening to take place only if referral resources including a mental health nurse, social worker, NGO, medical officer, counsellor, psychiatrist or other services are available (https://mailchi.mp/0250871bda7b/pmhp-news-june2019?e=4bad83b384). However, this is currently confined to one out of nine provinces in South Africa, and is dependent on scarce referral resources. In the event of scale-up of the revised stationery to other provinces, the PHC systems would first require an overhaul to include the requisite referral resources that are available in each setting, as well as sustainable training and supervision, and the inclusion of PND data elements and indicators in the health information system.

7.4 Limitations

Principally, this study was limited in terms of sample sizes. In sub-study one, phase one, the sample was limited to depressed perinatal PHC users predominantly from a single clinic. The

sample was not necessarily representative of depressed perinatal service users in other sites, who may require adaptations to the counselling intervention to accommodate requirements that may vary due to unique prevailing health, social and other contextual factors regionally and which may require further investigation.

In the second sub-study in phase two, the initial sample comprising the formative phase of investigation with service providers was also limited to the four PHC facilities in the PRIME implementation site, and therefore not necessarily fully representative of health service providers in DKKD. The recommendations of service providers in this formative component of phase two may accordingly not be as comprehensive as they could potentially have been, had all 16 facilities in the sub-district been represented. However, service providers from the other 12 facilities, as well sub-district-level representatives, were later included in the development and refinement of the model. The service providers who attended the participatory workshop as well as the key informants were predominantly familiar with the PRIME collaborative care model for depressed chronic care patients. Some providers had first-hand experience of the perceived benefits of task-shared counselling in their facilities through the PRIME intervention, which might have impacted on receptivity to the concept for task-shared care for PND and the acceptability of the model. Service providers who are unfamiliar with the concept of integrated task-shared collaborative care may not be as receptive to a similar model of care. This phase did not include service users in the development of the model or to gauge acceptability prior to conducting the feasibility study. This was somewhat mitigated in the third phase, during which service users were interviewed to assess acceptability and feasibility of the model through process evaluation interviews.

In the third sub-study, the initial recruitment plan for the study was to conduct the feasibility study at four health care facilities in the PRIME implementation area. However, the study was confined to one facility due to contextual challenges, i.e. the lack of human resources to conduct the counselling in the other three facilities. The small sample size was therefore also a limitation of the second phase and constrained meaningful outcome analysis as screening and detection was confined to a relatively small population of mostly repeat maternity care attendees in one facility, and recruitment was therefore slow and constrained.

A further limitation of the study relates to the familiarity of collaborative care for depression at the study site. Some service providers had practical experience in the workings of integrated collaborative care for depression, and were aware of the beneficial outcomes for depression in chronic care patients who were treated using an integrated collaborative care approach; thus they might have been more receptive to participating in the intervention. The outcome in terms of acceptability and feasibility might potentially differ in a context where collaborative care for mental health is an unknown concept.

7.5 Recommendations

7.5.1 Recommendations for future research

The promising outcome and process evaluation results suggest some worthwhile investments in future research for collaborative task-shared PND care may include:

- A pragmatic effectiveness trial which would include the reporting of mental health indicators for PND, adaptations to the BANC maternity guidelines to include detection in the form of brief screening, assessment and referral for PND, as well as economic costing.

- Further research that engages specialist mental health physicians and primary health doctors more intensively in the developmental phase, so as to improve upward referrals to these cadres of service providers was a component that did not work satisfactorily in this study.

7.5.2 Recommendations for future implementation

- The tension surrounding nurses' misgivings about the referral process for specialist care referred to in the third sub study in Chapter 6 is a significant factor that requires discussion and remedial action. This would ensure that the needs of women who require more intensive specialist mental health care, including pharmacological interventions, are adequately addressed.
- Flexibility in the cadre of worker to perform facility-based counselling is encouraged. In the absence of facility-based lay counsellors, existing staff such as enrolled nurses could perform counselling. However, regardless of the cadre of non-specialist counsellors, adequate and appropriate supervision and debriefing mechanisms should be in place to support these counsellors. Registered counsellors and intern psychologists can be utilized to provide supervision for lay or non-specialist counsellors. Psychologists and psychiatrists within the public health system can be harnessed to provide supervision for nurses and doctors who provide counselling services, provided that they (specialists) receive some training in supervision skills.
- Given the important role of social workers within the PND collaborative care model, collaboration with social services (such as social workers) within the health system, as well as intersectoral collaboration with social services outside the health system is important to promote holistic care and provide the necessary supportive resources required by socio-economically disadvantaged patients with PND. These social

resources will help to sustain the gains made in treating PND by addressing significant causes of PND rooted in socio-economic origins which may precipitate or worsen PND.

7.6 Conclusion

Using the MRC framework for the developing and evaluating complex interventions to guide the research (Craig et al., 2013; Moore et al., 2015), this study provides new evidence of how to integrate mental health care into the PHC maternal and child care stream resource-constrained settings using a task sharing model in South Africa and elsewhere. The study as a whole provides evidence of feasibility and acceptability of a collaborative model of co-located care embracing task sharing. The favourable results signify the potential for a larger study, based on the recommendations and lessons garnered from this feasibility study. At the time of this report, the policy developments within the mental health landscape (*National Mental Health Policy Framework and Strategic plan 2013-2020*, 2013), the perinatal mental health sector in the Western Cape Province, (Honikman et al., 2012), and research including the AFFIRM trial in the Western Cape (Davies & Lund, 2017) demonstrate a level of awareness among only a minority of researchers and health care providers of the need to promote perinatal mental health. The impetus to drive this process, at the very least, has begun at a provincial level in the Western Cape Province to detect and manage PND in the context of available resources. At a broader policy level, however, there is an urgent need to address the mental health gaps in the maternal health strategy, and to revise the BANC guidelines nationally to include the mental health.

While the repackaged PRIME collaborative care model for depression (Petersen et al., 2019) is being scaled up in KwaZulu-Natal (KZN) in collaboration with the KZN Department of Health using multiplier funding through the MhINT program which supplies technical

support to facilitate this (Petersen et al., in press), using existing clinic resources including facility-based lay counsellors, the difficulty in addressing PND lies in the separation of streams of care for chronic diseases and for perinatal care. Systemic changes are required to add indicators for CMDs, including depression, to the maternity stationery as well as integration of services for the different streams of care. In addition, there needs to be sensitization to PND of all levels of health care personnel who deal with or could potentially deal with perinatal patients, as well as training for the appropriate cadres of workers, including mental health specialists, PHC doctors and nurses, and lay counsellors to detect and treat PND within a task-shared collaborative care model.

Given the attention deployed towards maternal and infant morbidity and mortality, the perinatal mental health burden poses a significant threat to gains made in this arena, particularly in light of evidence showing the vulnerability of depressed women and their infants to health and social issues, and the long-term economic effects of untreated PND (Smith Fawzi et al., 2019). The failure to integrate mental and physical health care in perinatal care is a failure to invest in the well-being and optimal mental and physical health of our human capital. It is an issue of social justice and economic pragmatism to expand this vital mental health care to women who need it, to promote their well-being and that of their families and communities.

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Appendices

Appendix 1 Edinburgh Postnatal Depression Scale

Name:---------- Address:----------

Your Date of Birth:---------- ----------

Baby's Date of Birth---------- Phone: ----------

As you are pregnant or have recently had a baby, we would like to know how you are feeling. Please check the answer that comes closest to how you have felt **IN THE PAST 7 DAYS,** not just how you feel today.

Here is an example, already completed.

I have felt happy:

- ⎦ Yes, all the time
- ×Yes, most of the time
- ⎦ No, not very often
- ⎦ No, not at all

This would mean: "I have felt happy most of the time" during the past week. Please complete the other questions in the same way.

In the past 7 days:

1. I have been able to laugh and see the funny side of things
   - ⎦ As much as I always could
   - ⎦ Not quite so much now
   - ⎦ Definitely not so much now
   - ⎦ Not at all

2. I have looked forward with enjoyment to things
   - ⎦ As much as I ever did
   - ⎦ Rather less than I used to
   - ⎦ Definitely less than I used to
   - ⎦ Hardly at all

*3. I have blamed myself unnecessarily when things went wrong

- ⎦ Yes, most of the time
- ⎦ Yes, some of the time
- ⎦ Not very often
- ⎦ No, never

4. I have been anxious or worried for no good reason

- ⎦ No, not at all
- ⎦ Hardly ever
- ⎦ Yes, sometimes
- ⎦ Yes, very often

*5. I have felt scared or panicky for no very good reason

- ⎦ Yes, quite a lot
- ⎦ Yes, sometimes
- ⎦ No, not much
- ⎦ No, not at all

*6. Things have been getting on top of me

- ⎦ Yes, most of the time I haven't been able to cope at all
- ⎦ Yes, sometimes I haven't been coping as well as usual
- ⎦ No, most of the time I have coped quite well
- ⎦ No, I have been coping as well as ever

*7. I have been so unhappy that I have had difficulty sleeping

- ⎦ Yes, most of the time
- ⎦ Yes, sometimes
- ⎦ Not very often
- ⎦ No, not at all

*8. I have felt sad or miserable

- ⎦ Yes, most of the time
- ⎦ Yes, quite often
- ⎦ Not very often
- ⎦ No, not at all

*9. I have been so unhappy that I have been crying

- ⎦ Yes, most of the time
- ⎦ Yes, quite often
- ⎦ Only occasionally
- ⎦ No, never

*10. The thought of harming myself has occurred to me

- ⎦ Yes, quite often
- ⎦ Sometimes
- ⎦ Hardly ever
- ⎦ Never

Appendix 2 Structured Clinical Interview for DSM-IV (SCID II)

A. MOOD EPISODES

IN THIS SECTION, MAJOR DEPRESSIVE, MANIC, HYPOMANIC EPISODES, DYSTHYMIC DISORDER, MOOD DISORDER DUE TO A GENERAL MEDICAL CONDITION, SUBSTANCE-INDUCED MOOD DISORDER, AND EPISODE SPECIFIERS ARE EVALUATED. MAJOR DEPRESSIVE DISORDER AND BIPOLAR DISORDERS ARE DIAGNOSED IN MODULE D.

CURRENT MAJOR DEPRESSIVE EPISODE	**MDE CRITERIA**	
Now I am going to ask you some more questions about your mood	A. Five (or more) of the following symptoms have been present during the same two-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood, or (2) loss of interest or pleasure.	
In the last month . . . . . . has there been a period of time when you were feeling depressed or down most of the day nearly every day? (What was that like?) IF YES: How long did it last? (As long as two weeks?)	(1) depressed mood most of the day, nearly every day, as indicated either by subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). Note: in children or adolescents, can be irritable mood.	? 1 2 (3) A
. . . what about losing interest or pleasure in things you usually enjoyed? IF YES: Was it nearly every day? How long did it last? (As long as two weeks?)	(2) markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated either by subjective account or observation made by others).	? 1 2 (3) A IF NEITHER ITEM (1) NOR ITEM (2) IS CODED "3," GO TO **"PAST MAJOR DEPRESSIVE EPISODE,"** A. 12.

NOTE: WHEN RATING THE FOLLOWING ITEMS, CODE "1" IF CLEARLY DUE TO A GENERAL MEDICAL CONDITION, OR TO MOOD-INCONGRUENT DELUSIONS OR HALLUCINATIONS

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

FOR THE FOLLOWING QUESTIONS, FOCUS ON THE WORST TWO WEEKS IN THE PAST MONTH (OR ELSE THE PAST TWO WEEKS IF EQUALLY DEPRESSED FOR ENTIRE MONTH)

During this (TWO WEEK PERIOD) . . .

..how was your appetite? (What about compared to your usual appetite?) (Did you have to force yourself to eat?) (Eat [less/more] than usual?) (Was that nearly every day?) (Did you lose or gain any weight) (How much?) (Were you trying to [lose/gain] weight?)	(3) significant weight loss when not dieting, or weight gain (e.g., a change of more than 5% of body weight in a month) or decrease or increase in appetite nearly every day. Note: in children, consider failure to make expected weight gains. Check if: ___ weight loss or decreased appetite ___ weight gain or increased appetite	?	1	2	3	A3 A4 A5
. . how were you sleeping? (Trouble falling asleep, waking frequently, trouble staying asleep, waking too early, OR sleeping too much? How many hours a night compared to usual? Was that nearly every night?)	(4) insomnia or hypersomnia nearly every day Check if: ___ insomnia ___ hypersomnia	?	1	2	3	A6 A7 A8
. . were you so fidgety or restless that you were unable to sit still? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?) IF NO: What about the opposite -- talking or moving more slowly than is normal for you? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)	(5) psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down) NOTE: CONSIDER BEHAVIOR DURING THE INTERVIEW Check if: ___ psychomotor retardation ___ psychomotor agitation	?	1	2	3	A9 A10 A11
. . what was your energy like? (Tired all the time? Nearly every day?)	(6) fatigue or loss of energy nearly every day	?	1	2	3	A12

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

During this time . . .

. . how did you feel about yourself? (Worthless?) (Nearly every day?)

IF NO: What about feeling guilty about things you had done or not done? (Nearly every day?)

(7) feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick)

NOTE: CODE "1" OR "2" IF ONLY LOW SELF-ESTEEM

Check if:
___ worthlessness
_✓_ inappropriate guilt

? 1 2 (3) A13

unreasonably takes responsibility for son's long standing drug problem

A14
A15

. . did you have trouble thinking or concentrating? (What kinds of things did it interfere with?) (Nearly every day?)

IF NO: Was it hard to make decisions about everyday things? (Nearly every day?)

(8) diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others)

Check if:
____ diminished ability to think
____ indecisiveness

? (1) 2 3 A16

A17
A18

. . were things so bad that you were thinking a lot about death or that you would be better off dead? What about thinking of hurting yourself?

IF YES: Did you do anything to hurt yourself?

(9) recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide

NOTE: CODE "1" FOR SELF-MUTILATION W/O SUICIDAL INTENT

Check if:
___ thoughts of own death
___ suicidal ideation
___ specific plan
___ suicide attempt

? (1) 2 3 A19

A20
A21
A22
A23

AT LEAST FIVE OF THE ABOVE SXS [A (1-9)] ARE CODED "3" AND AT LEAST ONE OF THESE IS ITEM (1) OR (2)

NOTE: DSM-IV criterion B (i.e., does not meet criteria for a Mixed Episode) has been omitted from the SCID.

1 (3) A24

GO TO *PAST MAJOR DEPRES-SIVE EPISODE* A. 12

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

IF UNCLEAR: Has (DEPRESSIVE EPISODE/OWN WORDS) made it hard for you to do your work, take care of things at home, or get along with other people?

C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning

? 1 2 (3) A25

GO TO ***PAST MAJOR DEPRES-SIVE EPISODE*** A. 12

Just before this began, were you physically ill?

IF YES: What did the doctor say?

Just before this began, were you using any medications?

IF YES: Any change in the amount you were using?

Just before this began, were you drinking or using any street drugs?

D. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

? 1 (3) A26

DUE TO SUB-STANCE USE OR GMC GO TO ***PAST MAJOR DEPRESSIVE EPISODE*** A. 12

IF THERE IS ANY INDICATION THAT THE DEPRESSION MAY BE SECONDARY (I.E., A DIRECT PHYSIOLOGICAL CONSEQUENCE OF A GMC OR SUBSTANCE, GO TO ***GMC/SUB-STANCE,*** A.43, AND RETURN HERE TO MAKE A RATING OF "1" OR "3."

PRIMARY MOOD EPISODE

Etiological general medical conditions include: degenerative neurological illnesses (e.g., Parkinson's disease), cerebrovascular disease (e.g., stroke), metabolic conditions (e.g., Vitamin B-12 deficiency), endocrine conditions (e.g., hyper- and hypothyroidism, hyper- and hypoadrenocorticism); viral or other infections (e.g., hepatitis, mononucleosis, HIV), and certain cancers (e.g., carcinoma of the pancreas).

Etiological substances include: alcohol, amphetamines, cocaine, hallucinogens, inhalants, opioids, phencyclidine, sedatives, hypnotics, anxiolytics. Medications include antihypertensives, oral contraceptives, corticosteroids, anabolic steroids, anticancer agents, analgesics, anticholinergics, cardiac medications.

CONTINUE BELOW

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

Did this begin soon after someone close to you died?

E. Not better accounted for by bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.

1 SIMPLE BEREAVE-MENT **GO TO *PAST MAJOR DEPRES-SIVE EPISODE*** A. 12

3 NOT SIMPLE BEREAVE-MENT CONTINUE BELOW

A27

MAJOR DEPRESSIVE EPISODE CRITERIA A, C, D AND E ARE CODED "3"

1 GO TO ***PAST MAJOR DEPRES-SIVE EPISODE*** A. 12

3 CURRENT MAJOR DEPRE-SSIVE EPISODE

A28

How many separate times in your life have you been (depressed/ OWN WORDS) nearly every day for at least two weeks and had several of the symptoms that you described, like (SXS OF WORST EPISODE)?

