COMMUNITY PERCEPTIONS OF THE HYPERTENSIVE DISORDERS OF PREGNANCY

by

Marianne Vidler

BA(Hons)., Queen's University, 2007
MPH., Simon Fraser University, 2011

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

in

THE FACULTY OF GRADUATE AND POSTDOCTORAL STUDIES

(Reproductive and Developmental Science)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

April 2017

Abstract

Background

Two to four percent of pregnancies are affected by pre-eclampsia, the most serious of the hypertensive disorders of pregnancy. This results in a significant health burden, which disproportionately affects those in low- and middle-income countries. Research has largely focused at the facility level; however, such an approach does not address underlying beliefs and cultural practices. The aim of this dissertation is to explore community perceptions of the hypertensive disorders of pregnancy, with a focus on Nigeria, Mozambique, Pakistan and India.

Methods

An ethnographic research design was used to gain insight into the perceptions and, community characteristics that relate to understanding the hypertensive disorders of pregnancy. A systematic literature review and meta-synthesis was followed by in-depth qualitative studies in Nigeria, Mozambique, Pakistan and India. A qualitative evidence synthesis to ascertain women's comprehension of the hypertensive disorders of pregnancy was conducted using thematic synthesis of: (i) the published findings, and (ii) transcript data. All analyses were conducted following thematic analysis. CERQual ('Confidence in the Evidence from Review of Qualitative research') was used to present the confidence of findings.

Results

Findings of this dissertation indicate gaps in knowledge regarding the hypertensive disorders of pregnancy in all regions. The literature review suggests that insufficient evidence-based information was provided by health workers to women about the hypertensive disorders of pregnancy. The knowledge of aetiology and treatment of pre-eclampsia and eclampsia were

limited in Nigeria. In Mozambique and Nigeria, local beliefs associated with the supernatural, were implicated in the development and treatment of the hypertensive disorders. Overall there were mixed opinions regarding the causes of hypertension in pregnancy, and a poor understanding of the connection between these conditions and pregnancy in all regions. Qualitative syntheses revealed cultural similarities and distinct differences in the understandings of these conditions. A comparison of methods highlights the benefits of syntheses from original data, however, challenges in access and labour-intensity should be considered.

Conclusions

There is a need for efforts targeted at the community to improve knowledge of the hypertensive disorders of pregnancy. Culturally-specific findings should be used as a foundation for targeted education, information, communication initiatives.

Preface

Marianne contributed significantly to all elements of research presented in this dissertation. Marianne was intimately involved in the study design, development of data collection guides and processes including sample size and recruitment strategies. Marianne was solely responsible for the design of research conducted as part of the qualitative evidence syntheses. In collaboration with international partners, Marianne designed the analysis frameworks and protocols for the following thesis. Marianne served as the primary analyst for the Community Level Interventions for Pre-eclampsia (CLIP) feasibility studies in India and Nigeria; in addition, she contributed significantly to the analysis of these studies in Pakistan and Mozambique. Finally, Marianne was the primary analyst for all three qualitative evidence syntheses presented.

The work presented in the thesis has led to the following publications

1. Khowaja AR, Qureshi RN, Sawchuck D, Oladapo OT, Adetoro OO, Orenuga EA, Bellad M, Mallapur A, Charantimath U, Sevene E, Munguambe K, Boene HE, **Vidler M**, Bhutta ZA, von Dadelszen P. The feasibility of community level interventions for pre-eclampsia in South Asia and Sub-Saharan Africa: A mixed-methods design. Reproductive Health. 2016 Jun 8;13(1):1.

   This work outlines the methodological basis for the original studies to follow, and is associated with Chapter 3.

   As an author, MV provided critical manuscript input and revision. In addition, MV was involved in the conception of the manuscript and served as the central co-ordinator for the study. KM served as a principal investigator of the CLIP feasibility study and was involved in the conception and design of the manuscript. PvD served as the principal

investigator of the CLIP Trial, was involved in the conception and design of the feasibility study, and critically reviewed the manuscript providing key intellectual input.

2. Akeju DO, **Vidler M**, Oladapo OT, Sawchuck D, Qureshi R, von Dadelszen P, Adetoro OO, Dada OA. Community perceptions of pre-eclampsia and eclampsia in Ogun State, Nigeria: a qualitative study. Reproductive Health. 2016 Jun 8;13(1):17.

   This work is associated with Chapter 4.

   All analysis and writing for this manuscript was done in collaboration with the in-country team. As the second author of this manuscript, MV provided substantial input to study design, data collection, and manuscript writing. In addition, MV was responsible for all data analysis, this included development of appropriate thematic categories and coding. All analytic decisions were reviewed during two face-to-face meetings in Lagos and Ogun State, Nigeria. MV also served as the co-ordinator of the study. PvD contributed to the conception and design of the study.

3. Boene H, **Vidler M**, Sacoor C, Nhama A, Nhacolo A, Bique C, Alonso P, Sawchuck D, Qureshi R, Macete E, Menéndez C. Community perceptions of pre-eclampsia and eclampsia in southern Mozambique. Reproductive Health. 2016 Jun 8;13(1):27.

   This work is associated with Chapter 5.

   All analysis and writing was done in collaboration with the in-country team. As second author of this manuscript, MV provided critical manuscript input and revision. In addition, MV provided oversight of the qualitative analysis, including collaboration in the development of appropriate thematic categories and coding of select transcripts. Analytic decisions were made during a two-week face-to-face meeting in Manhica, Mozambique. MV also served as the co-ordinator of the study. KM adapted the study design to the local

context, supervised HB, supported analysis, interpretation and review of the manuscript. PvD contributed to the conception and design of the study as well as intellectual input to manuscript development regarding the and content area.

4. Khowaja AR, Qureshi RN, Sheikh S, Zaidi S, Salam R, Sawchuck D, **Vidler M**, von Dadelszen P, Bhutta Z. Community's perceptions of pre-eclampsia and eclampsia in Sindh Pakistan: a qualitative study. Reproductive Health. 2016 Jun 8;13(1):39.

   This work is associated with Chapter 6.

   As an author of this manuscript, MV provided critical manuscript input and revision. In addition, MV was involved in the conception of the manuscript and served as the co-ordinator for the study. PvD served as the principal investigator of the CLIP Trial, and was involved in the conception, design of the feasibility study, and critically reviewed the manuscript for intellectual input.

5. **Vidler M**, Charantimath U, Katageri G, Ramadurg U, Karadiguddi C, Sawchuck D, Qureshi R, Dharamsi S, Dadelszen P, Derman R, Goudar S. Community perceptions of pre-eclampsia in rural Karnataka State, India: a qualitative study. Reproductive Health. 2016 Jun 8;13(1):45.

   This work is associated with Chapter 7.

   All analysis and writing was led by MV in collaboration with the in-country team. As the first author of this manuscript, MV developed the manuscript for review and was responsible for all data analysis. Analysis included development of appropriate thematic categories, coding of all transcripts after translation and transcription, all analytic decisions were reviewed at a one-week face-to-face meeting in Karnataka State. MV also served as the co-ordinator of the study. PvD served as the principal investigator of the

CLIP Trial, and was involved in the conception, design of the feasibility study, and critically reviewed the manuscript for intellectual input.

The work presented in the thesis has led to the following manuscripts pending submission for publication:

1. Women's knowledge of the hypertensive disorders of pregnancy: a qualitative evidence synthesis

   This work is associated with Chapter 2.

2. Women's perceptions of the hypertensive disorders of pregnancy in Nigeria, Mozambique, Pakistan and India: A comparison of methods

   This work is associated with Chapter 8.

Ethics

Ethics approval for this study was obtained from Clinical Research Ethics Board of the University of British Columbia, Vancouver, Canada (H12-00132) as the co-ordinating centre and all four research sites: the Health Research and Ethics Committee of Olabisi Onabanjo University Teaching Hospital, Sagamu, Nigeria (OOUTH/DA/326/431), the CISM Institutional Review Board in Manhica, Mozambique (CIBS_CISM/08/2013), the Ethics Review Committee of Aga Khan University in Karachi, Pakistan (1917-OBS-ERC-11), and KLE University, Belgaum, India (MDC/IECHSR/2011-12). Written informed consent was obtained from each participant. All identifiable information was obscured through attribution of identification numbers to ensure confidentiality.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

ANC, antenatal care;

ANM, auxiliary nurse midwives;

AP, administrative post;

APE, agente polivalente elementar, CASP, Critical Appraisal Skills Programme;

ASHA, accredited social health activist; CEmOC, comprehensive emergency obstetric care;

CERQual, Confidence in the Evidence from Reviews of Qualitative research;

CHEW, community health extension workers;

CISM, Manhiça Health Research Centre;

CLIP, Community Level Interventions for Pre-eclampsia;

CRRH, Centre for Research in Reproductive Health;

ENTREQ, ENnhancing Transparency in Reporting the synthesis of Qualitative research;

FGD, focus group discussion;

HDP, hypertensive disorders of pregnancy;

IDI, in-depth interview;

IEC, information, education, communication;

IUGR, intrauterine growth restriction;

LGA, Local Government Areas;

LHW, lady health workers;

LMIC, low-and-middle-income countries;

MDG, millennium development goals;

MeSH, Medical Subject Headings;

MMR, maternal mortality ratio;

NPT, normalization process theory;

NRHM, National Rural Health Mission;

PHC, primary health centre;

PRE-EMPT, Pre-eclampsia/Eclampsia, Monitoring, Prevention and Treatment;

PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses;

QES, qualitative evidence synthesis;

SPA, service provision assessment;

SPIDER, sample, phenomenon of interest, design, evaluation, research type;

TBA, traditional birth attendants;

UBC, University of British Columbia

UNICEF, United Nations Children's Emergency Fund;

WHO, World Health Organization;

WRA, women of reproductive age;

Acknowledgments

I would like to thank my teachers, examiners and supervisors for their never-ending support, encouragement and guidance: Peter von Dadelszen, Khatia Munguambe, Shafik Dharamsi, Laura Magee, Rahat Qureshi, Simon Lewin, Dan Rurak, Patricia Spittal, Saraswati Vedam, Sam Sheps, and Tina Lavender. I would like to acknowledge everyone who has been involved with the CLIP studies. A special thanks to my colleagues and friends at the University of British Columbia and all four CLIP sites: Olalekan O. Adetoro, Olukayode A. Dada, Olufemi T. Oladapo, Charfudin Sacoor, Esperança Sevene, Zulfiqar Bhutta, Shivaprasad Goudar, Ashalata Mallapur, Mrutyunjaya Bellad, Asif Raza Khowaja, Sana Sheikh, Diane Sawchuck, Helena Boene, David O. Akeju, Umesh Charantimath, Geetanjali Katageri, Umesh Ramadurg, Chandrashekhar Karadiguddi, Richard Derman, Sharla Drebit, Beth Payne, Sumedha Sharma, Tang Lee, Larry Li, Mansun Lui, Domena Tu, Chirag Kariya, Michelle La, Tatenda Makanga, Tabassum Firoz, Kelvin Au, Roshni Nair, Jacqueline Ravel, and Dane De Silva.

Most importantly I would like to acknowledge the many communities who participated in the CLIP feasibility studies, the women and communities who shared their stories and welcomed me into their homes and health centres. None of this would be possible without the dedication of the local health workers and community advocates. I am forever grateful for the incredible opportunity you have allowed me by taking a glimpse into your communities.

Funding acknowledgment

This work is part of the University of British Columbia PRE-EMPT (Pre-eclampsia/Eclampsia, Monitoring, Prevention and Treatment) initiative supported by the Bill & Melinda Gates Foundation.

Chapter 1. Introduction

The problem

The hypertensive disorders of pregnancy

Pre-eclampsia is a complex condition affecting a subset of women in pregnancy. It is one of several hypertensive disorders of pregnancy (HDPs): chronic hypertension, gestational hypertension, and pre-eclampsia. The World Health Organization (WHO) defines pre-eclampsia as the new onset of hypertension (≥ 90mmg diastolic) with significant proteinuria (≥ 0.3g in a 24hr urine collection) (1). The HDPs are a common phenomenon, affecting up to 10% of pregnancies, of which 2-4% are related to pre-eclampsia (1, 2). They remain the second leading cause of maternal mortality globally, after postpartum haemorrhage, although the overall contribution of pre-eclampsia may be increasing (3). There has been little change in the burden of pre-eclampsia in recent years, attributed in part to a lack of focussed global research (4, 5).

The global burden

Pre-eclampsia is responsible for a significant burden to women, families, communities and health systems at large (3). The burden of disease is greatest in low- and middle-income countries (LMICs) where 99% of all maternal deaths occur (2). Fifty percent of all maternal deaths annually are attributed to only six countries; including three of this project's target countries India, Nigeria, and Pakistan (6). Nigeria and India have the highest burden of HDP-related mortality, together accounting for a third of all maternal deaths (7). Nigeria alone is responsible for 19% of global maternal mortality (7). Maternal mortality ratios (MMR) are notoriously inaccurate; however, a 2014 WHO report states an annual MMR of 560 in Nigeria,

480 in Mozambique, 170 in Pakistan, and 190 in India, all per 100,000 live births (8). In addition, accurate rates are not known for the HDPs or pre-eclampsia specifically in most LMIC.

Health outcomes related to the hypertensive disorders of pregnancy

Pre-eclampsia, which includes the complication of eclampsia, is responsible for 10-15% of all direct maternal deaths in LMIC; that equates to roughly 50-75,000 deaths annually. In addition to maternal outcomes, pre-eclampsia impacts the health of the fetus and newborn. Pre-eclampsia is responsible for 25% of all stillbirths and neonatal deaths in LMIC (2), and a vast number of perinatal morbidities. Most commonly, these morbidities include intrauterine growth restriction (IUGR) and prematurity, both known to have significant long-term health effects (2). It has become clear that pre-eclampsia is associated with an increased risk of cardiovascular complications and other health problems later in life (9).

The burden of pre-eclampsia goes far beyond women and their families. Cases of pre-eclampsia place strain on vulnerable health systems due to the need for high quality advanced health care services in pregnancy, yet health systems are often limited in LMIC. Pre-eclampsia-related morbidities and mortalities can also result in losses of productivity for families and local economies, as it is a condition affecting the otherwise young and healthy.

The purpose

The overarching aim of the following chapters is to explore women's perceptions of the HDPs and to identify how this knowledge and related beliefs vary between cultures in low- and middle-income countries.

The significance and research gaps

Research around the HDPs has been largely focused at the facility level. Although important, a focus at the facility-level does not address the underlying beliefs and cultural practices in which the facility is located (10). In addition, facility-based research does not represent the hard-to-reach vulnerable populations who less frequently interact with the health care system. With the high number of home deliveries in LMIC, it is imperative that community interventions be used in an effort to improve maternal and perinatal health outcomes. Despite their insufficient number, strategies at the home or neighbourhood level, have gained popularity since the proliferation of the Safe Motherhood programs in the late 1980s (11). Various community-based interventions have shown improvements in maternal and neonatal health indicators (12-16).

The socio-cultural factors influencing maternal health deserve more attention (17). Little research has been undertaken regarding community perspectives of pregnancy and its complications. This is particularly true for the condition of pre-eclampsia. The existing projects have been small and confined to targeted geographic and cultural areas. The importance of this type of research includes the ability to provide policy makers with key information to determine which strategies would be most effective in improving maternal health in their communities (18). Local beliefs and practices, including health care-seeking behaviours and decision-making dynamics, have an important role in maternal and neonatal outcomes. Existing studies reveal the limited knowledge that exists among community members and health care providers related to pregnancy complications (19). In addition, it is imperative that community research regarding maternal health include men, due to their influence on whether women access health care

services, yet it often fails to do so (4, 20). Given the socio-dynamic diversity of these countries, it is necessary to consider the influence of culture when targeting health outcomes for these women. A multitude of research has long acknowledged the interplay between social and cultural context and perceptions of health and illness (21, 22). Furthermore, perceptions of health can impact health-seeking behaviour and outcomes, and are frequently culturally-bound (23). Evidence suggests that women have limited knowledge of pregnancy complications and the knowledge they have is at times incorrect and potentially dangerous (24-27).

Although community-based research must include local understandings and practices, it is equally important to assess the health system. In order to choose effective strategies for improving maternal and neonatal health, there must be a good understanding of the existing health system infrastructure and the challenges it faces. This includes an assessment of health care providers, particularly those providing services at the community-level. Many maternal and child health programs have increased recruitment of community health workers to deliver basic maternal care services at the community-level (ie at home or at primary health centres). Nevertheless, this area remains in its infancy and there has been little research to uncover the feasibility of such initiatives.

Research questions

This dissertation is made up of three interrelated research questions, aimed at framing a holistic view of the HDPs.

1. What is known regarding women's knowledge of the hypertensive disorders of pregnancy?

A systematic literature review of relevant publications and qualitative evidence synthesis were conducted to determine the knowledge that pregnant and postpartum women hold regarding the HDPs.