Total number of Major Depressive Episodes, including current (CODE 99 IF TOO NUMEROUS OR INDISTINCT TO COUNT)

NOTE: TO RECORD DETAILS OF PAST EPISODES, GO TO J. 9 (OPTIONAL).

0 2

A29

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

MAJOR DEPRESSIVE DISORDER **MAJOR DEPRESSIVE DISORDER CRITERIA**

CODE BASED ON A27 (PAGE A.5) AND A77 (PAGE A.17)

At least one Major Depressive Episode that is not due to the direct physiological effects of a general medical condition or substance use — 1 → GO TO "DEPRESSIVE DISORDER NOS," D. 8 — (3) D21

At least one Major Depressive Episode that is not better accounted for by Schizoaffective Disorder and is not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified — 1 → GO TO "DEPRESSIVE DISORDER NOS," D. 8 — (3) D22

Has never had any Manic, Mixed, or unequivocal Hypomanic Episodes — 1 → GO TO NEXT MODULE — 3 D23

→ MAJOR DEPRESSIVE DISORDER

Indicate type:

1 - Single Episode

(2) Recurrent (i.e., to be considered separate episodes, there must be an interval of at least two months in which criteria are not met for a Major Depressive Episode) — D24

?=inadequate information 1=absent or false 2=subthreshold 3=threshold or true

Appendix 3 Phase 1 semi-structured interview guide - Service users

Objective of Questionnaire

To establish among potential users their subjective understanding of depression, what they think are the potential influences of depression in pre and postnatal women and how they think they can be helped with this mental health problem.

Research Questions

1) How do pre and postnatal women understand the phenomenon of depression, particularly in terms of its manifestations and course?
2) What influences do pre and postnatal women identify as a source of their depression
3) What interventions do they perceive as helpful?
4) How would these interventions meet the needs of pre and post-natally depressed women?
5) What are existing pathways to care and how can these be improved to promote greater identification, access and demand?
6) How can demand for mental health care services be increased?
7) What are attitudes to task shifting?
8) How to increase accountability of treatment facilities?
9) How to reduce stigma and discrimination?
10) How to increase support systems for women with maternal depression?

Guidelines

Welcome and introduction

Greeting

Thank participants for agreeing to participate

Explain the project (including what is meant by common mental health problems and depression)

Explain the rationale for the interview

INTRODUCTION

At present in South Africa, many people who suffer from mental disorders such as depression can't get treatment because there aren't enough specialists to deliver the care. In this study we are working with South Africa's Ministry of Health to try to improve this situation. In order to ensure that the service developed understands your context and fits with local understandings of depression and healing, we are interested to hear about your opinions on how people with depression can best be helped.

Thank you for agreeing to participate and giving your time

Interview questions

Cultural / General understanding/Causes of maternal depression

1) How would you know if a person is depressed? (Probe for understanding of depression e.g., is it understood as stress, nerves etc)
2) Do you see yourself as having this problem (being depressed)? Explain why or why not including if others have told him/her

that s/he is depressed (If yes, please explain how this (depression) feels for you?). Probe for signs and symptoms.

3) Have you ever told anyone about your feelings of depression? If Yes,

- Who did you tell?
- What was the person's reaction? Probe if they have given advice or dismissed the issue.

If No, why have you not mentioned your feelings of depression to anyone?

4) How does depression affect your life?

Probe for the problems they have caused for the participant.

5) When did you first start feeling depressed?

6) What do you think caused the depression?

Prompt: Cultural interpretations e.g. witchcraft, incidences and situations (e.g. illness, lack of money, death of someone close to you, lack of familial support, lack of support from partner, unwanted pregnancy, stigma and discrimination etc)

Probe: If personal illness is cited, when were you diagnosed with your illness? Are you receiving any treatment for this illness? Is the treatment effective / helpful?

7) Are you married or single? Probe

- Does your partner/ husband live with you?
- Does your partner/husband provide financial support?
- If Yes, is this adequate?
- If No, how do you support yourself financially?

- Do you have children? If YES, How many children do you have?

  Probe if from same partner and if partner or childrens' father provides financial support for the children.

If partner has deserted her or not willing to acknowledge paternity,

Probe:

- What problems has this caused for you?
- Were you happy or Unhappy to find out that you were pregnant?

Probe: If unwanted pregnancy,

What were you most concerned about when you realised that you were pregnant?

- Did you tell your partner and your family about your pregnancy or did someone else tell the others about your pregnancy? If someone else, who is this person? Did you ask them to tell your family about the pregnancy? Why?
- How was the pregnancy received by your partner?
- How was the pregnancy received by your family? How was the pregnancy received by your partner's family?

  Probe if partner and families were supportive or not.

- Is/Was this your first pregnancy?

If Yes, when did you start feeling depressed? Was it during pregnancy?

Probe if now delivered: Have these feelings of depression continued throughout the pregnancy and after giving birth?

OR

Did it get better sometime during pregnancy, but has now recurred after giving birth? Probe if the latter, when did it start?

If No, how many times have you been pregnant previously?

Probe,

- How many children do you have?
- Have you ever experienced being depressed previously during pregnancy?
- If Yes, for how long. Did you seek treatment for this? If yes, Where? What treatment did you receive? Did it help? For how long did you receive this treatment / take medication?
- Have you ever experienced being depressed after giving birth?
- If Yes, for how long? Did you seek treatment for this? If yes, Where? What treatment did you receive? Did it help? For how long did you receive this treatment / take medication?

8) Do you think the feelings of depression will go away or do you think it will always be there?

9) Can you describe days when you feel worse?

Prompt:

- What makes it worse?
- Are there particular situations?
- Is there something you did yourself?
- Is there something someone else did? What did they do?

10) How does feeling like this (being depressed) affect your ability to care for yourself? Probe: Do you neglect yourself in any way? If Yes, How?

11) How does feeling like this (being depressed) affect your ability to care for your baby?

Prompt:

- What makes it difficult?
- Can you remember situations when you didn't care for your baby properly?
- If no, how do you manage to care for your baby when you are feeling depressed?

What interventions are perceived as helpful?

12) What helps you to cope with your baby?

Prompt: What makes it easy?

13) Can you describe days when you feel better.

Prompt:

- What makes it better?
- Was there anything you did yourself?
- Was there someone who assisted you to feel better? If so, whom? What did they do?

14) If you could imagine the perfect way to help people like yourself who are troubled by depression in this community, what would it be like?

- What do you think can be done?
- Would it be best done alone or with other people (what are the reasons for your choice?)

 Where would it take place?

 Who would provide this help?

 What could the community do to help?

 What could be done by PHC nurses?

 What could be done by Community Health Workers?

What do you think some of the benefits of this help might be?

What do you think some of the difficulties / obstacles to getting this help might be?

Pathways to Care (including identification, access and demand)

15) Have you or someone you know who is troubled by depression ever sought help for this problem?

- If yes, what made you seek help?

 Did you identify yourself as having a problem with depression?

 Did someone else identify your problem of depression and suggest you seek help?

- If yes, who was this person and who did they suggest you seek help from?

 Who did you seek help from?

 How did you know where to seek help from?

 What was the nature of the help you received?

 What was your experience of the help you received?

 How long did it take to get help once identified as having depression?

 Would you seek help from this source again for your depression?

 If yes – Why?

 If no – Why not?

Do you / did you feel less depressed after this help?

16) Are you aware of any services specifically offered by the Department of Health to help you with your depression?

If No, do you think that if such services were available, people like

yourself would want to use them? Probe: Would you go to the clinic to use these services if it means going an extra day as well as your usual day to visit the clinic?

- What could be done to improve identification of people like yourself with depression in the community?
- What can be done to make mental health services easier to access for women in the community?
- What can be done to make mental health services easier to access for the poorest people in the community?
- What would help to make people want to use these services?

 Would increasing awareness that you can be helped with depression and mental health problems improve demand?

 Would making the service closer to where people live help improve demand?

 Would ensuring that the service fits with local understandings of depression and treatment help improve demand?

 If yes, what services are these?

 Were you able to access these services with ease?

 If you were not able to access them with ease,

 Is distance or transport an issue?

 Is cost of services an issue?

 Is finding someone to go with you an issue?

 Is there a problem with a lack of understanding of local views of depression and mental illness?

 Is there a concern about quality of care in PHC / availability of medicines?

- Can you think of anything else that could be done to make it easier to access these services?

17) How do you usually travel to the clinic? How far is it from your home? What does it cost you?

Probe: If you have children at home, who takes care of them when you go to the clinic?

18) Have you or anyone that you know who suffers from depression ever joined a support group? If yes

- Was this helpful?
- If No, Why not? Probe for expectations of what the participant expects from a support group.
- What would motivate you to join or remain in a support group?
- Where would it be most convenient for you to attend a support group? Would it be convenient at a clinic? Can you suggest any other venue that would be suitable for women like you who are mothers and who suffer from depression?
- If you were able to receive help from a person who came to your home, would this be acceptable to you? To your family? Would you have any privacy to receive counselling at home?

Attitudes to Task-Shifting

19) If general health workers, such as nurses and community health workers (CHWS) were trained to provide treatment such as medication or counselling for depression - would this be acceptable to people such as yourself and others in your community?

- Would treatment services provided by nurses be acceptable?

- If Yes, what kind of interventions would be acceptable for them to provide?
- If No, probe for why not.
- Would treatment services provided by CHWs be acceptable?
- If yes, what kind of interventions would be acceptable for them to provide?
- If no, probe for why not.

Accountability

20) Is there some way in which people can indicate whether they are satisfied with mental health care services?

- If Yes, what methods currently exist?
- If No, what method can you think of that could be put in place that would help with this?

Stigma and Discrimination

21) As someone with depression, have you experienced negative attitudes from service providers such as being disrespected, ignored or discriminated against ?

If Yes, can you describe this experience – what happened?

What could be done to change this?

- Do you think awareness-raising can be helpful?
- If you are working, how does feeling depressed affect your relationship with people that you work with?
- Does feeling depressed affect your ability to work / generate an income?

22) As someone with feelings of depression, have you experienced negative attitudes from your family or from community

members such as being disrespected, ignored or discriminated against?

- If yes, can you describe this experience – what happened?
- What could be done to change this?
- Do you think awareness-raising can be helpful?

23) Do you feel that your family members understand your depression?

Are there times when you feel you are not a valued member of your family? What makes this worse?

What makes you feel a valued member of your family?

24) Do you believe that it is possible to recover from depression?

- What would recovery mean for you?
- Does recovery mean being able to work and contribute in your family?
- What else would recovery mean for you?
- Probe: What personal growth and development would you like to pursue? (e.g. goals, dreams)

25) Do you feel that you have lost confidence in yourself since you have suffered from depression?

- What would it take for you to regain your self- confidence?
- What would make you feel like you are more in control of your life?
- What would give your life more meaning and purpose?

26) What social activities or groups do you miss out on since you have had this depression?

- What would you like to be involved in?
- What could be done to help you be more involved socially?

27) Do you have friends that you can rely on to help you? In what way would they be able to help?

Do you have friends that you trust and that you can talk to and confide in?

28) Do you have family members that you can rely on to help you? In what way would they be able to help?

Do you have family members that you trust and that you can talk to and confide in?

29) Do you think there may be any issues that we may have not adequately covered in this interview?

Appendix 4

Phase 1 Follow-up interview - Service users

Objective of Questionnaire

To establish among potential service users screened positive for postnatal depression what they think are the potential influences of depression, their home environment and family support structures.

Research Questions

1) What influences do pre and postnatal women identify as a source of their depression?

2) What are the family structures and home environments of women with postnatal depression?

3) What family support structures exist for these women?

4) How to increase support systems for women with maternal depression?

Guidelines

Welcome and introduction

Greeting

Thank participants for agreeing to participate

Explaining the project (including what is meant by depression)

Explaining the rationale for the interview

INTRODUCTION

At present in South Africa, many people who suffer from mental disorders such as depression can't get treatment because there aren't enough specialists to deliver the care. In this study we are working

with South Africa's Ministry of Health to try to improve this situation. In order to ensure that the service developed understands your context and fits with local understandings of depression and healing, we are interested in your home environment and family support structures.

Thank you for agreeing to participate and giving your time

Interview questions

Cultural / General understanding/Causes of maternal depression

1. How does stress/depression affect your life? Probe for the problems they have caused for the participant.
2. Physically, how do you feel?
3. Emotionally, how do you feel?
4. Do you drink alcohol to help you cope with stress?
5. Do you smoke to help you with stress?
6. Do you take any drugs to help with stress?
7. Do you take any medication (from the pharmacy or doctor) to help cope with stress?
8. Do you feel angry often? How often? What makes you feel angry?
9. Have you ever attempted to kill yourself? If Yes, probe how and why and number of attempts; if help was sought?
10. Do you think about killing your children?
11. Do you think about leaving your children for someone else to care for – because you cannot cope with their demands?
12. How does your depression affect your relationship with other people living in your home?

Home Environment and Support structures

13. Who owns the home that you live in?

14. Who are the people who live in this home?

15. Are you married or single? Probe

    - Does your partner/ husband live with you?
    - Does your partner/husband provide financial support?
    - If yes, is this adequate?
    - If no, how do you support yourself financially?
    - Who provides money for food?
    - Who provides money for clothes?

If partner has deserted her or not willing to acknowledge paternity, Probe:

    - What problems has this caused for you with your family?
    - Did you consider aborting this baby? If yes, what stopped you?

16. Are there particular things that make it difficult to care for your baby? Prompt:

    - Do you beat your children when you are angry?
    - Do you shout at your children when you are angry?

17. Do other people in your home help to care for your baby? If Yes

- Who?
- In what way?
- Who plays with the baby most?
- Who spends the most amount of time caring for the baby?
- Who makes decisions about the baby's health and other needs?
- Who supports the baby financially?

18. Are there times when you feel you are not a valued member of your family? What makes this worse?

- What makes you feel a valued member of your family? Probe: What personal growth and development would you like to pursue? (e.g. goals, dreams)
    - What stops you from doing this?
    - Do you have family members that you trust and that you can talk to and confide in? If yes, who?

19. What are your most immediate and important needs that are not being met properly?

Food for your baby	
Food for your other children	
Food for yourself	
Accommodation	
Clothing for your children	
Clothing for yourself	

Love from your partner	
Support from your partner	

20. How can your family members living with you assist you to cope better with the baby?
21. Do you have friends that you trust and that you can talk to and confide in?

    Do they visit you? If yes, how often?

    Do you have friends that you visit? Phone? If yes, how often?

22. If there was a support group for mothers like yourself where you could **talk** to others in a similar situation would you attend?

    If yes, where would it be most convenient?

    If no, Why would you not attend?
23. If there was a support group for mothers like yourself where you could **learn some skills to help them cope better with their lives**, would you attend?

    If yes, where would it be most convenient?

    If no, Why would you not attend?
24. Is there anything else that you would like to discuss in relation to coping and caring for your baby and yourself?

Appendix 5

Phase 2 Interview schedule - Service providers

Objective of Questionnaire

To establish among service providers their subjective understanding of maternal depression, what they think are the potential influences and how they think they can be helped to deliver services.

Research Questions

5) How do service providers understand the phenomenon of maternal depression particularly in terms of its manifestations and course?
6) What influences do service providers identify as a source of maternal depression?
7) What interventions do they perceive as helpful?
8) How do they feel about task shifting?

Guidelines

- Welcome and introduction
- Greeting
- Thank participants for agreeing to participate
- Explaining the project
- Explaining the rationale for the interview

Interview questions

Cultural / General understanding/Causes of maternal depression

1) How do you view mental illness? What do you think are the main reasons women people develop maternal depression? (probe bio-medical, cultural beliefs, stress)
2) What explanations do most people have for maternal depression? (probe bio-medical, cultural beliefs)
3) Do you think that there are any links between gender and poor mental health? (If yes, describe these links. What could be done to deal with these links?)

4) Would people in your area consult faith healers or traditional healers for maternal depression? (If yes, is this in conjunction with biomedicine?)

Pathways to Care (including identification and demand)

5) Do you provide support and care for women with maternal depression? (If yes, probe education, psychosocial support)
6) Are you willing to provide services for maternal depression if you are given proper training? If No, probe why?
7) What services are available for people maternal depression within this facility?
8) What human resources are available within this facility for people with maternal depression?