2. What is women's knowledge of the hypertensive disorders of pregnancy according to the Community Level Interventions for Pre-eclampsia (CLIP) feasibility studies in Nigeria, Mozambique, Pakistan and India?

This research question was addressed through multiple methods. Mixed-methods studies were conducted in the four target countries between 2012 and 2014 with the aim exploring facilitators and barriers to the upcoming implementation of a cluster randomized control trial to improve maternal and perinatal health. In addition, these studies explored community beliefs and practices surrounding pregnancy. Following these studies, a qualitative evidence synthesis of the raw transcript data from the four CLIP feasibility sites was completed. Finally, a qualitative evidence synthesis was undertaken of the publications that reported on qualitative studies in the four CLIP countries (Nigeria, Mozambique, Pakistan and India).

3. Is there added benefit of a qualitative evidence synthesis from either primary data or published findings?

Are there similarities or differences in findings when syntheses are grounded in primary data versus published findings?

A cross-comparison of methods and findings was completed to ascertain the similarities, differences, added benefit and drawbacks of a qualitative synthesis utilizing primary data, compared with published summarized findings.

Methods

Qualitative research provides 'thick description' – social context, intentions, and meaning – rather than simply 'the facts' (28, 29). Both methodologies have merit, but if the research question entails getting to the heart of the experience through the point of view of participants, the appropriate technique is qualitative or mixed-methods in design. The added value of qualitative research within quantitative studies are numerous and can be to identify problems at an early stage of study, to provide an explanation of findings, to increase utility of findings, to engage participants, communities and essential stakeholders, and to generate new knowledge (30).

Qualitative evidence syntheses and reporting

The synthesis of qualitative findings has emerged as an important and increasingly popular area of inquiry. There are various approaches, rooted in a similar core set of techniques and methods, but using many terms, resulting in confusion and lack of cohesion across studies (31). The guideline for the reporting of qualitative syntheses – enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) – will be followed within the qualitative evidence syntheses (QES) presented in this dissertation (31) (Table 1, pg 10). Syntheses utilized thematic analysis, wherein results remained close to the primary studies, yet also elucidated new interpretations of the findings (32). Multiple coders were involved to reduce the risk of bias and improve trustworthiness of findings.

The appraisal of QES findings includes the evaluation of the primary studies, as well as the patterns displayed in the findings. Quotes have been used to ensure the results reflect the primary data. Reciprocal translation (where similar findings were applied to additional studies)

and refutational translation (where contrasting findings were applied to additional studies) were performed throughout analysis. An audit trail was maintained during data review and synthesis.

Confidence in the synthesis findings was determined using the CERQual (Confidence in the Evidence from Reviews of Qualitative research) tool. CERQual examines four elements of each study: methodological limitations, relevance, coherence, and adequacy of the data. After the assessment of each construct, the confidence is determined to be high, moderate, low, or very low. CERQual has been used for similar topics in global maternal health, and due to its close connections with the Cochrane and the World Health Organization it is likely to influence future recommendations and global policies in maternal and newborn health (18, 33).

Theoretic framework

A clear identification and description of theoretical underpinnings is essential in qualitative research. A number of theories have guided the conduct and interpretation of this research.

Ethnography.

The research described in this dissertation utilized ethnography in its design, conduct and analysis. Ethnography has its origins in the field of anthropology, yet has become increasingly popular in health research (34). As described by Reeves, Kuper and Rodges (pg 512), the central aim of this methodology is to "provide rich, holistic insights into people's views and actions, […] through the collection of detailed observations and interviews" (35). This was an appropriate methodological choice due to the emphasis on exploration rather than hypothesis testing. An ethnographic approach focuses on observing and experiencing a group or phenomenon within a particular cultural group. This approach has often been at odds with other global health research that has focussed on action towards their health goal rather than

understanding (36). The use of ethnography includes an acknowledgment of the importance of culture as a key determinant of health that varies by region and population. Ethnographic research utilizes a variety of qualitative methods, including interviews, observations and focus groups. A key element of all ethnographic work is reflexivity, identifying and acknowledging the role and potential influence/bias of the researcher as an active participant in the research (35). The choice of ethnography reflects the researcher's personal beliefs and serves as the guide for "understanding, analysing, and designing ways to investigate a problem" (37).

Reflexivity.

Reflexivity is a crucial element of all well-conducted qualitative research, this is particularly important when the work is cross-cultural. The lines between insider and outsider can become blurred, therefore identifying one's position in the research is essential. There are inherent power relations built into my role as researcher that must be acknowledged, these include ethnicity (Caucasian Canadian), gender (woman), age (31 years), native-tongue (English), and education (academic expertise and training in western biomedicine). These characteristics bring with them a particular perspective and lens that need be acknowledged. This research included extensive engagement with local research teams with academic and community-based expertise. From research design to the interpretation of findings, a continuous personal practice of reflexivity, and member-checking of findings were instituted to ensure greatest accuracy. Member checking involved returning the summary of findings to principal investigators of the primary studies in the respective countries. These researchers then provided input on how results reflected their experience with primary data collection and analysis.

A critical awareness of the self and positionality is required to identify the power relations between researcher and participant, local investigator and international collaborator,

and patient and practitioner. The reflexivity adopted in the work to follow is strongly influenced by Michelle Fine and her description of ‘working the hyphen’ (38). This process (‘working the hyphen’) is a common struggle for ethnographic researchers who become deeply entrenched in their research and the communities in which they study. It is imperative that these principles expand beyond the field of anthropology to all global health research. Identities shape not only the research we chose to pursue but also the interpretation of the findings. The importance of positionality cannot be overstated (39, 40).

Learning theories.

Learning theories have guided the interpretation of findings of the following studies, some of which is based on Bandura’s social learning theory (20). Although this theory has been used primarily to explain behaviour change, it can also be used to explore health knowledge, the topic of greatest interest in this dissertation. Bandura and other proponents of the social learning theory hold that knowledge is acquired through direct observation of others, social interactions, personal experiences, and external influences (41). This theory presented a revolutionary concept at the time, that learning could evolve from sources other than direct experience. In addition, situated learning theory can be used to interpret findings, as it explains how learning is inextricable from the social world, and that the experience of learning itself is social (42). Learning in social structures may be explicit, through antenatal care education, or implicit, through witnessing the experiences of pregnancy of those around them. This theory argues that learning occurs through participation or practice. Sensory stimulation theory has also been used to explain knowledge acquisition, that learning occurs through the senses, greatest by seeing, then hearing (43). Finally, experiential learning can be described by the four-stage continuous cyclical process proposed by Kolb and colleagues (44). This theory describes learning in one of

four ways – concrete experience, observation and reflection, abstract conceptualisation, or active experimentation. Elements of these theories can be used to make sense of the knowledge women report regarding the HDPs.

Table 1. Enhancing Transparency in Reporting the synthesis of Qualitative (ENTREQ) research statement.

No	Item	Guide and description
1	Aim	State the research question
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).
4	Inclusion criteria	Specify the inclusion/exclusion criteria
5	Data sources	Describe the information sources used and when the searches conducted; provide the rationale for using the data sources.
6	Electronic search strategy	Describe the literature search
7	Study screening methods	Describe the process of study screening and sifting
8	Study characteristics	Present the characteristics of the included studies
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings, the domains assessed
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies
15	Software	State the computer software used, if any.
16	Number of reviewers	Identify who was involved in coding and analysis.
17	Coding	Describe the process for coding of data
18	Study comparison	Describe how were comparisons made within and across studies
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.
20	Quotations	Provide quotations to illustrate themes/constructs
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies
***adopted from Tong et al. [22]*		

Chapter 2. Women's knowledge of the hypertensive disorders of pregnancy: a qualitative evidence synthesis

Background

Patient knowledge and perceptions have long been fields of study and interest for researchers and clinicians alike. Studies have highlighted the limited nature of women's knowledge of pregnancy and pregnancy complications, and showed that formally educated women have improved health outcomes (33, 45, 46). However, there is limited information on the health knowledge of women regarding the complex conditions presented by the hypertensive disorders of pregnancy (HDP).

The aim of this qualitative evidence synthesis is to examine the qualitative literature on the topic and to determine the level of knowledge that pregnant and postpartum women hold regarding the HDPs.

Methods

This study undertook a systematic review of the literature and a qualitative evidence synthesis of the findings. The 'Preferred Reporting Items for Systematic review and Meta-Analysis Protocols' (PRISMA) checklist was followed, and the protocol was registered on PROSPERO (CRD42016043901) (47).