What interventions are perceived as helpful? (treatment and pathways through care and how can these be improved)

9) Have you been trained to identify, counsel and refer women with maternal depression? (If yes, describe the training in terms of frequency and comprehensiveness. If limited or none, what training needs do you still have?)
10) Is there a system of supervision and/or on-going support from specialist psychiatric staff to other mental health staff? (If yes, what is the nature of this support?)
11) What kind of training do you need to deal with maternal mental health

Attitudes to Task-Shifting

12) How do you feel about being trained to provide treatment such as medication or counselling for mental illness?

Prompt:

Would it be acceptable for lay counsellors/nurses to provide treatment services for maternal depression ?

If Yes, what kind of services would be acceptable for them to provide?

If No, probe for why not.

Accountability

13) Is there some way in which people can indicate whether they are satisfied with mental health care services?
    - **If yes**, what methods currently exist? Are these effective?
    - **If no**, what method can you think of that could be put in place that would help with this?

Stigma and Discrimination

- Have you experienced stigma and discrimination from your colleagues in relation to treating people with maternal depression? If Yes, describe.
- Do you think awareness-raising of maternal depression in relation to the causes, symptoms and how people can help, will be helpful for reducing stigma and discrimination?
- How do community members treat women with maternal depression?

14) Do you think there may be any issues that we may have not adequately covered in this interview?

Appendix 6

Phase 2 Interview guide-Institutional perspectives

1. What is your role within the maternal and child health platform? What does this entail?

2. What is your role within the PHC system? What does this entail?

3. What is your level of engagement with service users?

4. Are you involved in any capacity with mental health services? If so, please tell me exactly what this involves.

5. Do you engage with service users in antenatal and postnatal care (perinatal services)? If yes, please explain what your role involves.

6. Is there a specific policy to address mental health care in perinatal patients using PHC services?

- If yes, probe if they can elaborate
- If no, do you think this is needed? Why?
- What needs to be done to facilitate this?

7. Are there specific services for mental health care for perinatal service users? If yes, please explain what these services entail?

8. Are there any routine mental health screening services for common mental disorders such as

- Depression?
- Alcohol misuse?

If yes, probe what form this entails

9. If no, do you think these are necessary? Why? ; why not?

10. What if any mental health screening is available to perinatal patients?

Probe: When ?; How often? At every visit?

11. Please explain the consultation and referral process for perinatal patients including:

- Antenatal first visit (when is this likely;); how often are patients consulted?
- Perinatal (PNC) visits (when is this likely;); how often are patients consulted? Probe the 6 hour; 6day; 6 week visit and what it entails for mother and child

o Are PNC patients consulted for their own health after their 6 week checkup or is this the end of PNC care?

o For perinatal patients who visit the facility for ancillary care in between scheduled visits, where do they go? – ie Acute care or perinatal services?

12. Which category of health care worker/s will consult perinatal patients and at what stage?

13. What stationary is used for perinatal care?; Does it differ from the forms used in other care platforms?

14. Are there specific days on which perinatal patients are consulted?

15. Are nurses who consult perinatal patients trained to diagnose and refer perinatal patients for CMDs such as depression? If yes, what training, and what are the referral pathways?

If no, how do nurses manage perinatal patients with depression?

16. Are PHC doctors who consult perinatal patients trained to diagnose, treat and refer perinatal patients for CMDs such as depression? If yes, what treatments do they administer; what are the referral pathways?

17. Are there specialist psychological services available for perinatal patients with depression? Where?; How often? What therapies

18. Are there barriers to specialist psychological services available for perinatal patients with depression –what are these?

o Are any psychosocial services available to patients in their first language (indigenous to area)?

o What psychotropic medications if any are prescribed for perinatal patients with depression

o If any psychotropic medications, how acceptable are these and do patients consider them safe for use in pregnancy and breastfeeding?

19. Is there a body/Who/what body is responsible for the co-ordination/oversight of mental health care services for the perinatal population utilizing PHC?

If yes, Probe for: function and existing services

20. Are there adequate mental health services for perinatal women with cmds such as depression?

21. Are these services if they exist adequate?

22. If not, how can we facilitate appropriate and adequate mental health services for perinatal populations that are:

- o Appropriate for the specified conditions
- o Accessible at each visit
- o Based on evidence to support such services
- o Identify appropriate category of health care worker to implement services
- o Provide appropriate training and supervision for health workers implementing mental health services for perinatal patients
- o Integrate mental health screening into routine care
- o Monitor screening
- o Identify; collect and report appropriate mental health indicators within the routine collection of monthly indicators collected at PHC

23. What information systems interventions will need to be put in place for monitoring and evaluation of integrated mental health care for perinatal patients?

- o Current mental health indicators if used
- o New mental health indicators if required; who would suggest/approve these?
- o Inclusion of mental disorders on patient record sheets
- o Establishment of targets for screening for mental disorders
- o implementation and data capturing

24. Which service platform would be appropriate for this?

a) Would a task-sharing approach, if evidenced as feasible, be acceptable for such interventions in this population? Probe if supportive of providing training, supervision and support to non-specialist staff in mental health care?

25. What changes would need to be made practically to facilitate mental health services for perinatal health care?

Probe for stationary, manuals etc

26. What measures would need to be put in place to monitor the process?

27. What other suggestions do you have to extend mental health services to perinatal patients in PHC?

28. What challenges do you anticipate? How can these be addressed?

29. How important do you consider mental health services for perinatal patients to be? Is this a priority? Are there other health issues that are competing priorities in this domain?

Appendix 7

Phase 1 Study Information and consent - Service Users

Understanding mental disorders in the Dr Kenneth Kuanda district

Study Information Sheet

The Research Study

We are asking you to participate in a research study aimed at understanding mental disorders in the Dr Kenneth Kuanda district. The study will be conducted by researchers from the PRogramme for Improving Mental Health CarE in South Africa (PRIME-SA) which is a collaboration between the universities of KwaZulu-Natal, Cape Town and the Department of Health.

What are we trying to learn?

In this research we want to understand how service users understand mental disorders and what are appropriate psychosocial interventions.

Why is it important?

This study is important so that it can inform the development of culturally and contextually appropriate services for this problem.

Who will be involved?

Service users attending Clinics in Dr Kenneth Kaunda district will participate in the study.

What will it mean if you participate in the study?

If you agree to participate in this study you will be asked to answer a

number of questions about your mental health.

If you are thought to suffer from a mental health problem you will sit for an hour long tape

recorded interview during which a research assistant will ask questions on what you think influences the development of your problem as well your experiences of what is helpful. This information with be used to inform the development of appropriate psychosocial interventions for people with mental health problems.

Is there any disadvantage from participating in this study?

There is the possibility that you may have a mental health problem yourself or that participation in the study may remind you of a time that you had such a problem. If you get distressed by this, we will refer you for psychological help.

What if I change my mind later?

You are free to withdraw at any stage from participating in the study and your decision will not disadvantage you in any way.

Who will see the information that we collected?

All records will be kept completely confidential. Your identity will be anonymous and following analysis of the data, the tapes and transcripts will be destroyed. The data will only be seen by the researchers and investigators.

Who to contact if you want to know more, or if you have a problem at any time?

If you want more information on the study before deciding whether or not to participate, or if you participate and later need help or have questions, please contact:

Prof I. Petersen

School of Psychology

University of KwaZulu-Natal

Tel: 031 260 7970

If you wish to know more about your rights as a participant in this study you can contact:

Ms Phumelele Ximba, Research Office, University of KwaZulu-Natal.

Tel: 2603587

Consent to Enrol

I,_____agree to participate in the research study on understanding mental disorders in the Dr Kenneth Kuanda district to understand culturally and contextually appropriate ways for treating these disorders. I have received and understood the study information sheet. I have discussed the advantages and disadvantages of participating in the study and I agree to participate in the interviews as stated in the information sheet. I know I can leave the research study at any time without prejudice and be referred for psychological help if need be.

Signature: _____

Name: _____

Date: _____

Witness 1

Signature: _____

Name: _____

Date: _____

Witness 2

Signature: _____

Name: _____

Date: _____

You may keep the information sheet. The signed consent form will remain in our study files.

Appendix 8

Phase 3 Information and consent-Service users

You will be given a copy of this information sheet

Dear Service User,

You are invited to participate in a study that involves research about integrating mental health care into perinatal care provided at your primary health care clinic. Before agreeing to take part in this research study, please read the information below so that you understand what the study will involve. Please read this carefully and feel free to ask me if there is anything that is not clear or if you have any questions about your participation. We are asking you to participate in a study to provide information on the outcomes for patients treated for depression and alcohol use disorders at primary health care level.

What is the purpose of this study? The aim of the study is to gather information about whether treatments for depression provided at this clinic are helpful to patients. We would like to find out about the outcomes of these services on patients' health.

Who are we asking to participate? All antenatal and postnatal patients aged 18 years and older attending clinics in the Dr Kenneth Kaunda District are eligible to participate. You may volunteer to participate or you may be approached by a fieldworker in the waiting room and asked if you want to participate. We will try to recruit as many eligible people as possible as they exit their consultation with the nurse or doctor. We would like to enroll up to 130 patients from the clinics in this research study.

What will it mean if you participate in the study?

If you agree to participate in the study, you will be interviewed by me. The interview will take approximately 60 minutes. During the interview, you will be asked a number of questions about your mental health and your use and experience of the health services at this clinic. The interview is divided into 2 parts; only some patients will do part 2. The first part will assess for depression and alcohol use and ask you other questions related to your household and living conditions, work, experience of the healthcare system, medication, difficulties that you might have that are related to your illness and questions related to stigma and violence. During the second part of the interview a mental health professional may do a brief psychiatric assessment with you. This will take place immediately after the end of part 1. I would also like to look at the consultation notes in your clinic file, today and when we do the follow-up interviews if you agree to this.

We would like to do two follow up interviews with you after this interview. The follow-up interviews will be in 4 months and will be either at the clinic, your home or another agreed location. You will be asked to provide your contact details which will be confidential and will be stored on a password protected computer by the research manager of the project. A fieldworker will contact you at these times to arrange an interview time and a location for the follow up interviews. By agreeing to participate in this study today, you are agreeing to allow us to possibly contact you in 4 months to interview you again. We will not collect any biological samples from you i.e. we will not collect, blood, tissue or any other biological samples from you.

Will my information remain confidential? Yes. Should you agree to take part in the study, all your records will be seen by the study researchers only. Information and results of the study that are shared with other researchers will not contain any identifiable (personal) information such as names or contact details. Every effort will be made to keep your information confidential. Although we will try to conduct this interview in a private room, it might happen that, during the course of your interview, another patient or clinic staff member comes into the room. We are unable to guarantee the confidentiality of your participation in this study should this happen. (I will pause the interview when another person has entered the room, unless it is another member of the research team, such as my supervisor). However, if you express thoughts of suicide or intention to harm yourself or others, I will have to refer you to the clinic. In this case I will coordinate with my supervisor to immediately refer you to the clinic or to Dr Von Wiellig, the psychologist at the clinic.

The possibility also exists that, despite the absence of identifying data, the clinic could be identified as one of the research sites due to a process of deduction from the public information about the PRIME project. This does not mean that you yourself will be identified but that the aggregate data from the study may be linked back to your clinic.

No personal identifying details will be recorded from your clinic file notes. This information will only be used to see what happens in your consultation with the nurse today and on the days of the possible follow up study visits. The information from your interview as well as your

clinic consultation will be stored on a computer and protected with a password. Your data will be stored under password protection for up to five years on the study computers.

What are the possible benefits of participating in this study? You will be asked to give approximately 60 minutes of your time to participate in this interview. You will receive a R50 voucher for each interview you agree to complete. We hope that the study results will help us to improve the service provision for patients with mental illnesses at your clinic. As a patient at the clinic it is possible that you could benefit from any intervention that is developed for this study, should you be recruited into any such intervention. One group of Patients will receive the intervention, and one group of patients will not receive the intervention. If you agree to participate you may or may not receive the treatment depending on which group you are allocated to.

What are the possible drawbacks or discomforts of participating in this study? If you agree to participate in this study, you will be asked a number of questions about your mental health problem/s in an interview that should take approximately 20- 40 minutes of your time. We will ask you to be interviewed on three occasions over the course of a year. Each interview should take approximately 20 to 40 minutes. There is the possibility that you may have a mental health problem yourself or that participation in the study may remind you of a time that you had such a problem. If you get distressed by this, we will refer you to the nurse for clinical assessment.

Do I have to participate in this study?It is your choice whether you want to participate in this study or not. If you decide not to participate, you will not be prejudiced in any way, and your decision will not affect the treatment you receive at your clinic. If you decide to take part, you are still free to withdraw from the study at any time, including at the 4 month follow ups, and without giving a reason. Should you decide not to take part, or if you withdraw from the study, this will in no way affect the care you receive at the clinic. Should you agree to participate, we will ask you to sign the attached consent form.

How will we report this research: We will report our results and other aspects of the study in scholarly journals, conferences and to the Department of Health via policy briefs and other reporting structures.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (approval number 587/16).
In the event of any problems or concerns/questions you may contact:

For questions related to the study	For Your rights as a research participant
Tasneem Kathree Department of Psychology Howard College Private Bag X 54001 Durban 4000	**BIOMEDICAL RESEARCH ETHICS COMMITTEE** Research Office, Westville Campus Govan Mbeki Building

KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 260 1700 Email: Kathree@ukzn.ac.za	Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 2604769 - Fax: 27 31 2604609 Email: BREC@ukzn.ac.za

Consent form for service users' participation in the study

Please complete this form after you have been through the information sheet and understand what your participation in this study entails.

Thank you for considering taking part in this study. If you have any questions arising from the information sheet, please ask before you decide whether to take part. You will be given a copy of the information sheet and consent form.

I, (write your name here),_____have been informed about the perinatal study.

I understand the purpose and procedures of the study.

I have been given an opportunity to ask questions about the study and

have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions or concerns or queries related to the study or my rights as a research participant, I understand that I may contact:

Tasneem Kathree Department of Psychology Howard College Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 260 1700 Email: Kathree@ukzn.ac.za	**BIOMEDICAL RESEARCH ETHICS COMMITTEE** Research Office, Westville Campus Govan Mbeki Building Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 2604769 - Fax: 27 31 2604609 Email: BREC@ukzn.ac.za

	Please tick or initial
I understand that if I decide at any time during the study that I no longer want to take part, I can notify the researchers and withdraw without having to give a reason.	☐
I consent to the clinic consultation notes from my patient file being reviewed.	☐
I consent to the processing of my personal information for the purposes explained to me.	☐
I consent to the research team contacting me via an agreed method such as telephone, home-visit or any other agreed method for follow-up interviews. I understand that researchers may contact me for follow up interviews even if I have declined the service or have dropped out of the study. I understand that I may refuse to participate in the current interview or any follow-up interviews at any time.	☐

_____ _____

Signature of Participant **Date**

_____ _____

Signature of Witness **Date**

(Where applicable)

_____ _____

Signature of Translator (Where applicable)

Date_____

Appendix 9

Phase 3 Information and consent-Service Users. Evaluation of the study You will be given a copy of this information sheet

Dear Participant

You are being invited to participate in a study that involves research about the programme of integrating mental health care into the services provided at your primary health care clinic. Before agreeing to take part in this research study, please read the information below so that you understand what the study will involve. Please read this carefully and feel free to ask me if there is anything that is not clear or if you have any questions about your participation.

What is the purpose of this study?The aim of this research study is to evaluate how well the programme we have implemented at your clinic is working. The goal of this study was to improve the identification and management of depression. During this study, we used new guidelines to train nurses in identifying depression and referring patients with depression to the counsellors at your clinic. We also trained the counsellors to help patients who were suffering from depression. The study we are asking you to participate in now is to assess how well this programme is working. We want to learn what worked and didn't work in the study.

Who are we asking to participate? We are looking for participants who were recruited into the perinatal pilot study to take part in the study.

What will participation in the study involve? If you decide to participate in this study, the duration of your participation will be approximately 30-40 minutes, during which you will be asked a number of questions about your experience of the services you received for your mental health condition at the clinic you attended. We will not take any blood or other biological samples from you. The interview will be conducted by myself. With your permission, I will audiotape the interview and the audio recordings will be transcribed later. The audio recordings will be deleted as soon as they have been transcribed.

Will my information remain confidential? Yes. Should you agree to take part in the study, all your records will be seen by the study researchers only. Information and results of the study that are shared with other researchers will not contain any identifiable (personal) information such as names or contact details. Every effort will be made to keep your information confidential. Although we will try to conduct this interview in a private room, it might happen that, during the course of your interview, another patient or clinic staff member comes into the room. If this happens, we will pause the interview and only resume once privacy is restored. The posibility also exists that, despite the absence of identifying data, the clinic could be identified as the research site due to a process of deduction from the public information about the study. This does not mean that you yourself will be identified but that the aggregate data from the study may be linked back to your facility.

The transcript from your interview will be stored on a computer and protected with a password.