Systematic search and screening

For the purpose of this qualitative evidence synthesis (QES), the 'SPIDER' framework was used to outline the research question and search strategy (Figure 1, pg 26) (48). Additional

search strategies were employed to address the criticism that SPIDER may be insufficiently sensitive (47). All searches were conducted March 01 - May 31 2016.

Electronic database searches

Electronic database searches were optimized by the use of appropriate subject headings (MeSH terms), keywords, and synonyms. Search terms reflected the Context (pregnancy or 'pregnant women' or 'postpartum period'); Topic 1 (attitude OR comprehension OR 'health knowledge, attitudes, practice' OR knowledge OR awareness OR culture OR 'knowledge bases'); Topic 2 (pre-eclampsia OR eclampsia OR 'pregnancy-induced hypertension' OR hypertension OR seizures OR 'blood + pressure'); and Study Type ('focus groups' or 'qualitative research' or 'anthropology, cultural' or 'Surveys + questionnaires' or interview) (Figure 2, pg 27).

'Qualitative research' was not indexed as a medical subject heading (MeSH) until 2003; therefore, a number of diverse terms were combined as keywords. Other qualitative reviews have encountered similar challenges, at least partially due to inappropriate or delayed database indexing (47, 49). The relevant studies were identified using the following ten electronic databases: MEDLINE (via Ovid), EMBASE (via Ovid), CINAHL, PsycINFO, EMBASE, LILACS, AJOL, Sociological Abstracts, Global Health Library, and DARE. See Supplementary Table 1 (pg 190) for details of electronic database searches.

Hand-searching

The reference lists of included studies were reviewed. In addition, 11 journals likely to publish articles related to the topic were reviewed: BMC Pregnancy and Childbirth, Reproductive Health, Social Science and Medicine, Journal of Advanced Nursing, Qualitative Heath Research, Journal of Obstetrics and Gynaecology, African Journal of Reproductive

Health, BMC Women's Health, Maternal and Child Health Journal, Reproductive Health Matters, and Sociology of Health and Illness. See Supplementary Table 2 (pg 192) for details of hand-searching.

Inclusion and exclusion criteria

All searches were managed using RefWorks. A date limit of 1994 to 2016 was used to reflect the current generation of women of reproductive age, as used by other reviews interested in pregnancy and childbirth (50). Criteria for study inclusion were that it must: present primary findings, meet the study objectives, utilize qualitative methods for data collection and analysis, have the full text available through online libraries, be available in English, and be peer-reviewed.

All titles were screened against the inclusion criteria to determine relevance (n=308). A second level of review was done of all potentially-relevant abstracts (n=94) by two authors (MV and JR). Finally, the full texts were reviewed (n=33) for final decisions of inclusion. Any articles which raised disagreement were reconsidered by both reviewers until consensus could be reached (Figure 3, pg 28).

Critical appraisal of included studies

Although quality assessment has become increasingly common when synthesizing qualitative findings, it is still widely debated (49, 51, 52). This review assessed study quality using the Critical Appraisal Skills Programme (CASP) checklist (53). A numerical score between 10 and 30 was assigned to each study to reflect its quality. All manuscripts were of reasonable quality scoring between 18 and 28, with a median score of 26 (Table 2, pg 21). The most common deductions were due to a lack of clarity in the presentation of ethical

considerations and not providing transparent descriptions of relationships between participants and researchers. See Supplementary Table 3 (pg 193) for the appraisal of each included study.

Sub-group analyses

Findings were reviewed both overall and for sub-groups. Sub-group analyses were planned for the following groups:

1. History of pre-eclampsia: history of- or concurrent pre-eclampsia (or other HDP) vs. those with no history of pre-eclampsia (or other HDP)
2. Region: women in low- and middle-income countries vs. women in high-income countries

The two sub-groups were chosen due to their potential influence on knowledge of the HDPs. These sub-groups were not presented in all publications, limiting the possibility of sub-group analyses. In addition, in some studies using focus groups, a mix of participants inhibited the ability to conduct sub-group analyses.

Data extraction

Data regarding study setting and demographics, study objectives, study design, data collection and analysis, themes and conclusions were extracted for each study (Table 3, pg 23). Extracted data were entered and stored in QSR International NVivo 11 qualitative software 2016 for analysis. The synthesis was based on analysis of the 'findings/results' of each study.

Results

Nineteen studies were included from eight countries, seven in high-income countries, eleven in low- and middle-income countries, and one unspecified: Bangladesh, Brazil, Ghana, Malawi, Netherlands, Nigeria, United Kingdom, and the United States (Table 2, pg 21) (Figure

4, 29) (17, 18, 33, 45, 46, 54-67). Six studies looked only at women with a history of HDP, one study included women with chronic health conditions (including hypertension), two studies included women with previous pregnancy complications (including pre-eclampsia), and ten used a general mixed-population of women of reproductive age.

Thematic synthesis

Analysis was conducted by thematic synthesis as outlined by Thomas and Harden (32). Study findings, including key concepts, themes and quotations were reviewed. The use of analytic software allowed inclusion of study characteristics (journal, author, year of publication, method of data collection, and methodological approach) in the analyses.

This was a configurative synthesis, as findings were combined to identify new interpretations, rather than simply aggregated (68). An iterative approach to findings included a process of constant comparison between the themes generated and the manuscripts to ensure the appropriateness of findings (69). All relevant data were coded to at least one theme (initial concepts or first order themes). Following the initial coding, themes were regrouped into a smaller number of related categories (second-order or descriptive themes). Finally, the descriptive themes were further synthesized into three broad analytic themes (Figure 5, pg 30). The purpose of these themes is to provide an interpretation beyond those presented in the primary studies alone. Table 4 (pg 24) summarizes all themes and sub-themes.

Theme 1. Women expressed confusion regarding health information related to the hypertensive disorders of pregnancy and the nature of the condition itself

Several studies identified that women (with or without a history of pre-eclampsia) were confused about the nature of pre-eclampsia. This uncertainty was found in relation to the diagnosis, management and future health risks to themselves and their infants. In some instances,

the confusion was attribute to result from the quality of information provided while others pertained to the inherent complexity of the condition.

"*I really don't know why it happened*" (65)

Brown et al described how women with a history of pre-eclampsia were uncertain of prevention strategies, the cause, and symptoms: "*it was apparent that some women were confused about why preeclampsia had affected them*", and "*they perceived [pre-eclampsia] as confusing and unpredictable"* (62). There was also inadequate knowledge of how the management of chronic conditions may affect the development of pre-eclampsia (54). According to Jonkers et al "*immigrant women often did not interpret their complaints as early signs of complications, especially in the cases of pre-eclampsia*" (58). Furthermore, language proficiency was a barrier described for provision of pre-eclampsia information (46), and women with low levels of education had difficulty understanding the health information provided (58, 62).

Amongst some women, there were complaints about how and when health information was delivered. Their confusion was attributed to the inappropriate delivery of information and the timing of information for the best comprehension, particularly in regards to the long-term health risks (62).

"*How much information I would have taken on immediately afterwards I don't know"*

(65)

The clarity of information and consistency between providers was also important to patients: "*day shift staff and night shift staff often [give] different information"* (54, 67).

Theme 2 - Women claimed that insufficient information was provided regarding the hypertensive disorders of pregnancy

According to women in ten of the nineteen studies, inadequate information was provided regarding the HDPs (33, 45, 54-56, 58, 62, 64, 65, 67). Insufficient information by health care providers led to many women being unaware of pre-eclampsia. Even those diagnosed and treated for pre-eclampsia would have liked more information.

"If someone had told me what was going on, I would have felt okay…" (58)

"*I need to know more, nobody explained it to me"* (55)

"A bit more information before and afterwards would have helped the whole situation" (65)

Lima de Souza et al showed that women were not provided information related to pre-eclampsia prior to diagnosis and hospitalization (45). Some of those who felt they did not have enough information were reluctant to inquire further (67). A lack of information led some women to seek answers elsewhere, particularly the internet, which could result in misinformation or further confusion (33, 62).

"I feel like I had to do most of the research on my own" (33)

One study stated that participants would have liked to receive information from other women who had similar experiences:

"That's something I've missed, women who have been through the same thing to share experiences with" (56)

A common complaint was related to insufficient information about future health risks (33, 54, 62). This may be influenced by the fact that two studies focused specifically on the long-term and cardiovascular risks of pre-eclampsia (33, 62). Some women demonstrated greater concern for their infants' health, than their own, or the effect of pre-eclampsia on future

pregnancies. Women explained that doctors had not informed/warned them of the potential risks to their baby (54).

Theme 3 - Emphasis on lifestyle and personal responsibility for avoiding the hypertensive disorders of pregnancy

Participants in nine of the studies associated the HDPs with one or more lifestyle factor: diet, weight gain, exercise, or stress (18, 54-56, 59, 62, 63, 67). Amongst these studies, there was substantial emphasis on women's personal responsibility in the development of pre-eclampsia.

> *"All women emphasized the importance of taking personal responsibility for health before future pregnancies to further reduce the risk"* (62)

The most common lifestyle-related factor attributed to the HDPs was diet, often related to salt intake (55, 56, 59, 62, 63).

> *"[Pre-eclampsia] was avoidable as long as you make the changes to keep yourself healthy and to eat healthily and to look after yourself and exercise"* (62)

Stress was also frequently discussed as an important factor in the development of pre-eclampsia (18, 56, 62, 63, 67). Other lifestyle factors – physical activity, work-related stress, and weight gain – were reported only in high-income countries (Netherlands, United Kingdom, United States) (56, 62, 67). This differences in beliefs, between women of high and low- or middle-income countries, demonstrates the influence of the cultural context in their understanding of pre-eclampsia.

Appraisal of findings

Confidence in the synthesis findings was determined using the CERQual (Confidence in the Evidence from Reviews of Qualitative research) tool. (18, 33). The CERQual assessment of this synthesis indicates that there should be high and moderate confidence in the three primary

findings (Table 5, pg 25). For details of methodological limitations, concerns over relevance, coherence and adequacy for each finding see Supplementary Table 4 (pg 200).

Discussion

Other qualitative studies and syntheses have identified the limited patient knowledge of complex medical conditions. Nevertheless, few of those studies have demonstrated confusion of other health conditions and pregnancy complications. The confusion described here in relation to pre-eclampsia may reflect the unpredictable and complex nature of the condition, as well as conflicting explanations of the condition particularly when there are discordant biomedical and traditional beliefs. The challenge in understanding the HDPs as a result of language barriers highlights the need for education to be locally adapted and delivered. Information, education, communication (IEC) initiatives are known to be effective; however, women are often provided with insufficient or inadequate health information in pregnancy (23). Increased health education, as delivered in regular antenatal care, has been shown to effectively increase awareness of pregnancy complications in Tanzania and Uganda (70, 71). Some women in the included studies complained about conflicting health information from providers, this underscores the importance of a continuum of care in pregnancy (72). Despite a wide geographic spread of studies, the findings were largely consistent between regions. One difference identified was a greater focus on lifestyle factors in the development of the HDP in studies conducted in high-income countries.

Our findings suggest that there is insufficient well-crafted cohesive health information provided about the HDPs to women who are, or may become pregnant. There is a need for

additional culturally-relevant health education for women of reproductive age regarding pregnancy complications and the complexity of the HDP.

Conclusion

There are widespread knowledge gaps regarding the hypertensive disorders amongst pregnant women, recently pregnant women and women who may become pregnant. Much of the findings were consistent across regions, nevertheless differences highlight the need for culturally-specific approaches to future health IEC strategies.

Table 2. Summary of included studies.

Authors	Year	Country	Country income group	Participants	Relevant study objective(s)	Methods	Quality rating
Chuang CH, Velott DL, Weisman CS	2010	United States	High income	12 FGD (n=72) with pregnant women 18-45 years of age with chronic medical conditions	Pregnancy and pre-conception health knowledge and attitudes in the context of chronic medical conditions	Focus groups	28
de Azevedo DV, de Araujo,Ana C P F., Clara Costa IC	2011	Brazil	Upper middle income	Word association: 61 pregnant/postpartum women with pre-eclampsia, 87 health care professionals. Interview: 18 pregnant women, 2 postpartum women, and 20 health care providers	to understand the meaning of pre-eclampsia to pregnant and postpartum women with the disease	Word association test and interviews	26
el-Nafaty AU, Omotara BA	1998	Nigeria	Lower middle income	16 FGD, 1167 community surveys, and 30 interviews with men and women of the community: young fathers, young mothers, elderly fathers, elderly mothers, admitting medical officers, midwives, members of research team	to identify perceived causes of eclampsia	Focus groups, questionnaires, and interviews	25
Hoedjes M, Berks D, Vogel I, Franx A, Duvekot JJ, Oenema A, Steegers EA, Raat H	2012	Netherlands	High income	6 FGDs with women with pre-eclampsia, intra-uterine growth restriction, or gestational diabetes	to describe the motivators and barriers to the adoption of a healthy postpartum lifestyle after a complicated pregnancy	Focus groups	27
Islam KS, Sachchu SA, Sandani R, Bullough C, Siraj N, Dimmock P, et al.	2001	Bangladesh	Lower middle income	15 women (mothers, mothers-in-law, young girls), 15 men (community leaders, husbands, and young boys)	to assess the impact of theatre based educational initiatives on the knowledge and attitudes to eclampsia and its treatment	A before and after knowledge and attitude questionnaire	26
Jonkers M, Richters A, Zwart J, Öry F, van Roosmalen J.	2011	Netherlands	High income	40 interviews with immigrant women who experienced pregnancy complications and partners	*Not listed*	Interviews	23
Kalim N., Anwar I., Khan J., Blum L.S., Moran A.C., Botlero R., et al.	2009	Bangladesh	Lower middle income	80 free-listing participants, 40 WRA rated free listed complications, and 38 interviews with women of reproductive age and elder women	to examine knowledge and care seeking behaviours related to obstetric hemorrhage and eclampsia	Free listing, rating exercises, interviews, and case scenarios	28
Lima de Souza N., Fernandes Araujo A.C., Dantas de Azevedo G., Bezerra Jeronimo S.M., Barbosa L.M., Lima de Sousa NM	2007	Brazil	Upper middle income	28 women with preeclampsia, preterm delivery and NICU admission	maternal experience of pre-eclampsia and newborn care in the neonatal intensive care unit	Focus groups	28
Oiyemhonlan B, Udofia E, Punguyire D.	2013	Ghana	Lower middle income	2 interviews, and 4 focus groups (n=29) with women with pre-eclampsia and ANC attendants	women's knowledge of obstetric emergencies	Focus groups and interviews	25
Seely EW, Rich-Edwards J, Lui J, Nicklas JM, Saxena A, Tsigas E, et al.	2013	United States	High income	5 FGDs (n=20) with women with previous pre-eclampsia	to assess knowledge of the link between pre-eclampsia and later cardiovascular disease	Teleconference-based focus groups	27
Osubor KM, Fatusi AO, Chiwuzie JC.	2006	Nigeria	Lower middle income	225 mothers, 6 FGDs (4 with community women and 2 with health workers)	to assess maternal health services and health-seeking behavior	Structured questionnaire and focus groups	22
Abdulkarim GM, Kawuwa MB, Kullima A.	2008	Nigeria	Lower middle income	6 FGDs and 10 interviews (n=168)	to find out community's knowledge and perceived implications of maternal	Focus groups and interviews	24

Authors	Year	Country	Country income group	Participants	Relevant study objective(s)	Methods	Quality rating
					mortality and morbidity		
Kumbani L, Me Inerney P.	2002	Malawi	Low income	33 primigrade 28-42 weeks	to explore primigraivdae's knowledge of obstetric complications	Interviews	23
Brown MC, Bell R, Collins C, Waring G, Robson SC, Waugh J, Finch T.	2013	United Kingdom	High income	12 women with a recent history of pre-eclampsia with postnatal follow-up	to elicit women's personal understanding of future cardiovascular risk, following a pregnancy complicated by preeclampsia, and to identify the postnatal needs of these women	Interviews	28
Atkinson SJ, Farias MF.	1995	Brazil	Upper middle income	51 women at least seven months pregnant	to explore the influences on the perceptions of potential risks of pregnancy	Interviews	20
You W.B., Wolf M., Bailey S.C., Pandit A.U., Waite K.R., Sobel R.M., et al	2012	United States	High income	112 pregnant women	to explore the extent to which pregnant women understand the symptoms and potential complications related to preeclampsia and to determine the factors associated with better understanding	Cross-sectional study, survey	19
Mapp T	2005	*Not stated*	NA	10 postpartum women with obstetric complications	to provide descriptions of women's lived experiences of specific obstetric emergencies and to provide a research project on obstetric emergency drill training	Interviews	18
Fleury C, Parpinelly M, Makuch MY.	2010	Brazil	Upper middle income	15 women with high-risk pregnancies with babies 1-4 months	assess the development of this relationship (mother-child) in primiparous women diagnosed with pre-eclampsia in the third trimester of pregnancy	Interviews	28
Barlow JH, Hainsworth J, Thornton S.	2008	United Kingdom	High income	12 women admitted with hypertension	to document women's experiences of admission to hospital with a pregnancy-related complication, hypertension, from their own perspective	Interviews	27

Table 3. Data extraction criteria.