The audio recording of your interview, if you consented to it being recorded, will be destroyed immediately after it has been transcribed. To protect your privacy and to ensure confidentiality your interview data will be stored under your study identification number, not your name and will be stored under password protection on the UKZN computers. If hardcopies are made, these will be stored securely in a locked storage space at UKZN.

What are the possible benefits of participating in this study?

You will receive a R50-00 voucher to acknowledge your time and effort in participating in this study. You will be asked to give 30-40 minutes of your time in participating in this study. We hope that the study results will help us to improve the programme at your clinic so that service provision and treatment for patients will depression will be improved. The information that we get from this study will also help us to identify any issues that need to be addressed before we implement the new programme in other primary health care clinics.

What are the possible drawbacks or discomforts of participating in this study? The only cost to you of participating in this study is your time. If you agree to participate in this study, you will be asked a number of questions about your experience of any mental health services you received or were referred to, in an interview that should take approximately 30 to 40 minutes of your time.

If you experience any discomfort or distress during the course of this interview, related

to your condition or to the service you received at your clinic, we will refer you to the PHC psychologist to speak about your concerns.

Do I have to participate in this study?It is your choice whether you want to participate in this study or not. If you decide not to participate, you will not be prejudiced in any way, and your decision will not affect the treatment you receive at your clinic. If you decide to take part, you are still free to withdraw from the study at any time and without giving a reason. Should you decide not to take part, or if you withdraw from the study, this will in no way affect the care you receive at the clinic. Should you agree to participate, we will ask you to sign the attached consent form.

How will we report this research? We intend to publish the findings so that others can also learn from the study .We will report our results and other aspects of the study in scholarly journals, conferences and to the Department of Health via policy briefs and other reporting structures.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (approval number BFC 587/16). If you have any questions or require more information about this study, please contact the following:

For questions related to the study	**For Your rights as a research participant**

Tasneem Kathree Department of Psychology Howard College Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 260 1700 Email: Kathree@ukzn.ac.za	**BIOMEDICAL RESEARCH ETHICS COMMITTEE (BREC)** **Research Office, Westville Campus** **Govan Mbeki Building** **Private Bag X 54001** **Durban** **4000** **KwaZulu-Natal, SOUTH AFRICA** **Tel: 27 31 2604769 - Fax: 27 31 2604609** **Email: BREC@ukzn.ac.za**

Consent Form for Service Users:

Participation in the study to evaluate the perinatal study. Please complete this form after you have been through the information sheet and understand what your participation in this study entails. Thank you for considering taking part in this study.

If you have any questions arising from the information sheet, please ask before you decide whether to take part. You will be given a copy of the information sheet and consent form.

I, (write your name here),_____have been informed about the study to evaluate the perinatal pilot study.

I understand that if I decide at any time during the study that I no longer want to take part, I can notify the researchers and withdraw without having to give a reason.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

Please Tick the box	
I consent to the processing of my personal information for the purposes explained to me.	☐
I agree to my interview being audio recorded	☐
I understand the purpose and procedures of the study.	☐

I have been given an opportunity to ask questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures. I understand that researchers may contact me for follow up interviews even if I have declined the service or have dropped out of the study. I understand that I may refuse to participate in the current interview or any follow-up interviews at any time.

Signature of Participant **Date:**

Signature of Translator (if applicable) **Date:**

Appendix 10

Ethical clearance, Humanities and Social Sciences Research

Ethics Committee, University of KwaZulu-Natal

UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

Research Office (Govan Mbeki Centre)
Private Bag x54001
DURBAN, 4000
Tel No: +27 31 260 3587
Fax No: +27 31 260 4609
Ximbap@ukzn.ac.za

14 September 2011

Professor I Petersen (3106)
School of Psychology

Dear Professor Petersen

PROTOCOL REFERENCE NUMBER: HSS/0880/011
PROJECT TITLE: PRIME-SA: PRogramme for **I**mproving **M**ental **H**ealth Car**E** in South Africa

EXPEDITEI

I wish to inform you that your application has been granted Full Approval through an expe process:

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedu Consent Form, Title of the Project, Location of the Study, Research Approach and Meth reviewed and approved through the amendment/modification prior to its implementation. have further queries, please quote the above reference number. PLEASE NOTE: Research da securely stored in the school/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

.....
Professor Steven Collings (Chair)
HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

cc. Dr Arvin Bhana
cc. Dr Lara Fairall
cc. Dr Beverly Draper
cc. Dr Crick Lund
cc. Dr Mark Sibanyoni
cc. Nomvula Sibanyoni

1910 - 2010
100 YEARS OF ACADEMIC EXCELLENCE

Founding Campuses: Edgewood Howard College Medical School Pietermaritzbu

Appendix 11 Ethical clearance, Department of Health, North West province

health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

2ND Floor Tirelo Building
Dr. Albert Luthuli Drive
Mafikeng, 2745
Private Bag X2068
MMABATHO, 2735

Tel: (018) 387 5757
Fax: (018) 392 6710
kshogwe@nwpg.gov.za

POLICY,PLANNING, RESEARCH, MONITORING & EVALUATION DIRECTORATE

FAX COVER PAGE

To	: PRIME-SA
Att	: Caire Van Derventer
FAX	: 086 6461 789
FROM	: Keitumetse Shogwe
TEL	: 018 387 5747
CELL	: 076 3135 861
FAX	: 018 392 6710

health
Department of
Health
North West Province
REPUBLIC OF SOUTH AFRICA

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www.nwhealth.gov.za

POLICY, PLANNING, RESEARCH, MONITORING AND EVALUATION

To : Prof I Petersen
University of KwaZulu-Natal

From : Policy, Planning, Research, Monitoring & Evaluation

Subject: **Approval Letter- Programme for Improving Mental Health Care in South Africa**

The Subject matter above bears reference

Purpose

To inform your good selves that permission to undertake the above mentioned study has been granted by the North West Department of Health. The researcher is expected to issue this letter as prove that the Department has granted approval to the districts or health facilities that form part of the study.

Arrangements in advance with managers at district level or facilities shall be facilitated by the researcher and the department expects to receive the final research report upon completion.

Kindest regards

Director: Policy, Planning, Research, Monitoring & Evaluation
Mr B Redlinghys

17/10/11
Date

DEPARTMENT OF HEALTH
PRIVATE BAG X2068
2011 -10- 17
SUPERINTENDENT GENERAL

1

Healthy Living for All

Appendix 12 Institutional Approval

UNIVERSITY OF KWAZULU-NATAL
INYUVESI
VAKWAZULU-NATALI

12 May 2017

Ms T Kathree (861861183)
Disdpl1ne of Psychology
School of Applied Human Sciences
Humanities
kathree@Ukzn.ac.za

Dear *Ms* Kathree

Title: Addressing the treatment gap for perinatal depression wfthfn an Integrated primary health care model: Pilot of a psychosocial Intervention for a depression in a perinatal population.
Degree: PhD
BREC REF NO: BFC587/16

The Bfomedfcal Research Ethics Committee (BREC) has considered the abovementioned application at a meeting held on 13December 2016.

The study was provisionally approved by BREC pending appropriate responses to queries raised. Your responses received on 28 March 2017 to queries raised on 17 March 2017 have been noted and approved by the Biomedical Research Committee at a meeting held on 09 May 2017.

This approval of the study is valid for one year from 12 May 2017. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to SREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance wfth South African National Research Ethfcs Guidelines (2015), South African National Good Clinical Practfce Guidelines (2006) (if applicable) and with UKZN BREC etMcs requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at http://research.ukzn.ac.za/Research- Ethics/Biomedical-Research-Ethics.aspx.

BREC ;s registered with the South Afrfcan National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

Pg. 2/ ...

Biomedical Research Ethics Committee
Professor J Tsoka-Gwegweni (Chair)
Westville campus, Govan Mbeki Building
Postal Addl9S8: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 2486 Facs Imile : +'Z7 (0) 31 260 4809 Em•il: brecfllukm.■c.p

The following Committee members were present at the meeting that took place on 13 December 2016:

Prof J Tsoka-Gwegweni	Public Health - Chair: BREC
Prof R Bhimma	Paediatrics & Child Health
Rev. S D Chiti	External - Community member
Dr T Hardcastle	Surgery
Dr R Harrichandparsad	Neurosurgery
Mr K Hlongwana	Public Health
Dr M Khan	Obstetrics and Gynaecology
Dr Z Khumalo	KZN Health (External) General Medicine
Prof TE Madiba	General Surgery
Dr S Paruk	Psychiatry
Dr D Singh	Critical Care
Mr T Popoola	Public Health (HIV)
Dr T Sookan	Biokineticist
Prof V Rambiritch	Pharmacology (Deputy Chair)
Prof D Wassenaar	Psychology (Deputy Chair)

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

PROFESSOR JOYCE TSOKA-GWEGWENI
Chair: Biomedical Research Ethics Committee

cc supervisor: peterseni@ukzn.ac.za
cc postgraduate administrator: ntutia@ukzn.ac.za

Amendment to Appendix 12 – BFC 587/16 permission to change study title

UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI
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BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Westville Campus
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Tel: 27 31 2604769 - Fax: 27 31 260-4609
Email: BREC@ukzn.ac.za
Website: http://research.ukzn.ac.za/ResearchEthics/BiomedicalResearchEthics.aspx

08 July 2019

Ms T Kathree (861861183)
Discipline of Psychology
School of Applied Human Sciences
Humanities
kathree@ukzn.ac.za

Dear Ms Kathree

Previous Title of Study: Addressing the treatment gap for perinatal depression within an integrated primary health care model: Pilot of a psychosocial intervention for a depression in a perinatal population.
NEW TITLE: Addressing the treatment gap for perinatal depression within an integrated primary health care model in South Africa. Development and feasibility study in the Dr Kenneth Kaunda District, North West Province.

Degree: PhD
BREC REF NO: BFC587/16

We wish to advise you that your application for amendments received on 18 June 2019 to change the title to the above for the above study has been noted and approved by a subcommittee of the Biomedical Research Ethics Committee.

The committee will be notified of the above at its next meeting to be held on 13 August 2019.

Yours sincerely

Prof V Rambiritch
Ethics Committee
Chair: Biomedical Research

Appendix 13

Patient Health Questionnaire-9 (PHQ-9)

PHQ9+1				
I am going to describe some feelings people have, and ask if you have felt any over the past two weeks. After those questions, I will ask if you have been bothered by any of the same problems for a period of two weeks or more at some other time in the past year. Over the last two weeks, how often have you been bothered by any of the following problems?				
	Little interest or pleasure in doing things	Not at all	0	PHQ1
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Feeling down, depressed, or hopeless	Not at all	0	PHQ2
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Trouble falling/staying asleep, sleeping too much.	Not at all	0	PHQ3
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Feeling tired or having little energy	Not at all	0	PHQ4
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Poor appetite or overeating	Not at all	0	PHQ5
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Feeling bad about yourself – or that you are □a failure or have let yourself or your family down.	Not at all	0	PHQ6
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Trouble concentrating on things, such as reading the newspaper or watching television.	Not at all	0	PHQ7
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.	Not at all	0	PHQ8
		Several days	1	
		More than half the days	2	
		Nearly every day	3	
	Thoughts that you would be better off dead or of hurting yourself in some way.	Not at all	0	PHQ9
		Several days [Prepare suicidality referral]	1	
		More than half the days [Prepare suicidality referral]	2	
		Nearly every day [Prepare suicidality referral]	3	

Appendix 14 2-Item Whooley screening tool

FACILITY: XX CHC
ANTENATAL SCREENING TOOL FOR DEPRESSION

Instructions: Ask the patient the following 2 questions at each visit. Score: Add the Yes responses: If the patient answers **Yes** to any question go to **page 81 (DEPRESSION AND ANXIETY: DIAGNOSIS) in the PC101+ guideline or page 89 in the Adult Primary Care guideline and follow the steps to assess for depression.**

	Name		**Clinic file number**		**Consultation**	
	1D		**Age**		**Date:**	
	Address					
	Tick **Yes** or **No** I am going to ask you these 2 questions about how you are feeling during your pregnancy				**Yes**	**No**
1.	During the past month have you been feeling down, depressed or hopeless?					
2.	During the past month did you feel you have little interest or pleasure in doing things?					
	TOTAL					

FACILITY: XX CHC

POSTNATAL SCREENING TOOL FOR DEPRESSION

Instructions: Ask the patient the following 2 questions at each visit. Score: Add the Yes responses: If the patient answers **Yes** to **any** question go to **page 81 (DEPRESSION AND ANXIETY: DIAGNOSIS) in the PC101+ guideline or page 89 in the Adult Primary Care guideline and follow the steps to assess for depression.**

	Name		**Clinic file number**		**Consultation**	
	1D		**Age**		**Date:**	
	Address					
	Tick **Yes** or **No** I am going to ask you these 2 questions about how you are feeling during your pregnancy				**Yes**	**No**
1.	During the past month have you been feeling down, depressed or hopeless?					
2.	During the past month did you feel you have little interest or pleasure in doing things?					
	TOTAL					

Appendix 15

Baseline and follow-up questionnaire for perinatal cohort -online version used on handheld devices

Maternal depression (English)

Last Modified by: Emily Baron on 20 Sep 2018 1 1 : IS IS Revision number: 394 Field Count: 283

Sections 1-3 comprise instructions and codes for the questionnaire which is administered on a handheld device and uploaded in real time onto a secure server. The questionnaire format is as it appears on the server.

Section 4. Demographics

4M sex

[Interviewee sex)

Expects a singl& option raspans— (required)

C] Female 1

---

42 age

How old are you? (completed years)

:xpects a numeric response (**required**)

Expects _____ numeric response (required)

Constraints

Response must be Greater Than or Equal '16'

---

43 edu

I%at is the highest level of education you have completed?

Expects a single agtian response (required)

C] neducated 1

C] Non-formal 2

C] Primary sr:hßßl[3]

C] Secondary school[4]

C] College/Üniversity[5]

4.4 marit

M,mat is your marital status?

Expect: Eingle option response (required)

] Single[1]

Married 2

Divorced 3

Widowed 4

Married but not living together[5]

48 kids

Do you have children ?

Expects a single option response (required)

☐ No [0]

☐ Yes [1]

Prerequisites

Skip '.ohan kids (4.5) Not Equal 'Yes [1]'

48 youngyears

How old is your YOUNGEST child? Enter age in YEARS) [If age is years, then enter o]

Expects a numeric response (required)

Expect: _____ numeric response (required)

Constraints *Response* must be
Not Equal '1'

Prereguisites

Skip whan youngyears (4.6) Greater Than ᵛ I' OR.

Skip when kids (4.5) Not Equal 'Yes[1]'

47 youngmonths

How old is your youngest child? Enter age from o to 23 months]

Expects a numeric re—pans— (required)

Constraints

Response be between '1' and '23' .ÅNO

must be Equals '88'

Prerequisites

Skip country (31) Not Equal 'South Africa - or KK[4]'

48 rel sa

M,mat is your religion?

Expect: single cption response (required)

C] Moslem 2

C] Hindu 5

C] Buddhist 6

C] Christian 7

C] Other77

P re u isites

Skip 'than re/_ sa (4.8) Not Equal ᴸ Other [77]'

4v9 relo vmat other

religion?

Expects a single line text response (required)

Section 5. AUDIT

5.1 AUDIT SAI

In this section we '"ill ask questions about drinking alcohol. By alcohol I mean drinks like...
[show alcohol chart here- FLASH CARD 1]

5.2 AUOEVER

Have you ever had a drink containing alcohol?

Expects a single agtian response (required)

C] I have never consumed alcohol 0

C] Yes, I have consumed alcohol[1]

Branches

If response Equals 'No, I have never consumed alcohol then skip to endofaudit (517)

5.3AUOYEAR

Now I am going to ask you some questions about your use of alcoholic beverages during the past THREE months. That is, your use of alcohol beverages since Q(threemonth (1.7) .

54 AU03MONTH

Have you had a drink containing alcohol in the past three months?

Expects a single aptian response (required)

I have not consumed alcohol 0

Yes, I have consumed alcohol[1]

Branches

If response Equals 'No, 1 have not consumed alcohol then skip t' AU09 (515)

How often do you have a drink containing alcohol?

Expects a Eing12 option respznE2 (required)

C] Never 0

C] Monthly or less[1]

C] 2-4 times a month[2]

2-3 times a week[3]

4 or more times a week[4]

Branches

If Equals 'Never then skip to AU09 (5.15)

---

58 AU02

How many drinks containing alcohol do you have on a typical day when you are drinking?

Expects single option response (required)

☐ 1-2 [0]

0 3-4[1]

☐ 5-6 [2]

☐ 7-9 [3]

10 or more

P re u isites

Skip when country (3r1) Not Equal 'South Africa- Dr KK

67 AUO SA2

[show FLASH CARD2]

5.8 AU03

How often do you have six or more drinks on one occasion?