	Inclusion Criteria	Exclusion Criteria
Participants	Pregnant women	Health workers
	Recently pregnant women	Partners
	Postpartum women	Mothers
	Nursing mothers	Mothers-in-law
	Women of reproductive age	Other family members
Data Sources	Peer-reviewed qualitative data	Non-peer-reviewed qualitative data
	Interviews	Quantitative data
	Ethnographies	Secondary analyses
	Narratives	Systematic reviews
	Focus groups	
	Case studies	
Themes	Findings deemed to be related to the stated research question	Findings deemed not to be related to the stated research question

Table 4. Summary of themes and sub-themes.

Initial concepts (first order)	Emerging themes (second-order/ descriptive)	Final themes (third-order/ analytic)	References
Anxiety, fear, worry	Knowledge of medical instructions, medications, treatments	Women expressed confusion	(46, 54, 55, 58, 59, 62-67)
Relationship of chronic illness and knowledge of pre-eclampsia	Knowledge of outcomes, complications	• Cause	
Circulatory system, blood	Future health risks	• Symptoms	
Confusing, unpredictable	Infants risks	• Prevention	
Danger, severity	Future pregnancy risks	• Management	
Diagnosis	Knowledge of prevention strategies	• Diagnosis	
Experience with health care services and/or providers	Knowledge of screening, diagnosis	Information provided was insufficient	(33, 45, 55, 56, 58, 62, 64, 65, 67, 73)
Blood pressure measurement	Knowledge of susceptibility and causes	• Future health	
Postnatal clinic and care	Link with chronic conditions	The emphasis on lifestyle factors and personal responsibility in the development of the HDPs	(54-56, 59, 62, 63, 67)
Proteinuria results or measurement	History of pre-eclampsia	• Diet	
Family history	Lifestyle and diet	• Weight, exercise	
Future health	Supernatural causes or natural elements	• Stress	
Future pregnancies	Stress		
Personal health	Family history		
History or pre-eclampsia	Knowledge of symptoms, disease characteristics		
Delivery of information			
Information needs			
Lifestyle factors, diet, personal responsibility			
Infant outcomes			
Personal experience or experiences of others			
Positive attitude			
Prevention			
Recognition or awareness			
Spiritual explanations			
Symptoms			
Temperature			

Table 5. Summary of qualitative findings.

Review finding	CERQual assessment of confidence	Explanation of CERQual assessment	Studies contributing to review finding
Women expressed confusion regarding the hypertensive disorders of pregnancy	**High confidence**	Consistent finding across studies and regions displaying rich supporting data	(46, 54, 55, 58, 59, 62-67)
Women perceived information provided regarding the hypertensive disorders of pregnancy was insufficient	**Moderate confidence**	Moderate methodological limitations, and moderate limitations in relevance and adequacy of findings	(33, 45, 54-56, 58, 62, 64, 67)
Emphasis on lifestyle and personal responsibility for avoiding the hypertensive disorders of pregnancy	**Moderate confidence**	Moderate limitations in relevance and adequacy of findings	(18, 54-56, 59, 62, 63, 67)

Figure 1. SPIDER search framework.

S	**Sample**	• Women of reproductive age • Women planning to become pregnant • Pregnant women • Recently pregnant women • Postpartum women • Women with or without history of a hypertensive disorder of pregnancy
P **I**	**Phenomenon of Interest**	• The hypertensive disorders of pregnancy • Pre-eclampsia • Eclampsia • Superimposed pre-eclampsia • Gestational hypertension • Pregnancy induced hypertension • Hypertension in pregnancy • Convulsions in pregnancy
D	**Design**	• Ethnography
E	**Evaluation**	• Knowledge • Awareness • Beliefs • Comprehension • Attitude • Health knowledge
R	**Research type**	Qualitative studies • Focus groups • Interviews • Narrative accounts/ case studies • Ethnographies • Surveys or questionnaires

Figure 2. Electronic database search graphic.

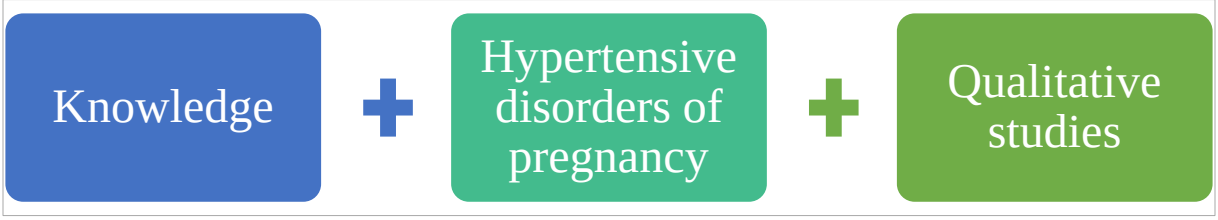


Figure 3. Flow diagram of search and inclusion process.

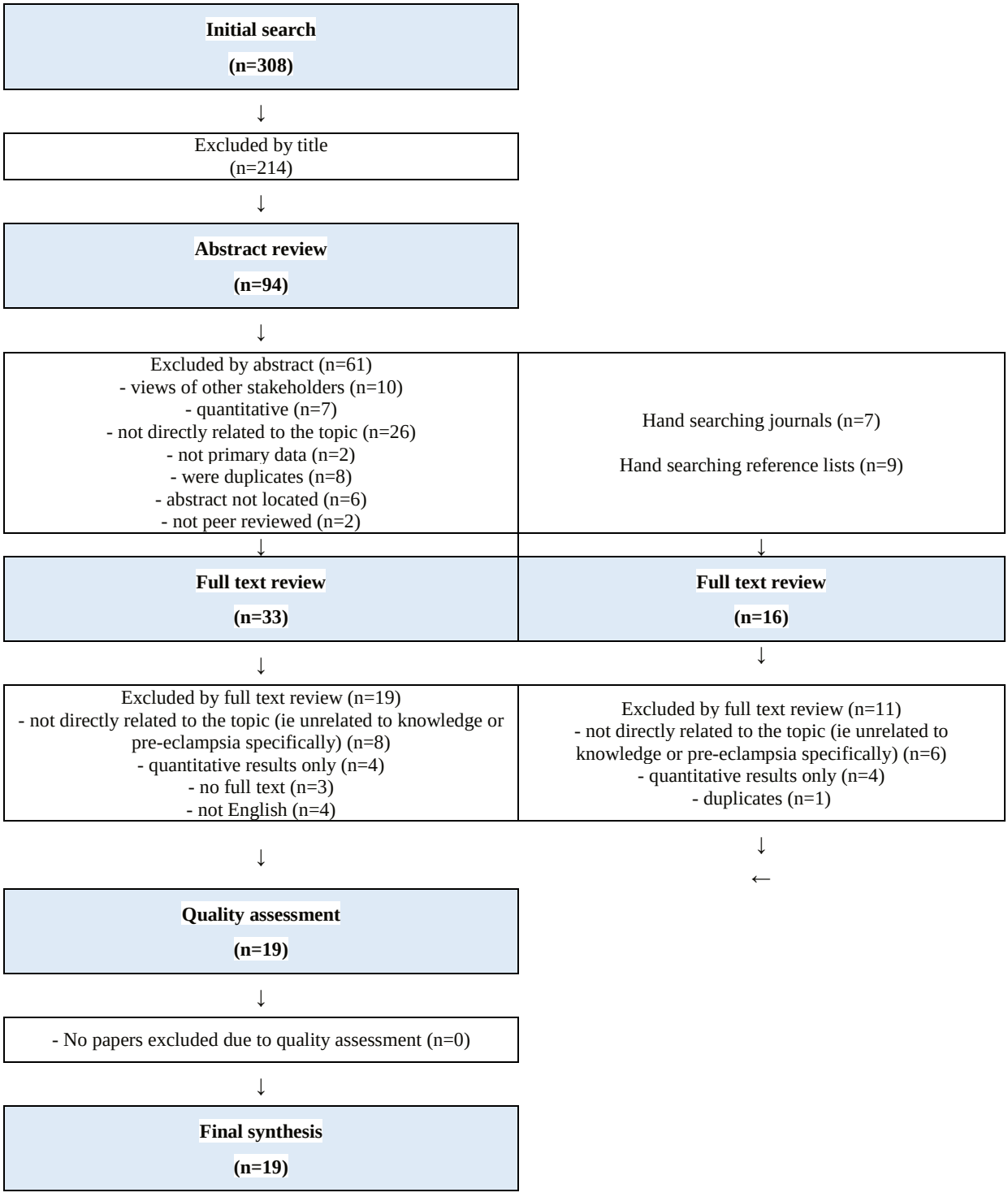
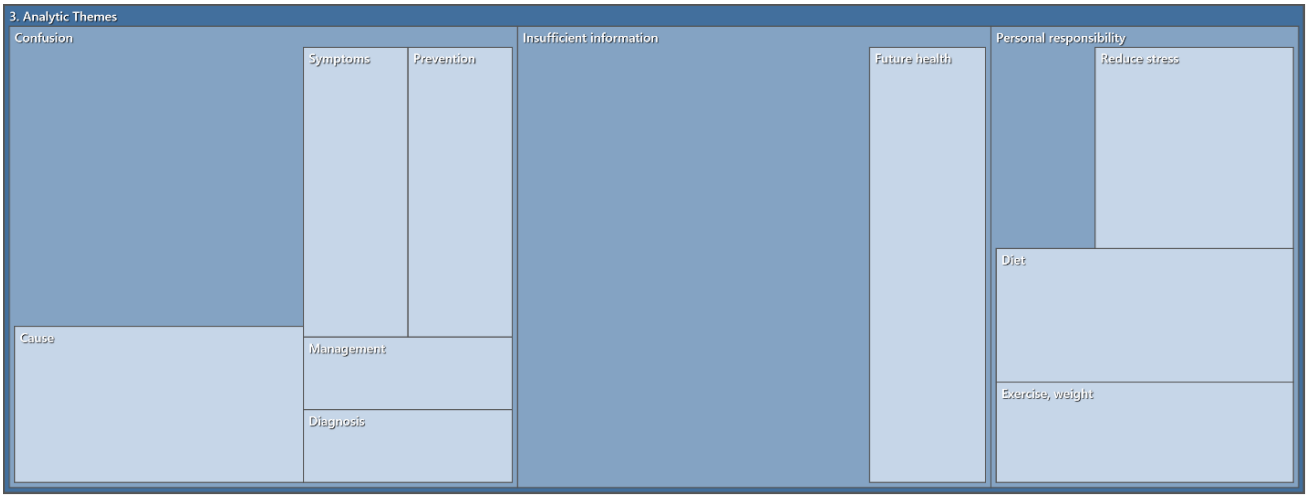