Expects a Eingle option response (required)

C] Never 0

C] Less than monthly[1]

C] Monthly[2]

C] Weekly[3]

C] Daily or almost daily[4]

5.9 Set Total of AU02 AU03

Operator

This field is not displayed an the device, Operator: set(Total of AUD2and AU03 (1.2) sum of (AU02 (5.6) AU03 (5.8) 0)))

Prerequisites

Skip Total ofAU02 and AU03 (12) Equals 'O'

5.10 AU04

How often during the last 3 months have you found that you were not able to stop drinking once you had started?

Expects a Eingle option response (required)

C] Never 0

C] Less than monthly[1]

C] Monthly[2]

C] Weekly[3]

C] Daily or almost daily[4]

P re req uisites

Skip whan Total ofAU02 and AU03 (Ir2.1 Equals 'O'

5.11 AU06

How often during the last 3 months have you failed to do what was normally expected from you because of drinking?

Expect: Eingle option response (required)

Never 0

Less than monthly[1]

Monthly[2]

C] Weekly[3]

C] Daily or almost daily[4]

Prereq uisites

Skip when Total ofAU02 and AUD3 (Ir2) Equals 'O'

5.12 AU06

How often during the last 3 months have you needed a first drink in the morning to get yourself going after a heavy drinking session?
Expects a Eing12 option response (required)

Never [0]

Less than monthly [1]

Monthly [2]

Weekly [3]

Daily or almost daily [4]

Prerequisites
Skip Total ofAU02 and AU03 (12) Equals 'O'

5.13 AU07

How often during the last 3 months have you had a feeling of guilt or remorse after drinking?
Expects a single agtion response (required)

C] Never [0]

C] Less than monthly [1]

C] Monthly [2]

C] Weekly [3]

C] Daily or almost daily [4]

Pre reg u isites
Skip Tot—I ofAU02 And AUD3 (1.2) Equals ¹0'

5.14 AU08

How often during the last 3 months have you been unable to remember what happened the night before because you had been drinking?
Expect: single cptizn (required)

C] Never [0]

C] Less than monthly [1]

C] Monthly [2]

C] Weekly [3]

C] Daily or almost daily [4]

5.15 AU09

Have you or someone else been injured as a result of your drinking?
Expects Eing12 option response (required)

☐ No [0]

Yes, but not in the last year [2]

C] Yes, during the last year[4]

5.16AUDIO

Has a relative or friend or a doctor or another health worker been concerned about your drinking or suggested you cut down ?
Expects a single aptian response (required)

☐ No [0]

Yes, but not in the last year[2]

Yes, during the last year[4]

5.17 endofaudit

[End ofAUDIT section]

Hon 6 PTIQ9

1 PHQ-9 Instruction_SA

Now I am asking you some of the problems that may have experienced in the past TWO weeks (that is, since [illegible]

CARD 3] Please tell me how often have you been bothered by the following problems.

8? PHQ1

[illegible]things.

,o)). [show FLASH

Little interest or pleasure in doing things.

Expects a : option response (required)

- ☐ Not at all (o days) [0]
- ☐ Several days (1-7days) [1]
- ☐ More than half the days (8-11 days) [2]
- ☐ Nearly every day (12-14 days) [3]

6.3 pHQ2

Feeling down, a depressed, or hopeless.(required)

[0
Not at all
(o days)

[1
Several days (1-7 days)

[2
O half the days (8-11 days)

O Nearly every day (12-14

6.4 PHQ3 leeping too

Trouble alling/ asleep, much.

a option response (required)

[0
Not at all (o
days)

[1
Several days (1-7 days)

-11 days) [2

O More than half the days
days) every day (12-
14 days)

66 PHQ4

Feeling tired or having little energy.ed)

Expects a single option response (requir

[0
Not at all (o days)

[1
Several days 0-7 days)

[2
O More than half the days (8-11 days)

L 31 O every day (12-14

Poor appetite or overeating.ired]

Expects a single option response (requvr

C] Not at all (o days) [0

Several days (1-7 [1

days) ☐ More than half [2 the days (8-11 days)

[3

O Nearly every day (12-14 days)

67 PHQ6

Feeling bad about yourself or that you are a failure or have let yourself or your family down.

Expects a single option response (required)

Not at all (o days)[0]

Several days (1-7 days)[1]

More than half the days (8-11 days) [2]Nearly every day (12-14 days) [3]

6.8 PHQ7

Trouble concentrating on things, such as reading the newspaper or watching television.

Expects a single option response (required)

C] Not at all (o days)[0]

Several days (1-7 days)[1]

C] More than half the days (8-11 days)[2]

Nearly every day (12-14 days)[3]

6.9PHQ8

Moving or speaking so slowly that other people could have noticed. Or the opposite being so fidgety or restless that you have been moving around a lot more than usual.

Expects a single option r—sponse (required)

C] Not at all (o days)[0]

C] Several days (1-7 days)[1]

C] More than half the days (8-11 days) [2]C] Nearly every day (12-14 days) [3]

6.10 PHQ9

Thoughts that you would be better off dead or of hurting yourself in some way.

Expect: Eingle option response (required)

C] Not at all (o days) [0]

C] Several days (1-7 days) [1]

C] More than half the days (8-11 days) [2] C] Nearly every day (12-14 days) [3]

6.11 PHQIO

How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Expect: Eingle option response (required)

C] Not difficult at all [0]

Somewhat difficult [1]

Very difficult [2]

Extremely difficult [3]

6.12 Set total

Operator

Thi: field i: not displayed on the device, Operator: set(TotalPHQ (1.18) SUM (PHQI (6.2) PHQ2 (6.3) PHQ3 (6.4) Q PHQ4 (6.5) e Q (PHQ5 (6.6) [0], Q(PHQ6 (5.7) QC PHQ7 (6.8) QC PHQ8 (6.9) QC PHQ9 (6.10))

6,,13 score_phq

Te PHQ9 is TotalPHQ,o)

Section 7. Suicidality

7.1 suicdalttyinstruction

The next questions are about feelings and events that may have occurred in the past THREE months. That is, since Q(threemonth' ,o) .

---

72 SUITHINK

Have you thought of taking your life in the past 3 months?
Expects a single aptian response (required)

☐ No [0]

☐ Yes [1]

Branches
If response Equals 'No [o] ᵛ then skip t' endofsuicidality (Z 11)

---

73 SUIPLAN

Did you make a plan for taking your own life at any time in the past 3 months?
Expects single option respansz (required)

☐ No [0]

☐ Yes [1]

Branches
If Equals 'No [o] ᵛ then skip to endofsuicidality (7w 11)

---

704 SUIATT

Have you attempted to take your own life in the past 3 months?
Expects a single option responE2 (required)

☐ No [0]

☐ Yes [1]

Branches
If response Equals 'No then skip to endofSuicidSlity (7.11)

78 SUIMEO

Did it require medical attention ?
Expect: single option (required)

☐ No [0]

[1] Yes : [2] :

---

78 SUIOISC

In the past 3 months, have you spoken to anyone about thinking about or attempting to take your own life?
Expect: Eingle option response (required)

☐ No [0]

☐ Yes [1]

Branches

If response Equals 'No then skip ta SUITX (7r9)

---

77 suidisc

To whom have you spoken?

Expects multiple selected options (required)

C] Friend / neighbor[1]

C] Spouse/partner[2]

C] Other family member[3]

C] Employer/coworker[4]

C] Traditional healer 5

C] Health care worker (e.g. nurse/doctor, specialist) [6 C]

Religious or spiritual healer[7]

C] Other77

Prereq u isites

Skip suidisc_ (7.7) Occludes 'Other [77]'

7.8 SUIOISCO

Please specify:

Expects a Eingle line text response (required)

7.9SUITX

Did you receive any treatment for thinking about or attempting to take your own life?

Expects single option (required)

☐ No [0]

☐ Yes [1]

C] Don't know988

Branches

If response Equals 'No [o] ᵛ then skip t' endofsuicidality (Z 11)

7.10SUITXO

I%at treatment did you receive?

:xpects a single line text response (required)

Expects single line text

7.11endofsuicidaltty

[End of section]

Section Prerequisites
Skip v.hen visit (3.4) Not Equal 'Baseline [1]'

Section 8. Clinical History

8M starty

You are part of this study due to problems with depressive symptoms. How long ago did you MOST RECENTLY start to have these problems? [Enter
YEARS ago. If less than 1 year, enter o)
Expects a numeric responsa (required)

Prereq u isites
Skip starty (8.1) Greater Than 'O'

82 startm

How long ago did you MOST RECENTLY start to have these problems? [Enter MONTHS ago. If less than 1 month, enter o)
Expects a numeric response (required)

Constraints
Response must be Less Than '11'

Prerequisites
Skip startrn (8.2) Greater Than 'O' OR Skip star-
ty (8.1) Greater Than 'O'

83 startd

How long ago did you MOST RECENTLY start to have these problems? [Enter number of DAYS ago)
Expect: numeric (required)

Constraints
Response ntL.Et BE Less Than '31'

---

84 rechelp

Did you seek any help for these problems? By help I mean the kind of support you can get from someone like a traditional healer, community health worker or medical professional.

Expect: Eingle option response (required)

☐ No [0]

☐ Yes [1]

Branches

If Equals 'No then skip to endofc/inicalhistory (823)

88 rechelpy

How long ago did you first seek help for this MOST RECENT episode of depressive symptoms? [Answer in YEARS. If < 1 year, then enter o]

Expect: numericresponse (required)

8.6

Prerequisites

Skip rechelpy (8.5) Greater Than 'O'

rechelpm

How long ago did you first seek help for this most recent episode? [Answer in MONTHS. If < 1 month, enter o)

Expects numericre-panse (reguired)

Constraints

Respvnse must between 'O' and '11'

P re u isites

Skip when rechelpm (8.6) Greater Than OR.

Skip •ah—n rechelpy (845) Greater Than 'O'

87 rechelpd

How long ago did you first seek help for this most recent episode? [Enter number of DAYS]

Expects a numeric response (required)

Constraints

Response rnu•st be between 'O' and '30'

8.8 rechelpwho

From whom did you FIRST seek help for problems with depressive symptoms?

Expects Eing12 option respznE2 (required)

C] Traditional healer 1

Religious or spiritual advisor[2]

C] Community health worker [3]

Nurse/midwife[4]

C] Pharmacist 5

General doctor 6

C] Specialist doctor (non-psychiatrist)[7]

Psychiatrist[8]

C] Another mental health worker 9

Someone else (specify)[77]

Prerequ isites

Skip when rechelpwho (9.8) Not Equal 'Someone else (specify) [77]'

8v9 rechelpwhoo

First sought help from other (specify):

Expects a single line text response (required)

8r10 rechow

Howmuch did Label(rechelpwho (8.8) , QC 'rechelpwho")) help you?

Expect: Eingle option response (required)

C] Did not help at all[0]

C] Helped a bit[1]

C] Helped a lot[2]

C] Don't know88E

8.11 txseen

Have you sought help from any of the following people since the problems with depressive symptoms most recently started?

Expects multiple selected options (required)

☐ None [0]

Traditional healer 1

C] Religious or spiritual advisor[2]

Community health worker[3]

C] Nurse/midwife[4]

Pharmacist 5

General doctor 6

Specialist (non-psychiatrist) doctor [7]Psychiatrist

[8]

C] Another mental health worker 9

Others (specify)[77]

Prerequisites

Skip when txseen (8v11) Excludes 'Others (specify) [77]'

8n12 txseeno

Also sought help from other (specify):

Expects a single line text response (required)

Prerequisites

Skip txseen (Sr 11) Excludes 'Traditional healer[1]'

8.13 txtrad_help

How much did the TRADITIONAL HEALERhe1p you?

Expects single option response (required)

C] Did not help at all[0]

C] Helped a bit[1]

C] Helped a lot

[2]

C] Don't know[88]

Pre reg uisites

Skip '.qhen txseen (Ell) Excludes 'Religious or spiritual advisor[2]'

8v14 txrel_help

How much did the RELIGIOUS OR SPIRITUAL ADVISOR help ?

Expects a single option response (required)

Did not help at all[0]

Helped a bit[1]

Helped a lot[2]

Don't know[88]

P rereg uisites

Skip when txseen (Sr 11) Excludes 'Community health worker[3]'

8.15txchw_help

How much did the COMMUNITY HEALTH WORKER help you?

Expects a single option response (required)

Did not help at all[0]

Helped a bit[1]

Helped a lot[2]

Don't know[88]

P re req u isites

Skip when txseen (8.11) Excludes 'Nurse/ midwife[4]'

8v16 txnur_help

How much did the NURSE/MIDWIFE help you?

Expects a single option r—spanse (required)

C] Did not help at all[0]

C] Helped a bit[1]

C] Helped a lot[2]

C] Don't know[88]

Pre reg u isites

Skip •ah—n txseen (811) Excludes [Pharmacist [5] '

8v17 txpharm_help

How much did the PHARIVIACIST help you?
Expect: single cptizn respon:e (required)

C] Did not help at all[0]

C] Hélped a bit[1]

C] Helped a lot[2]

C] Don't know ceee]

P re req u isites

Skip •ah—n txseen (811) Excludes 'General doctor[6]'

8.18 txgen_help

How much did the GENERAL DOCTORhe1p you?
Expects single option response (required)

Did not help at all[0]

Helped a bit[1]

Helped a lot[2]

Don't know888

Prereq uisites

Skip when txseen (8&11) Excludes 'Specialist (non-psychiatrist) doctor[7]'

8.19 txspec_help

How much did the SPECIALIST DOCTOR help you?
Expects a single aptian response (required)

Did not help at all[0]

Helped a bit[1]

Hélped a lot[2]

Don't know888

P re reg u isites

Skip when txseen (E 11) Excludes 'Psychiatrist[8]'

820 txpsy_help

How much did the PSYCHIATRIST help you?
Expects a singl& option raspans— (required)

C] Did not help at all[0]

C] Helped a bit[1]

C] Helped a lot[2]

C] Don't know888

Prereq u isites

Skip txseen (Ell) Occludes 'Another mental health worker [9] ᵣ

821 txoment_help

How much did the OTHER MENTAL HEALTH WORKER help you?

Expects a Eingle option response (required)

C] Did not help at all[0]

C] Helped a bit[1]

C] Helped a lot[2]

C] Don't know88

Prerequisites

Skip txseen (811) E*cludes 'Others (specify) [77]'

822 txo_help

How much did the Q(txseeno') help you?

Expects single option esponse (required)

Did not help at all[0]

Hélped a bit[1]

Helped a lot[2]

Don't know88

8.23 endofclin icalhistory

[End of section]

Section 9. Economic Activity

9M occ

Tv%at is your main occupational status? Expects a single agtian response (required)

C] Home worker (e.g. housewife)[1]

C] Unskilled labour (farmhand / domestic worker / subsistence farmer) [2]

C] Skilled labour (builder)[3]

C] Services-sales (shop worker)[4]

C] Clerical worker (secretary)[5]

C] Professional (nurse, lawyer, doctor)[6]

C] Student 7

C] Retired-pensioned[8]

C] Other77

Prerequisites

Skip occ (9.1) Not Equal 'Other [77] '

9.2 occo

Specify the occupational status:

:xpects a single line text response (**required**)

Expect: single tine text response (required)

---

93 empnow

V,mat is your CURRENT employment status?

Expect: single option (required)

C] Self-employed (including subsistence farmer)[1]

C] Full- or part-time employment by someone else (wage or salaried) [2 C]

Voluntarily employed (unpaid)[3]

C] Not employed (including housewife)[4]

Branches

If response Equals Voluntarily employed (unpaid) then skip to econworkhrs (9.6)
If response Equals 'Not employed (including housewife) [4]' then skip to empever (9.8)

Prereq uisites

option responE2 (required)

Skip when empever (9.8) Equals 'No[0]'

94 econearn

How much do you usually earn ? (before taxes and other deductions)? [Enter salary in Label(currency (1.11) , 'country)) units]
Expects a numeric responsa (required)

---

905 econ payment

[Enter frequency of earnings, for the previous answer]
Expects a single

C] per day[1]

per week[2]

per month [3]

per year

98 econworkhrs

About how many hours did you work in the past 4 weeks (28 days)?
Expects a numeric responsa (required)

97 gotowhodas

Operator

This field i: nat displayed an the device, Operator: GaTa(ECON-WHOOAS (9.13))

98 em paver

Have you EVER worked for income / had employment?
Expects a single option response (required)

☐ No [0]

☐ Yes [1]

Branches
If response Equals 'No [o] ' then skip to econreturn (9.12)

P rereg uisites

Skip when empever• (9.8) Equals 'Yes[1]'

9v9 econunempy

option responE2 (required)

How long ago did you LAST work for income have employment? Enter number of YEARS] [Enter o if unemployment is < 1 year]

Expects a numeric responsa (required)

Prerequisites

Skip empever (9.8) Equals 'Yes OR

Skip when econunempy (9.9) Greater Than 'O'

9v10 econunempm

How long ago did you LAST work for income have employment? Enter 1 to MONTHS] [Enter o if unemployment is < 1 month)

Expect: numericresponse (required)

Constraints

Response must be Less Than or Equal *11'

Prerequ isites

Skip empever (9.8) Equals 'yes [1]' OR

Skip econunempm (9, 10) Greater Than 'O[R]

9M 1 econunempd

How long ago did you LAST work for income / have employment? [Enter to 30 DAYS]

Expect: numeric (required)

Constraints must be between '1'

and '30'

Prerequisites

Skip empever (9.8) Equals 'Yes[1]'

9.12 econreturn

Are you looking for work or intending to return to work?