Figure 4. Study regions.

Figure 5. Analytic theme hierarchy.



Women's knowledge of the hypertensive disorders of pregnancy according to the Community Level Interventions for Pre-eclampsia (CLIP) studies in Nigeria, Mozambique, Pakistan and India?

Chapter 3. The feasibility of community level interventions for pre-eclampsia in South Asia and sub-Saharan Africa: a mixed methods design

Background

Globally, hypertensive disorders of pregnancy (HDP) mainly pre-eclampsia and eclampsia are major contributors to maternal and perinatal mortality and morbidity, with the highest burden is in low and middle-income countries (LMIC) (2, 74). Management of pre-eclampsia and eclampsia has focused on hospital-based interventions (75), and the only intervention possible at the community level is stabilization and referral to higher-level facility (1). As these conditions are dependent on timely and appropriate intervention, many women in hard-to-reach areas suffer from severe disability or death as a result of delays in early identification, triage, transport and treatment (76). To effectively reduce maternal and perinatal complications resulting from pre-eclampsia and eclampsia, community-level identification, prompt intervention and referral are required (77). Therefore, a package of evidence-based interventions that are applicable in the home and primary health centre (PHC) represents a critical step towards addressing excess maternal and perinatal deaths and disabilities resulting from the failure to identify and rapidly manage pre-eclampsia and eclampsia at the community level. Such a package would require community health care providers to use a simplified triaging tool to identify women at high risk of adverse outcomes, provide emergency treatment and facilitate their referral to hospital. A systematic review of strategies to improve maternal and perinatal health in LMICs demonstrated the benefits of using such community-based interventions for improving maternal and newborn outcomes (78).

The Community Level Interventions for Pre-eclampsia (CLIP) Trial

The CLIP Trial [clinicaltrials.gov number ID NCT01911494] is an ongoing cluster randomized controlled trial, which aims to address the maternal and perinatal mortality resulting from the failure to identify and rapidly manage pre-eclampsia and eclampsia at the community level in LMICs. Specifically, the CLIP intervention consists of:

I. *Community engagement* including women from the communities, dyadic household decision-makers (husbands, fathers-in-law) and community leaders about: pre-eclampsia, its origins, symptoms, signs and potential consequences, pre-permissions for maternal transport and fundraising activities for transport and treatment costs;

II. *Provision of HDP-oriented antenatal care through household visits* by community healthcare providers (cHCPs) who carry a mobile health (m-health) application for identifying women at risk of pre-eclampsia. The m-health application is programmed with a validated Pre-eclampsia Integrated Estimate of Risk (PIERS) on the Move (POM) (79, 80);

III. *Use of the CLIP package for women with a CLIP 'trigger'* (i.e. oral antihypertensive therapy or intramuscular (i.m.) magnesium sulphate ($MgSO_4$) when indicated, and appropriate referral to a comprehensive emergency obstetric care (CEmOC) facility as needed).

IV. *Capacity building through continuous medical education of healthcare providers in referral health facilities.*

The cHCPs assess pregnant women with a target frequency of every 4 weeks at a minimum. These visits can occur in the home or PHC. The cHCPs are trained to enquire about the woman's symptoms (using country-specific pictograms), take blood pressure and check urine for protein to inform diagnosis of and risk assessment for pre-eclampsia. The control group (without intervention) continues with routine pregnancy care.

Feasibility assessment of the CLIP Trial

Implementation of the complex CLIP interventions significantly depended on positive interactions with the community and existing health system. (Figure 6, pg 54) The CLIP Trial is recruiting in four countries, which have country-specific healthcare delivery systems, diverse population characteristics, varied perceptions of care seeking and treatment preferences. Therefore, a prior assessment of the acceptability and feasibility of the CLIP interventions was needed to ensure effectiveness, while addressing applicability and sustainability issues relating to implementing the trial.

Very few clinical trials (81, 82), particularly in the area of pre-eclampsia and eclampsia (83, 84), have conducted feasibility assessments prior to initiating large-scale community-based interventions. Failure to fully understand the study context risks the effective implementation of the intervention and limits the likelihood of post-trial scale-up. Consequently, in the absence of a feasibility assessment the benefits of the intervention may not be maximized at population level, despite being shown to be effective. Therefore, the role of such a feasibility study was integral to successful trial implementation and programmatic sustainability.

Feasibility study objectives

The feasibility assessment of the CLIP Trial aimed to describe the health system, identify community and individual barriers and facilitators that influence care of pregnant women in the community, particularly as they relate to pre-eclampsia and eclampsia, in preparation for the conduct of a community-based cluster randomised trial. The primary objectives of the CLIP Trial feasibility study were to:

1. Explore the local cultural beliefs related to pregnancy and its complications
2. Understand current care seeking behavior and practices

3. Identify local stakeholders and determine support
4. Establish rates of maternal and perinatal mortality and morbidity in study communities to confirm sample size

Secondary objectives were to assess each health care system including organization, infrastructure and human resource capacity, cost of maternity services, and training needs for health care providers.

Methods

Theoretical framework

The study design was guided by May et al.'s normalization process theory (NPT), as it has been used in designing, implementing and evaluating trials of complex clinical interventions (85, 86). As the CLIP Trial aims to integrate an innovative and complex healthcare intervention into regular practice, the NPT theoretical framework was an appropriate fit (87).

NPT emphasizes on the collective work of individuals and groups to make the intervention normalized. Particularly, it seeks to understand the context that increases or decreases the likelihood of adoption of an intervention into existing system. There are four key components to NPT including coherence, cognitive participation, collection action and reflexive monitoring (88). The application of NPT key components guided CLIP feasibility study as follows:

(I) Coherence: This component refers to aspects of a complex intervention that are similar to existing practice. The CLIP introduces m-health technology that builds on the existing infrastructure of cHCP and enhances health system capacity through additional trainings. It also implies cooperative interaction between cHCP and collective effort to integrate m-health into

current practices. This assessment required review of health workers' curriculum, practice guidelines and policies.

(II) Cognitive participation: This component refers to understanding the dynamics of intervention and potential benefits/risks from participation. The CLIP Trial proposes immediate and long-term benefits to the community and health system. The qualitative methods in the CLIP feasibility study provided an opportunity to discuss in detail importance and potential benefit/risk with wide range of stakeholders.