Expects a single

☐ No [0]

☐ Yes [1]

9M3 ECON-WHOOAS

For your HOUSEHOLD tasks... In the past 30 days how much difficulty did you have in...

9.14 econhhwell

How much difficulty did you have in... Doing your most important household tasks well ?

Expects a singl& option raspans— (required)

option responE2 (required)

C] None 1

C] Mild 2

C] Moderate 3

C] Severe 4

C] Extreme or cannot do 5

9.15 econoone

How much difficulty did you have in... Getting all the household work done that you needed to do?
Expects single option response (required)

C] None 1

☐ Mild [2]

C] Moderate 3

C] Severe 4

C] Extreme or cannot do 5

9E16 eapquickly

How much difficulty did you have in... Getting your household work done as quickly as needed?
Expect: single option response (required)

☐ None [1]

C] Mild 2

C] Moderate 3

Severe 4

Extreme or cannot do 5

9.17 eapmiss

In the past 30 days, on how many days did you reduce or completely miss household work because of depressive symptoms? [Enter o to 30 DAYS]
Expects a numeric response (required)

Constraints

Response be between 'O' and '30'

9.18 hhfood

option responE2 (required)

Has anyone in your household, including yourself, been hungry in the last month due to lack of resources/food?

Expects a single

☐ No [0]

☐ Yes [1]

option responE2 (required)

Section 10. WHODAS

10M WHO Oisability Assessment Instruction 1

The next part of this interview is about difficulties people have because of health conditions. [Fieldworker: Hand flashcard to respondent] By health condition I mean diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems and problems with alcohol or drugs.

10.2 WHO Disability Assessment Instruction 2_SA

I remind you to keep all of your health problems in mind as you answer the questions. h,nuen I ask you about difficulties in doing an activity think about: [Show FLASH CARD 4). Increased effort Discomfort or pain Slowness Changes in the way you do the activity

---

10.3 WHO Disability Assessment Instruction 3 vmen answering, Id like you to think back over the last 30 days (since Q('onemonth')). I also would like you to answer these questions thinking about how much difficulty you have, on average over the past 30 days, while doing the activity as you usually do it.

10.4 WHO Disability Assessment Instruction 4

[Hand flashcard to interviewee] Use this scale when responding. [Read scale aloud): None, mild, moderate, severe, extreme or cannot do.

[Fieldworker: Note, Flashcards #4 and #5 should remain visible to the respondent throughout the interview]

10.5 OVERALL

How do you rate your overall health in the past 30 days?

Expects a single option response (required)

Very good [1]

☐ Good [2]

Moderate 3

C] Bad 4

Very bad [5]

10.6 WHO Disability Assessment Instruction 8_SA

[Show FLASH CARD In the last 30 days how much difficulty did you have in:

---

107 STAND

Standing for long periods such as 30 minutes?

Expects a single aptian response (required)

☐ None [1]

☐ Mild [2]

Moderate 3

Severe 4

Extreme/cannot do[5]

10.8 HOUSE

Taking care of your household responsibilities?
Expects a singl& option raspans— (required)

☐ None [1]

C] Mild 2

C] Moderate 3

C] Severe 4

C] Extreme/cannot do[5]

10.9 LEARN

Learning a new task, for example, learning how to get to a new place?
Expects single option response (required)

C] None 1

☐ Mild [2]

C] Moderate 3

C] Severe 4

C] Extreme/cannot do[5]

10.10JOIN

How much of a problem did you have in joining community activities (for example, festivities, religious or other activities) in the same way as anyone elsecan?
Expects a single option response (required)

☐ None [1]

C] Mild 2

Moderate 3

Severe 4

Extreme/cannot do[5]

10.11EMOTE

How much have you been emotionally affected by your health problems?
Expects a single agtion response (required)

☐ None [1]

☐ Mild [2]

Moderate 3

C] Severe 4

Extreme/cannot do[5]

10v12 WHO Disability Assessment Instruction 9

In the last 30 days, how much difficulty did you have in:

0.13 conc

Concentrating on doing something for 10 minutes?
Expects a single option response (required)

☐ None [1]

c:] Mild 2

C] Moderate 3

Severe 4

C] Extreme/cannot do[5]

0.14 WALK

Walking a long distance such as a kilometer?
Expects a single agtion response (required)

☐ None [1]

C] Mild 2

C] Moderate 3

C] Severe 4

C] Extreme/cannot do[5]

0.15 WASH

Washing your whole body?
Expect: Eingle option response (required)

☐ None [1]

C] Mild 2

C] Moderate 3

C] Severe 4

C] Extreme/cannot do[5]

0.16 ORESS

Getting dressed?
Expects a single aption response (required)

C] None 1

☐ Mild [2]

Moderate 3

Severe 4

C] Extreme/cannot do[5]

0.17 DEAL

Dealing with people you do not know?
Expects single option (required)

c:] None 1

☐ Mild [2]

Moderate 3

C] Severe 4

Extreme/cannot do[5]

10.18 FRIEND

Maintaining a friendship?
Expects a single option r—spanse (required)

☐ None [1]

C] Mild 2

C] Moderate (3]

C] Severe 4

C] Extreme/cannot do[5]

10.19OAY

Your day to day work?
Expects a single agtian response (required)

c:] None 1

☐ Mild [2]

C] Moderate 3

C] Severe 4

C] Extreme/cannot do[5]

10.20INTERF

Overall, how much did these difficulties interfere with your life?
Expect: Eingle option response (required)

C] None 1

O Mild 2

C] Moderate 3

Severe 4

C] Extreme/cannot do[5]

10.21OIFFOAYS

Overall, in the past 30 days, how many days were these difficulties present?
Expects a numeric response (required)

Constraints
Response must be Less Than or Equal '30'

1022 UNABLE

In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?
Expects a numeric responsa (required)

Constraints
Response be Less Than or Equal '30'

1023 CUTBACK

In the past 30 days, not counting the days you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?
Expects a numeric response (required)

Constraints
Response must be Less Than or Equal '30'

Section 11. Medications

11.1 rx instructions

[Instruction for country teams: List all known psychotropic medications being used in any PRIME country and list them for use in Question 2. Nonpsychotropic will fall under Other (specify)

11.2 rxmeds

In the past THREE months (since Q('threemonth' ,o)), how many new or continuing medications have you been prescribed for ANY health condition?
Expect: numericresponse (required)

Repeat this section for value of rxmeds (11.2)

Section 12. Medication repeat

12M rxname

Tv%at is the name of the _{LABEL(823138,REPEAT IDX medication you were prescribed? If you do not remember what medication you have been prescribed you can show me the pills or prescriptions.

Expects a single agtion response (required)

☐ Amytryptyline [15]

Carbemazepine [2]

Diazapam [4]

Fluoxetine 1

Haloperidol [10]

C] Imipramine [17]

Lamotrigine [8]

C] Orphenadrine [11]

Phenobarbitol 14

C] Phenytoine [9]

Promethazine 18

C] Resperidone [5]

Sodium valproate [7]

C] Thiamine 3

Trihexiphenyidil [6]

C] Other medication 77

Prerequ isites

Skip when rxname (12r1) Not Equal 'Other medication [77]'

'122 rxnameo

1%at is the name of the other medication?

Expects a single line text response (required)

Expects single line text response (required)

'123 rxdays

For how many days was Label(rxname (12.1) , Q('rxnameV)) most recently prescribed? [Don't know=881

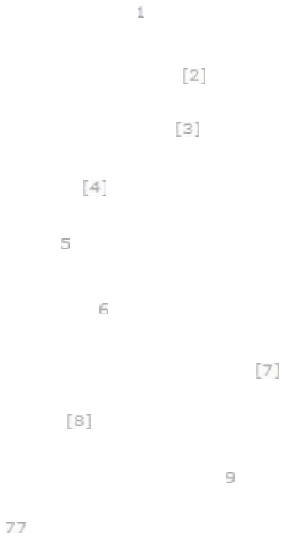
Expects numericresponsæ (required)

12.4 rxdose vmat was the daily dosage for Label(rxname (12.1) , QC 'rxname')) ? Enter the milligrams / entire day. Note: lg = 1000 mg.] CDon't know= 881

Expects a numeric response (required)

128

rxwho Whoprescribed the Label(rxname (12.1) , QC 'rxname))
for you?
Expects a single option response (required)



Prereq uisites
Skip When rxwho (12 S) Not Equal 'Other [77]'

12.6 rxwhoo

Specify who prescribed the Label(rxname (12.1) , QC ᵛrxname'))
Expects a single line text response (required)

Prereq u isites
Skip rxname (12r1) Not Equal 'Other medication [77]'

127 notpsychotropic-s kiptonext

[This drug is not a psychotropic. Skip ahead.]
Expect: Eingle option response (optional)

☐ Next [1]

Branches
If response Equals 'Next then skip t' endofnaedications (12.15)

'128 rxforget

Do you forget to take Label(rxname (12.1) , QC 'rxname)) ?
Expects a single option response (required)

☐ No [0]

C] Yesc ᵗJ

42.9 rxcareless

Are you careless at times about taking the Label(rxname (12.1) , Q('rxname")) ?
Expects a Eingle option response (required)

☐ No [0]

☐ Yes [1]

12.10 rxbetter vmen you feel better do you sometimes stop taking Label(rxname (12.1) , QC ᵛrxname')) ?

Expect: Eingle option response (required)

☐ No [0]

☐ Yes [1]

1 rxworse

Sometimes if you feel worse when you take Label(rxname (12.1) , QC 'rxname')) , do you stop taking it?

Expects a single option response (required)

☐ No [0]

☐ Yes [1]

12v12 rxmanth

In the past ONE MONTH (since Q('onemonth')), have you been taking the Label(rxname (12.1) , QC 'rxname')) as prescribed by the Label (rxwho (12.5) , QC 'rxwho")) ?

Expects a singl& option raspans— (required)

C] All the time 1

C] Most of the time of the last 4 weeks)[2]

C] Sometimes (at least 2-3/4 weeks)[3]

C] Took the medicine occasionally of the last 4 weeks)[4]

C] Did not take any medicine at all [5]

12.13 rxadvice

Did the Label(rxwho (12.5) , QC 'rxwho)) give you advice and support with taking Label(rxname (12.1) , QC 'rxname)) ?

Expects single option response (required)

☐ No [0]

☐ Yes [1]

C] Don't know/Can"t remember[88]

12v14 rxsfx

Did the Label(rxwho (12.5) , QC 'rxwho)) talk to you about potential side effects of Label(rxname (12.1) , Q('rxnameᵗ)) and what to do if you experience any of those side effects?

Expects a single option response (required)

☐ No [0]

☐ Yes [1]

Don't know/Can't remember[88]

12.15 endofmedications

[End of this medication]

Section Internalized Stigma

13.1 ISM"

You have mentioned that you frequently experience some problems %ith [your drinking/emotions] in the past year. I will Rsk you some questions about these problems. Let me know if you agree or disagree with the f0110%ing statements.

---

132 ISMIOI

I feel out of place in the world because of these problems
Expects a single option response (required)

C] Strongly disagree[1]

☐ Disagree [2]

C] Agree[3]

C] Strongly agree[4]

13.3 ISM105

I am embarrassed or ashamed of these problems
Expects single option response (required)

C] Strongly disagree[1]

C] Disagree[2]

☐ Agree [3]

C] Strongly agree[4]

13.4 ISM116

I am disappointed in myself due to these problems
Expects single option response (required)

Strongly disagree[1]

Disagree[2]

Cl Agree[3]

Strongly agree[4]

13.5ISMM7

These problems have spoiled my life
Expects a single option response (required)

Strongly disagree[1]

Disagree[2]

☐ Agree [3]

Strongly agree[4]

13.6ISMM9

Because of these problems, I need others to make most of my decisions for me

---

128

Expects a singl& option raspans— (required)

C] Strongly disagree[1]

C] Disagree[2]

Agree[3]

C] Strongly agree[4]

137 ISM123

I can't contribute anything to society because of these problems
Expects a single option responE2 (required)

C] Strongly disagree[1]

C] Disagree[2]

☐ Agree [3]

C] Strongly agree[4]

13.8ISM103

People discriminate against me due to these problems
Expects a single option response (required)

Strongly disagree[1]

☐ Disagree [2]

Agree[3]

C] Strongly agree[4]

13.9ISM115

People often patronize me, or treat me like a child, just because of these problems
Expect: single option (required)

Strongly disagree[1]

Disagree[2]

☐ Agree [3]

Strongly agree[4]

13.10ISM122

People ignore me or take me less seriously just because of these problems
Expect: single option (required)

C] Strongly disagree[1]

☐ Disagree [2]

C] Agree[3]

C] Strongly agree[4]

13.11ISM126

Nobody would be interested in getting close to me because of these problems
Expect: Eingle option response (required)

C] Strongly disagree[1]

C] Disagree[2]

☐ Agree [3]

C] Strongly agree[4]

3.12 ISM128

Others think that I cant achieve much in life because of these problems

Expects Eing12 option response (required)

C] Strongly disagree[1]

Disagree[2]

Agree[3]

Strongly agree[4]

Section 14. Maternal Health

14.1 pregstatus

[Participant's pregnancy status]
Expects single option response (required)

C] Antenatal 1

Postnatal 2

Branches

If response Equals 'Postnatal then skip to postnatal (1410)

14.2 antenatal

The next few questions about your experience in antenatal care.

143 monpreg

How many months pregnant are you? [Enter 88 if you don^{v}t know]
Expects numericresponse (required)

Constraints
Response ni'JSt be between 'O' and OR
Response be Equals '88'

144 eddknown

Do you know approximately when your due date is?
Expect: single cption response (required)

☐ No [0]

☐ Yes [1]

Prerequisites
Skip eddknown (144) Equals [No [O}

146 edd

^{T}O,men is your approximate due date?
Expect: dete (required)

14.6 antecare

How many times have you received antenatal care during this pregnancy?
Expects a numeric response (required)

---

147 tetinj

During this pregnancy, were you given an injection in the arm to prevent the baby from getting tetanus, that is, convulsions (infections) after birth?

Expects a single agtian response (required)

☐ No [0]

☐ Yes [1]

C] Don't know88

P re reg u isites

Skip 'then tetinj (14m 7) Not Equal 'Yes [1]'

'148 tetinjnum

During this pregnancy, how many times did you get this tetanus injection ?

Expects a numeric responsa (required)

14v9 gotoend

Operator

This field i: nat displayed an the device, Operator: GaTa(endofmaternal (14.23))

14.10 postnatal

The next few questions about your experience with postnatal care.

'14.11 pregendm

How long ago did your pregnancy end? [Enter in MOIVTHS ago. If months ago, enter o)

Expects a numeric responsa (required)

Constraints

Response rnu•st be Not Equal 1 '

P re reg u isites

Skip 'then pregendm (i4.11J Not Equal'0'

14M2 pregendw

How long ago did your pregnancy end? Enter in WEEKS ago. If weeks ago, enter o)

Expects a numeric response (required)

Constraints

Response 'e Not Equal '1'

Pre reg uisites

Skip pregendw (14.12) Not Equal OR.

Skip win—n pregendm (14.11) Not Equal 'O'

14E13 pregendd

How long ago did your pregnancy end? Enter DAYS ago]

Expect: numericrespon:e (required)

Constraints

Response nib's: Be between '1' and '14'

14.14livebirth

[Assess how the pregnancy ended]

Expect: single option response (required)

Abortion/miscarriage/stillbirth/infant mortality

[O]C] Live birth 1

Branches

If response Equals 'Abortion/ miscarriage/stillbirth/infant mortality [O]' then Ekip to endofmaterna/ (14.23)

14.15 everbreastfed

Have you ever breasfed your baby?

Expects a Eingle option response (required)

☐ No [0]

☐ Yes [1]

P re reg u isites

Skip 'then ever-breastfed (14.15) Equals 'Yes [1] '

14E16 everbreastfedwhy Whydid you decide not to breastfeed

? (Enter primary reason]

Expects a single option response (required)

Didn't like breastfeeding[1]

I was too busy[2]

1 had to go back to

work [3]I was sick 4

1 didn't have enough milk[5]

C] Baby was crying all the time[6]

My mother/partner/family member advised not to[7]

C] A health worker advised me not to breastfeed 8

Because of my HIV status[9]

C] Other reason77

Don't know88

Prerequisites

Skip when everbreastfedwhy (14.16) Not Equal 'Other reason [77] ˅

14.17 everbreastfedwhyo

[Please specify other reason for never breastfeeding]

Expects a single line text response (required)

Prerequisites Skip when everbreastfed (1415)

Equals 'No[0]'

14v18 breastfeed

Are you still breastfeeding?

Expects a single option responE2 (required)

☐ No [0]

☐ Yes [1]

P re req u isites

Skip when everbreastfed (1415) Equals 'No OR. Skip

'.4hen breastfeed (1418) Equals 'Yes[1]'

14E19 breastfeedingwhy

Why did you decide to stop breastfeeding your baby? [Enter primary reason]

Expects a single option response (required)

1 didn't like breastfeeding[1]

C] I was too busy[2]

1 had to go back to work[3]

C] I was sick 4

1 didn't have enough milk[5]

Baby was crying all the time [6]

Breastfeeding was painful[7]

My baby was not gaining weight[8]

My mother/partner/family member advised me to stop[9]

C] A health worker advised me to stop[10]

Because of my HIV status[11]

Other reason 77

Don't know88

Prerequ isites

Skip •ah—n everbreastfed (1415) Equals 'No OR.

Skip breastfeedingwhy (14.19) Not Equal 'Other reason [77]'

14.20 breastfeedingwhyo

[Please specify other reason for stopping breastfeeding]

:xpects a single line text response (required)

Expects single line text response (required)

14.21 vacccard

Do you have a card where your child's vaccination are written down? May I see it please?

Expects a single agtian response (required)

C] Yes, and can see card[2]

C] Yes, but can't see card[1]

C] No card [0]

Prerequisites

Skip when vacccard (1421) Equals 'No card[0]'

14.22 vacctype

Please tell me if your child received any of the following vaccinations: CUse vaccination card if available] [Choose all that apply]

Expects multiple Eälected option: [required)

C] A BCG vaccination against tuberculosis, that an injection in the right upper arm that usually causes a scar [1]

C] Polio vaccine, that is, drops in the mouth[2]

A DPT vaccination, that is, an injection given in the upper thigh sometimes at the same time as polio drops[3]

C] A measles injection or an injection, that is: a shot in the left upper arm lat the age of 9 months or older] to prevent him/her from getting measles [4]

1423 endofmaternal

[End of section]

Section 15.

Disclosure-participant

15.1 pdisclosure

In general, how happy would you feel talking to a friend or family member about your mental health, for example telling them you have depressive symptoms and how it affects you ?

Expects a single option response (required)

C] Very happy[1]

C] Slightly happy[2]

C] Slightly unhappy[3]

C] Very unhappy [4]

Section 16.
OSLO

16.1 oslo Instruction 1

The following 3 questions ask about how you experience your S06R1 relationships. The inquiry is about your immediate personal experience.

16.2 oslo Instruction 2

Please indicate the option that represents your experience. If you are not sure of your answer, try to do your best to give an answer.

16.3 oslocount

How many people are so close to you that you can count on them if you have serious personal problems?
Expects a single option response (required)

c:] None 1

i or?

☐ 3-5 [3]

C] More than S[4]

16.4 osloconcern

How much concern do people show in what you are doing?
Expects a single agtion response (required)

A lot of concern and interest 5

C] Some concern and interest 4

C] Uncertain 3

C] Little concern and interest 2

C] No concern and interest 1

---

168 oslohelp

How easy is it to get practical help from neighbors if you should need it?
Expect: Eingle option response (required)

C] Very easy[5]

C] Easy[4]

C] Possible 3

C] Difficult 2

C] Very difficult[1]

Section 17.

Violence against women

17.1 VInstruction 1 vmen two people marry or live together, they usually share both good and bad moments. I would now like to ask you some questions about your current and past relationships and how your husband/ partner treats (treated) you.

---

172 VInstruction 2

If anyone interrupts us I will change the topic of conversation. I would like to assure you that your answers will be kept secret, and that you do not have to answer any questions that you do not want to. May I continue?

---

173 vdisc

In general, do (did) you and your (current or most recent) husband/partner discuss the following topics together? (Choose all that apply]

Expects multiple selected option: (required)

Things that have happened to him in the day[1]

C] Things that happen to you during the day [2]Your worries or feelings[3]

C] His worries or feelings

[4]c:] None

174 vquar

In your relationship with your (current or most recent) husband/ partner, how often would you say that you quarreled? Would you say rarely, sometimes or often?

Expects a single option r—spanse (required)

C] Rarely[1]

C] Sometimes 2

C] Often 3

C] Never 0

---

178 vsitu

I am now going to ask you about some situations that are true for many women. Thinking about your (current or more recent) husband/partner, would you say that it is generally true that he: [Choose all that apply]

Expects multiple selected options (required)

C] Tries to keep you from seeing your friends[1]

C] Tries to restrict contact with your family of birth[2]

C] Insists on knowing where you are at all times[3]

C] Ignores you and treats you indifferently[4]

Section 18.

C] Gets angry if you speak with another man[5]

C] Is often suspicious that you are unfaithful

[6]

C] Expects you to ask his permission before •eeking health care for yourself[7]

C] None of the above □

---

178 VInstruction 4

The next questions are about things that happen to many women, and that your current partner, or any other partner, may have done to you.

177 VInstruction 6

I want you to tell me if your current husband/partner, or any other partner, has ever done the following things to you.

'17.8 insutt

Insulted you or made you feel bad about yourself?
Expects a single option r—spanse (required)

☐ No [0]

C] Yesc ᵗ J

Branches
If respznsa Equals 'No [OI ᴸ then skip to belittle (17r 12)

17.9 insutt_yr

Has this happened in the past 12 months?
Expects a single option response (required)

☐ No [0]

☐ Yes [1]

Branches

If response Equals 'No then skip to insuft_past (17r11)

17.10 insutt_freq

In the past 12 months, would you say that this has happened once, a few times or many times?

Expects single option response (required)

O Once1

Few times 2

Many times[3]

P u isites Skip When insult_yr (i7.9) Equals 'Yes [1]'

17.11insutt_past

Before the past 12 months, would you say that this has happened once, a few times, or many times?
Expects a single option response (required)

☐ Once [1]

Few times 2

C] Many times[3]

17.12 belittle

Belittled or humiliated you in front of other people?
Expects a single agtion response (required)

aption response

☐ No [0]

☐ Yes [1]

Branches

If response Equals 'No then skip to scare (17.16)

47.13 belittle_yr

Has this happened in the past 12 months?

Expects a single option response (required)

☐ No [0]

☐ Yes [1]

Branches

If response Equals 'No [o] ' then skip to belittle_past (17r 15)

17r14 belittle_freq

In the past 12 months, would you say that this has happened once, a few times or many times?

Expects a Eing12 option response (required)

☐ Once [1]

Few times 2

C] Many times[3]

Prereq uisites

Skip when belittle_yr (1 Z 13) Equals 'Yes[1]'

17.15 belittle_past

Before the past 12 months would you say that this has happened once, a few times or many times?

Expects a single option response (required)

☐ Once [1]

Few times 2

Many times[3]

17E16 scare

Did things to scare or intimidate you on purpose (e.g. by the way he looked at you, by yelling and smashing things)?

Expect: single option (required)

☐ No [0]

C] Yee:

Branches

If response Equals 'No [OY then skip t' hurt (17.20)

17.17 scare_yr

Has this happened in the past 12 months?

aption response

Expects a single option response (required)

☐ No [0]

☐ Yes [1]

Branches
If Equals 'No then skip t' scare_past (17r19)

17.18 scare_freq

In the past 12 months, would you say that this has happened once, a few times or many times?
Expect:- a single (required)

☐ Once [1]

Few times 2

Many times[3]

P u isites
Skip when scare_yr (17.17) Equals 'Yes [1] '

17.19 scare_past

Before the past 12 months would you say that this has happened once, a few times or many times?
Expects a single option response (required)

☐ Once [1]

Few times 2

C] Many times[3]

1720 hurt

Threatened to hurt you or someone you care about?
Expects a single agtion response (required)

☐ No [0]

☐ Yes [1]

Branches

If response Equals 'No then skip to Vlnstruction 6 (17r24)

17.21 hurt_yr

Has this happened in the past 12 months?
Expects a single aptian response (required)

CI NC C o :

☐ Yes [1]

Branches

If response Equals 'No [o] ' then skip to hurt_past (17.23)

1722 hurt_freq

aption response

In the past 12 months, would you say that this has happened once, a few times or many times?
Expects a Eing12 option respznE2 (required)

☐ Once [1]

C] Few times 2

C] Many times[3]

Prerequisites

Skip when hurt_yr (i 7.21) Equals 'Yes[1]'

1723 hurt_past

Before the past 12 months would you say that this has happened once, a few times or many times?
Expects a single agtion response (required)

C] Once 1

C] Few times 2

Many times[3]

17.24 Vlnstruction 6

Has he or any other partner ever...

---

aption response

17.26 slap

Slapped you or thrown something at you that could hurt you?
Expects a single option response (required)

☐ No [0]

☐ Yes [1]

Branches
If response Equals 'No [o] ' then skip to push (17.29)

1726 slap_yr

Has this happened in the past 12 months?
Expects a Eing12 option response (required)

☐ No [0]

☐ Yes [1]

Branches
If response Equals 'No [O} then skip to sfap_past (1728)

1727 slap_freq

In the past 12 months, would you say that this has happened once, a few times or many times?

Expect: single option response (required)

C] Once

single aption response

If Equals 'No then skip (17.32)

single aption response

Branches
If Equals 'No then skip (17.32)

response [OY to push_past Cl Few times 2

C] Many times[3]

P re reg u isites

Skip '.qhen slap_yr (17.25) Equals 'Yes [1] '

'1728 slap_past

Before the past 12 months, would you say that this has happened once, a few times or many times?

Expects a single option response (required)

☐ Once [1]

Few times 2

Many times[3]

17.29 push

Pushed you or shoved you ?

Expects a single aption response (required)

☐ No [0]

☐ Yes [1]

Branches If esponse Equals 'No then skip t'
fist (1703)

'1730 push_yr

Has this happened in the past 12 months?

Expect:- a (required)

☐ No [0]

☐ Yes [1]

17M push_freq

In the past would you say that this has happened once, a few times or many times?

Expects a Eingle option response (required)

☐ Once [1]

C] Few times 2

C] Many times[3]

Prereq uisites

Skip push_yr (17.30) Equals 'Yes[1]'

single aption response

If Equals 'No then skip (17.32)

17.32 push_past

Before the past 12 months, would you say that this has happened once, a few times or many times?

Expects single option response (required)

☐ Once [1]

Few times 2

C] Many times[3]

17.33 fist

Hit you with his fist or with something else that could hurt you ?

Expect: single option (required)

☐ No [0]

☐ Yes [1]

Branches

If response Equals 'No [o] ᵛ then Ekip to kick (17.37)

1734 fist_yr

Has this happened in the past 12 months?

Expect: Eingle option response (required)

☐ No [0]

☐ Yes [1]

Branches

If response Equals 'No then skip t' fist_past (17.36)

17.35 fist_freq

In the past 12 months, would you say that this has happened once, a few times or many times?

Expects a single agtian response (required)

C] once 1

C] Few times 2

C] Many times[3]

Pre reg u isites

Skip fist_yr (17.34) Equals 'Yes[1]'

1736 fist_past

single aption response

2

If Equals 'No then skip (17.32)

Before the past 12 months, would you say that this has happened once, a few times or many times?

(required)

○ 1

1737 kick

Kicked you, dragged you or beaten you up?

Expects a single option response (required)

☐ No [0]

☐ Yes [1]

Branches

If responsa Equals 'No then skip ta choke (17r41,1

1738 kick_yr

Has this happened in the past 12 months?

Expects a single option response (required)

☐ No [0]

☐ Yes [1]

Branches

If esponse Equals 'No [O]' then Skip to kick_past (1740)

1739 kick_freq

In the past 12 months, would you say that this has happened once, a few times or many times?

Expect: Eingle option response (required)

C] Once 1

C] Few times 2

C] Many times [3]

P re req u isites

Skip when kick_yr (17.38) Equals 'Yes [1] '

1740 kick_past

Before the past 12 months, would you say that this has happened once, a few times or many times?

Expects Eing12 option response (required)

☐ Once [1]

single aption response

If Equals 'No then skip (17.32)

Few times 2

C] Many times[3]

1741 choke

Choked you or burnt you on purpose?
Expects a single aptian response (required)

☐ No [0]

☐ Yes [1]

Branches

If response Equals 'No [o] ˅ then skip t' threat (17r45)

17.42 choke_yr

Has this happened in the past 12 months?
Expects (required)

☐ No [0]

☐ Yes [1]

Branches

esponse [o] ˅ to choke_past '17.43 choke_freq

In the past would you say that this has happened once, a few times or many times?
Expects a single option responE2 (required)

o once 1

C] Few times 2

C] Many times[3]

Pre reg uisites

Skip choke_yr (17r42) Equals 'Yes [1]'

1744 choke_past

Before the past 12 months, would you say that this has happened once, a few times or many times?
Expects a single aption response (required)

☐ Once [1]

C] Few times 2

Many times[3]

single aption response

If Equals 'No then skip (17.32)

1746 threat

Threatened to use or actually used a gun, knife or other weapon again you?

Expects single option (required)

☐ No [0]

☐ Yes [1]

Branches

If Equals 'No then Skip to VInstruction 7 (17r49)

1746 threat_yr

Has this happened in the past 12 months?

Expect: single option response (required)

☐ No [0]

☐ Yes [1]

Branches

If response Equals 'No then skip t' threat_past (17,48)

1747 threat_freq

In the past 12 months, would you say that this has happened once, a few times or many times?

Expects single option response (required)

C] once 1

C] Few times 2

C] Many times [3]

Prereq uisites

Skip threat_yr (17r46) Equals 'Yes[1]'

1748 threat_past

Before the past 12 months, would you say that this has happened once, a few times or many times?

response (required)

C] 1

2

[3]

single aption response

If Equals 'No then skip (17.32)

1749 Vlnstruction 7

Has he or any other partner ever...

1780 force

Physically forced you to have sexual intercourse when you did not want to?
Expects a single option response (required)

☐ No [0]

☐ Yes [1]

Branches
If response Equals 'No [OI └ then skip to intercourse (17.54)

1781 force_yr

Has this happened in the past 12 months?
Expects a Eingle option response (required)

☐ No [0]

☐ Yes [1]

Branches

If Equals 'No then skip to force_past (17.53)

1782 force_freq

In the past 12 months, would you say that this has happened once, a few times or many times?
Expect: single cption response (required)

C] Once 1

C] Few times 2

C] Many times[3]

P re u isites
Skip whan force_yr (17.51y Equals 'Yes [1 Y
'1783 force_past

Before the past 12 months, would you say that this has happened once, a few times or many times?
Expects a single option responE2 (required)

o once 1

C] Few times 2

C] Many times[3]

17.84 intercourse

If Equals 'No then skip (17.58)

Did you ever have sexual intercourse you did not want because you were afraid of what he might do?

Expects single option response (required)

☐ No [0]

☐ Yes [1]

Branches

re:spanse t' degrade

'1786 intercourse_yr

Has this happened in the past

Expects a single option responE2 (required)

☐ No [0]

☐ Yes [1]

Branches

If response Equals 'No then skip to intercourse_past (17.57)

1786 intercourse_freq

In the past 12 months, would you say that this has happened once, a few times or many times?

Expects a single option response (required)

☐ Once [1]

C] Few times (.21

C] Many times[3]

Prerequisites

Skip when intercourse_yr (17455) Equals 'Yes [1] ʳ

1787 intercourse_past

Before the past 12 months, would you say that this has happened once, a few times or many times?

Expects single option response (required)

☐ Once [1]

C] Few times2

C] Many times[3]

1768 degrade

Did he ever force you to do something sexual that you found degrading or humiliating?

Expect: single option response (required)

☐ No [0]

☐ Yes [1]

Branches

If response Equals 'No then skip t' endofviolenceagainst women (17r62)

17.59 degrade_yr

Has this happened in the past 12 months?
Expects single option response (required)

☐ No [0]

C] Yee:

Branches

If response Equals 'No then skip to degrade_past (17.51)

1780 degrade_freq

In the past 12 months, would you say that this has happened once, a few times or many times?
Expects a single agtion response (required)

C] 1

C] 2

C] [3]

P re u isites

Skip when degrade_yr (17.59) Equals 'Yes[1]'

'17.61 degrade_past

Before the past 12 months, would you say that this has happened once, a few times or many times?
Expects a single option responE2 (required)

o once 1

C] Few times 2

C] Many times[3]

17.62 endofviolenceagainst women

[End of violence section]

Section 18. end

Prerequisites

Skip when SUITHINK (72) Not Equal Yes[11]

18.1 suicideref

[Prepare the form for suicidality referral. You will complete the form with the participant AFTER this Interview, as part of the incentives. If the participant accepts the referral, you will walk the patient to the consulting nurse with the referral. Suicidal ideation response = Label (SUITHINK (7.2) , QC SUITHINK (7.2) , o)) Suicidal planning response = Label(SUIPLAN (7-3) , QC SUIPLAN (7-3) , o)) Suicidal action response= Label(SUIATT (7-4) , SUIATT (7-4) ,o))]

18.2 comments

Any comments on participants or interview?

Expects single line text response (optional)

183 endofquestionnaire

[End of questionnaire. Thank you.]

Appendix 16 Referral form

COBALT/PRIME

	Clinic:
	Date:
Patient name:	ID Number:
Gender:	Contact number:

INSTRUCTION: This data sheet is to be completed for each patient with a mental health diagnosis

1a. **Patient status**

1 New patient

2 Returning patient - reassessment

1b. **Impressions of severity for depression- current**

1 Stable - asymptomatic

2 Mild depression

3 Moderate – severe depression Other:

INDENTIFICATION

2a*. **Mental health diagnosis.** Circle the disorders that in your clinical judgment, the patient is suffering from, or circle the disorder for which the patient is currently under treatment.

1 Depression

2 Alcohol Use Disorder

3 Psychosis (including schizophrenia, manic depression/bipolar)

4 Epilepsy

5 Other:

TREATMENT

3a*. **Interventions administered by clinician.** Tick all that apply.

Psychoeducation

Medication: specify

None

Other

2b. **Referred for other services.** Tick all that apply or "none."

1 Lay counsellor

2 Psychologist

3 Doctor

4 Hospital

5 Other

6 None

Professional Nurse/ Doctor name:_____

Appendix 17

Phase 3 Process evaluation interview guide- Service users

We would like to know your experience in being identified, referred and treated for symptoms of depression.

1. Do you know what depression is?

   Probe for whether they knew it what it was before they were referred to the counsellors

2. How did you feel when you were informed you have depression?
3. When you were referred to the counsellors, did the nurse explain to you that you had symptoms of depression when she referred you? Did s/he explain who they were referring you to and why?

   Probe for what the nurse said and did.

4. Did you follow-up on the referral?
   - **If no**, ask for reasons why the patient did not follow-up the referral to the counsellor. Probe for what would help them to follow-up on a referral to the counsellors the next time. **TERMINATE THE INTERVIEW (THOSE WHO DIDN'T REACH THE COUNSELLOR BUT WERE REFERRED).**
   - If yes, ask for reasons why they followed up on the interview and proceed with the following questions below.
5. What did the counsellor do when you saw him/her?

   Probe for:

   - *Whether they asked them whether they would be able to attend group counselling or would prefer individual counselling.*

- *Whether they booked them for another appointment or said they would contact them.*
-
- *Whether they made them feel comfortable enough to want to come back for a counselling session.*

6. Did you return for another counselling appointment?
    - **If no,** ask for reasons why the patient did not follow-up the counselling appointment. Probe for what would help them to follow-up on a counselling appointment the next time. **TERMINATE THE INTERVIEW (THOSE WHOSE REFERRAL DETAILS ARE TAKEN BUT DON'T PRESENT FOR COUNSELLING)**
    - If yes, ask for reasons why they followed up on the appointment and proceed with the following questions below.
7. Did you have individual or group-based counselling?

    Probe for:

    - *Why they chose individual/group counselling*
    - *For service users who started with individual counselling and later changed to group or vice versa, probe for what made them change to the group/ individual counselling.*

8. How did you experience the intervention?

    Prompting questions:

    a) Did participation in the counselling programme change the way you think and feel about yourself, and the way you act?
        - *If yes, probe for how.*

- *Ask participants to describe the way the programme has changed the way they think, feel and behave after participating in the programme compared with before the programme.*

b) Did participation in the counselling programme change the way you think, feel about others and the way you relate to others?

- *If yes, probe for how.*
- *Ask participants to describe the way they think and feel about other people and their relationships now after participating in the programme compared with how they felt about other people/their relationships before the intervention.*

c) Did counselling help you deal better with situations that were troubling you?

- *If yes, probe for how.*
- *If no, probe for why.*

d) Which session(s) did you find most useful?

- *Probe for in what ways they were useful.*
- *Ask for examples.*

e) Which parts of the programme were not useful to you?

- *Probe for why these aspects were not useful.*

f) Did the counselling help with:

- *Personal problems? Probe for how.*
- *Other ways e.g., income generation, interpersonal relationships etc? Probe for other ways that it was helpful.*

g) What aspects of the programme would you say did not work well?

- *Probe for what they think made these not work well.*

- *If these were to be changed, how would you change these?*

h) Were you comfortable with the way counselling intervention/ group counselling was carried out?

i) Are there aspects that you feel could be improved?

- *If yes, probe what aspects?*
- *How could these be improved?*

j) If in group counselling, were you comfortable sharing your opinions, feelings, and thoughts in the group?

- *Probe for whether the group meetings were organised and carried in an appropriate manner.*
- *Probe for whether they got all the attention they needed in the group.*

k) Were you comfortable speaking to the counsellors?

l) From your experience of the counselling, do you think the counsellors were adequately trained for their job?

- *Probe for any difficulties with the facilitators.*

m) How would you rate how you feel now, compared to how you felt before participation in the group?

Probe for:

- *Feeling worse.*
- *Unsure/ don't know.*
- *Feeling the same.*
- *Feeling a lot better.*

n) How have individual counselling/ group sessions changed your life?

o) Would you recommend this programme to another person? Why?

p) If you could change any aspect of the programme, which aspects would you change?

ADDITIONAL QUESTIONS FOR THOSE WHO DROPPED OUT OF INTERVENTION

1. What were your reasons for dropping out / not coming back?

   Probe for:

   - *Comfort / discomfort in the individual counselling/group they were in*
   - *Whether they were getting sufficient attention from the group and facilitators.*
   - *Other reasons.*

Whether leaving the programme was by choice or due to contextual factors beyond their c

Appendix 18

Process Evaluation interview guide -Service providers

We would like to know about your experiences in identifying and referring perinatal patients with symptoms of depression.

1. **What was your experience of diagnosing depression in perinatal patients after being trained in the PC 101 mental health modules**?

   Prompting questions:

- Do you feel that you are now able to recognise when a patient is clinically depressed, compared with simply "having a hard time"?
- How useful did you find the depression algorithm on page 81 in helping you to decide whether or not someone depressed?
    - *Probe for whether they used this algorithm or not. If they did, probe for whether they worked through it while they were with the patient..*
- What signs and symptoms alert you to the fact that a patient might be depressed?
    - *Probe for particular symptoms, other problems like non-adherence to medication for other conditions, patients who appear down.*
- What things make it difficult for you to diagnose depression as per the PC 101+ guideline?

  Probe for:
    - *Issues of time or privacy. If yes to either time or privacy, prompt for how this impacts on their ability to provide routine perinatal care.*
    - *Other demands or clinical issues to attend to that seem more pressing than depression.*
    - *Whether they feel confident to diagnose and refer depression.*

- *Attitudes towards depression as a 'real' clinical problem that can be addressed with counselling interventions.*
- *Whether there are issues referring patients to the counsellors or primary health care doctor.*

- What could the training and guidelines better help you to recognise and diagnose depression?

2. What was your experience of referring patients with depression to the counsellors?

- If they seem to be positive about referring patients to counsellors, prompt for how they experienced the referral process.

  Probe for:

  - *Whether it was easy to arrange.*
  - *Whether they got any feedback from the counsellors.*
  - *Whether they got any feedback from the patients themselves.*

- If they seem reluctant to refer patients to counsellors, prompt for why this is the case.

  Probe for:

  - *Uncertainty about what the counsellors do.*
  - *Lack of confidence in counsellors or counselling services.*
  - *Whether they would prefer to help the patient themselves.*
  - *Issues about counsellor availability to accept referrals.*
  - *Reluctance on part of patients to see the counsellors.*
  - *Requires too much extra effort in limited space of time.*

3. What was your experience of referring patients to the primary health care doctor for their depression?

- If they seem positive about referring to the doctor, probe for how this process went.

  Probe for:

  - *How soon patients were seen by the doctor.*
  - *Whether they got any feedback from the doctor and whether they saw patients again after they had been seen by the doctor.*
  - *Whether the doctor prescribed antidepressants and, if not, whether they know why not.*

- If they seem reluctant to refer to the doctor, probe for why this is the case.

  Probe for:

  - *Doctor is too busy? Wasn't sure whether the referral was really necessary? Patient was not keen to have to see the doctor?*

4. **How did your patients respond to being told that you thought that they might be depressed?**

   Probe for:

   - *Relief at having an explanation for symptoms; confusion or lack of understanding about what depression is.*
   - *How patients reacted to being advised to see the counsellor for this problem.*
   - *How patients reacted to being advised to see the doctor for this problem.*

5. **Care for depression is a team effort, requiring you as nurses to recognise and diagnose it, the counsellors to offer the counselling, and the doctor to prescribe medication if necessary. How did you experience working as part of a team like this?**

- How did you experience your own role within the team?

- Do you think the counsellors are a useful addition to the team, or would you prefer to be trained to provide the counselling yourself?
- Do you think the training prepared you well enough for this role as the 'gate-way" to care? What could be done to better prepare you for this?

6. How has a typical workday changed since the intervention for depression in perinatal patients?

Probe for:

- *Whether this has affected the way they work*
- *Whether this has affected their attitudes to their work and patients*

Probe for whether they have adopted a different approach to patient care in line with holistic person centred care and patient self- management

- *How they feel about having to deal with the whole patient including their emotional difficulties*

Probe for how they cope with dealing with the emotional issues of their patients during the consultation as well as after. Whether this has led to increased levels of stress

2. What demands do the patients place on you?

Probe for:

- *What patients expect from you*
- *Why they have these expectations*
- *How they think that the clinic is meeting the needs of the community*
- *Possible interventions to help change patient expectations towards patients taking more responsibility for their health*

3. What is the purpose of the clinic?

   Probe for:

   - *Probe for how they see their role as a nurse in fulfilling the objectives of the clinic for care including perinatal mental health*

4. What values guide the management of the clinics?

   Probe for:

   - *What is the decision making process in the clinic*
   - *How do their managers relate to them*
   - *Do they feel supported by their managers to work within a patient centred approach*

If not – how do they feel management could change to make it easier to work within this approach

5. If you/the nursing staff are unhappy, what is the procedure for voicing this?

   Probe for:

   - *Are nurses comfortable reporting if they are unhappy*
   - *In what ways do the nursing staff feel empowered to voice their needs in order to be able to do their job better*

6. Do you have any ideas on how the system can be improved to support the implementation of the intervention for depression for perinatal patients?

Appendix 19

Phase 3 Process evaluation interview guide - Counsellors

We would like to know about your experiences in the counselling intervention to counsel perinatal patients with depression.

After your training in the intervention for depression, did you feel confident to counsel perinatal care patients with symptoms of depression?

Probe for how the counsellor experienced the training.

How is the referral system from the nurses to you as a counsellor working?

Probe for:

- *What is working and what is not working well and the reasons for this.*
- *Reasons why patients with depression referred to the counsellors do not follow up on these referrals.*
- *Any suggestions to improve the referral process.*

How have you experienced implementing the counselling guidelines in a group? *Probe for:*

- *What is working and what is not working well and the reasons for this.*
- *Any suggestions to improve the guidelines.*

How have you experienced implementing the counselling guidelines for an individual counselling session?

Probe for:

- *What is working and what is not working well and the reasons for this.*
- *Any suggestions to improve the guidelines.*

Have you used the resource materials?

Probe for:

- *What is useful/not useful.*
- *How the resource materials could be improved.*

What was your experience of on-site supervision?

Probe for:

- *What is useful/not useful.*
- *How the resource materials could be improved.*

Do you think patients who have received counselling from you have benefitted?

- *If yes, probe for any evidence that supports this.*
- *If not, probe for why they think they have not benefitted.*

What challenges have you encountered when providing counselling?

If you could change any aspect of the programme (including the training and the counselling service provision), which aspects would you change?

Appendix 20

Phase 3 Information and consent -Service providers

To participate in a study to evaluate an intervention for perinatal mental health care

You will be given a copy of this information sheet

Dear Service Provider

You are being invited to participate in a study to evaluate service delivery for mental health care for perinatal patients using PHC services. Before agreeing to take part in this research study, please read the information below so that you understand what the study will involve. Please read this carefully and feel free to ask me if there is anything that is not clear or if you have any questions about your participation. You should only participate if you want to; choosing not to take part will not disadvantage you in any way.

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation 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.

What are we trying to learn from this study? We are requesting you to participate in a study to an intervention for the implementation of mental health services for perinatal populations using primary health care (PHC) services in South Africa

Who will be involved in the study and how long will it last? We are recruiting service providers and key stakeholders involved in the development and implementation of care for perinatal health services, mental health services and integrated care. The interviews will run over a period of two months.

What will happen if you agree to take part? If you agree to participate in this study, you will be asked to answer a number of questions about an intervention to integrate perinatal mental health care services and implications of provision of mental health care for perinatal populations at PHC level. The interviews will take up to one hour. If you agree, your interview will be audio recorded. After the interview, the audio recordings will be transcribed and analysed, after which the recordings from your interview will be deleted.

Are there any risks or disadvantages associated with taking part in the study? For this study, you will be asked to give one hour of your time, during which you will be interviewed. There are no known disadvantages or risks to you from participating in this study.

Are there any benefits of taking part in the study? There are no direct benefits to you by taking part in the study. You will not be remunerated for your time. However, this study will help us identify the system level implications of integrating mental health care for perinatal populations. This will improve our understanding of the benefits of integrated care as well as systems strengthening interventions needed to enable integration of mental health care for perinatal patients.

What will we do with your information?If you consent to your interview being audio-recorded, we will make sure that the audio recordings do not include your name or any information from which you can be identified. If notes are taken instead of audio-recordings, these notes will also not include your name or information from which you can be identified. The audio-recordings and notes will be stored on password protected computers. Once the interview audio-recordings have been transcribed and the data has been analysed, the recordings will be deleted.

We will take every reasonable step to keep your information and identity confidential.

What will we do with the results of the study? We plan to use the information to evaluate the intervention to integrate mental health care for perinatal populations

Do I have to take part in the study?It is up to you to decide whether to take part or not. If you decide not to participate, this will in no way prejudice you. If you decide to take part but later change your mind, you are still free to withdraw from the study at any time and without giving a reason and without prejudice. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (approval number BFC 587/16). In the event of any problems or concerns/questions you may contact:

For questions related to the study	For Your rights as a research participant
Tasneem Kathree Department of Psychology Howard College Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 260 1700 Email: Kathree@ukzn.ac.za	**BIOMEDICAL RESEARCH ETHICS COMMITTEE** Research Office, Westville Campus Govan Mbeki Building Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 2604769 - Fax: 27 31 2604609 Email: BREC@ukzn.ac.za

Consent Form for Service Providers

Please complete this form after you have been through the information sheet and understand what your participation in this study entails.

Thank you for considering taking part in this study. If you have any questions arising from the information sheet, please ask before you decide whether to take part. You will be given a copy of the information sheet and consent form.

I, (write your name here),_____have been informed about the study to research service delivery and pathways to care for perinatal mental health care.I understand the purpose and procedures of the study. I have been given an opportunity to ask questions about the study and have had answers to my satisfaction. I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting my position at the facility I work at. I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures. In the event of any problems or concerns/questions you may contact:

For questions related to the study	For Your rights as a research participant
Tasneem Kathree Department of Psychology Howard College Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA	**BIOMEDICAL RESEARCH ETHICS COMMITTEE** Research Office, Westville Campus Govan Mbeki Building Private Bag X 54001 Durban 4000

Tel: 27 31 260 1700 Email: Kathree@ukzn.ac.za	KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 2604769 - Fax: 27 31 2604609 Email: BREC@ukzn.ac.za

	Please tick or initial
I understand that if I decide at any time during the study that I no longer want to take part, I can notify the researchers and withdraw without having to give a reason.	☐
I consent to the processing of my personal information for the purposes explained to me.	☐
I agree to my interview being audio recorded.	☐

_____ _____

Signature of Participant **Date**