(III) Collective action: This component refers to collaboration between individuals and groups responsible to implement intervention. The implementation of the CLIP Trial highly depended on the collective action of all stakeholders (i.e., care providers, care receivers and community at large). The collective action was gauged through discussion of participatory activities, such as community engagement, capacity building of healthcare providers, and on-going support of research staff.

(IV) Reflexive monitoring: This component refers to reflecting upon the enabling and impeding factors that could potentially normalize the intervention. We used reflexive monitoring for researchers to provide feedback during data collection and to assess the level of community and stakeholder support. Reflexive monitoring was also done throughout FGDs and interviews through the use of paraphrasing by facilitators for community and individual appraisal of benefit.

Study design

This study used a pragmatic mixed-methods (qualitative-and-quantitative) design informed by the theoretical framework NPT. The quantitative and qualitative components were used to complement one another and allow for triangulation between methods (89, 90).

Study sites

Four countries were selected for this feasibility study: Nigeria (Figure 7, pg 55), Mozambique (Figure 8, pg 56), Pakistan (Figure 9, pg 57), and India (Figure 10, pg 58). In-country activities were led by: the Centre for Research in Reproductive Health (CRRH) in Nigeria; the Manhiça Health Research Centre (CISM) in Mozambique; the Aga Khan University (AKU) in Pakistan; and KLE University's JN Medical College and the SN Medical College in India. These sites were selected in consultation with lead organizations in each country, as well as existing academic relationships, understanding and experience of community-based maternal or perinatal health research work, and research infrastructure.

Study duration

The feasibility studies were completed in Pakistan during February 2012 to May 2013; India during September 2012 to August 2013; Mozambique during July 2013 to February 2014; and Nigeria during February 2012 to May 2013.

Data collection: Qualitative methods

Ethnography is a methodology born out of the field of anthropology (91). This qualitative approach is used to explore differences and similarities between cultural groups. The underlying assumption is that several differing perceptions or understandings exist and that these are socially constructed, they are influenced by their cultural group and subject to future change (92). Therefore, an ethnographic lens is often adopted when researchers aim to explore beliefs and practices related to a particular phenomenon within or between groups.

As our study aimed to describe the knowledge, attitudes and behaviours of various cultural groups, ethnography was an appropriate methodological approach. In our study, we were interested in how various cultural groups and communities make sense of pregnancy and

pregnancy complications with a particular focus on pre-eclampsia. In addition, we explored how the cultural group of 'health care providers' act in the face of pregnancy complications, particularly pre-eclampsia.

The following methods were used to understand culturally based practices and their underlying factors.

(I) Focus Group Discussions (FGDs). FGDs were conducted to elucidate in-depth information and to encourage group dialogue. This method allowed researchers to select and engage a large number of participants from varied groups. FGDs were preferred to explore the collective experiences of community members, health care providers, and policy makers in parallel groups.

One researcher, assisted by a second to record field notes and audio recordings, facilitated all FGDs. Moderators were local researchers with backgrounds in community or obstetric medicine or qualitative researcher. Facilitators were locally recruited based on their research experience, community knowledge, familiarity with the health care system, and qualitative research expertise. All researchers were provided basic qualitative training prior to data collection; the process was supervised by at least one social scientist at each site. To respect local preferences of participants, FGDs were held separately for men and women in all countries. In addition, facilitators were most often of the same gender as participants. FGD facilitators had high proficiency in all locally spoken dialects.

There was no known relationship between respondents and participants; facilitators did not provide health care services for any participants. Rapport building with communities was essential in each site prior to data collection. Approval was obtained by community leaders and chiefs prior to conduct of the study. All participants were briefed on the study prior to providing written informed consent.

Participants were considered eligible for the study if they expressed availability for at least 60 minutes and a willingness to participate. A non-probability sampling approach was taken; study participants identified through the primary health centre networks, as well as local community workers. Women of reproductive age were defined as women 15-49 years (except in Mozambique where reproductive age was considered to be 12-49 years). In India, male and female decision-makers were approached for participation when they accompanied women of reproductive age to the health centre. Culturally appropriate yet feasible strategies were employed to approach, invite, and ensure participation of stakeholders at respective sites. These were designed to strengthen the rapport with the community in a way that enabled participants to benefit from participation. One benefit was for participants to freely discuss issues related to pregnancy in the community. Participants were approached by phone or face-to-face. Each FGD included an average of 7 to 10 participants. No incentives were given for participation in FGDs; however, refreshments and transport costs were provided in some sites. Project staff arranged refreshments and provided children with group play during the FGDs. The desired number of FGDs was determined by data saturation, and data collection stopped when saturation was reached at each site (93). The FGDs were transcribed verbatim in local language and translated for analysis. A total of 123 FGDs were completed, as determined by data saturation. (Table 6, pg 49)

Centrally located venues were chosen to best accommodate participants: primary health centres, local households, and other community gathering locations. Non-participants were not present during FGDs with the exception of small children in some cases. Community perspectives were obtained from women of reproductive age (represented by pregnant women and mothers of children under five years of age), opinion leaders, religious leaders, village

community leaders, husbands, and male and female decision-makers (including family members, and particularly mothers-in-law). In addition, FGDs were conducted with community health workers who were represented by various cadres in the four countries: Community Health Extension Workers (CHEW) in Nigeria, Agente Polivalente Elementar (APE) in Mozambique, Lady Health Workers (LHW) in Pakistan, and Accredited Social Health Activists (ASHA), staff nurses and Auxiliary Nurse Midwives (ANM) in India. In addition, a variety of other health care providers were included given their key role in health care service delivery: medical officers, obstetricians, faith-based providers, and traditional birth attendants. These groups were chosen to represent the breadth of the communities' views.

FGD guides were developed from the literature and broadly categorized as knowledge and perceptions of pregnancy (94, 95), maternal care seeking practices (60), household and community dynamics (96, 97), use of alternative medicines and providers (98), as well as the cost and availability of health care services and transport (99). The guides were translated into the local language in all sites to best promote interaction with the community members and obtain the richest data: Yoruba in Nigeria, Changana and Portuguese in Mozambique, Sindhi and Urdu in Pakistan, and Kannada and Marathi in India. Guides underwent pilot testing for content validity review by each country-specific research team, and questions were adapted for cultural sensitivity and local use. FGD guides developed for the study were semi-structured to promote a natural discussion progression. (for a sample transcript see Supplemental Table 5)

(II) In-depth interviews. Interviews allowed rich in-depth data collection from individuals (100). Interviews were utilized for stakeholders for whom convening groups was not always either feasible or appropriate. This included health care providers, opinion leaders, and policy makers.

Interviewers were responsible for facilitating the discussion, recording field notes and audio. These researchers were familiar with the study and received training on qualitative data collection, qualitative data management, ethical conduct and discussion guides. Many facilitators had a medical background with experience in community medicine or obstetrics, while the rest were qualitative researchers. Facilitators were locally recruited based on their research experience, community knowledge, familiarity with the health care system, and qualitative research expertise. They were both men and women, and none were the direct health care providers or supervisors of participants. Approval for interviews was obtained by the relevant community leaders or supervisors as needed. All participants were briefed on the study prior to providing written informed consent.

The participants were considered eligible for interviews if they expressed availability for at least 45 to 60 minutes, a willingness to participate, and met the desired stakeholder description. A purposeful sample was used in all sites, where eligible participants were selected with the help of community representatives and hospital administration, and were contacted in person or by phone. All interviews were conducted privately, one-to-one, which ensured no undue pressure or discomfort for participants. Data collection was done at a place suitable for the interviewees. Participants were provided compensation for their time in some sites, while others provided transport and refreshments only. The desired number of interviews was determined by data saturation, and data collection stopped when saturation was reached at each site (93). The interviews were transcribed verbatim in local language and translated for analysis.

A total of 100 interviews were completed, as determined by the data saturation. (Table 7, pg 50)

Interviewees included medical officers and obstetricians from the public and private health care system. Traditional health care providers, including female elders and traditional birth attendants, were interviewed in all sites, except India. Various community and facility-level policy makers were interviewed: local government representatives, non-governmental organization representatives, hospital administrators, and community leaders.

Interview guides were developed for this study based on key constructs and themes of interest: health care related experience, obstetric knowledge, treatment practices, access to health care services, and health care provider and community dynamics.

Interviews were conducted in a variety of languages – English and Yoruba in Nigeria, Portuguese and Changana in Mozambique, Sindhi and Urdu in Pakistan, and English in India. Guides were pilot tested and modified based on input from the research team and the field-test prior to use. Semi-structured interviews allowed facilitators to tailor questions and probes to the context and participants. The sessions began with broad questions to initiate discussion. Some sensitive questions related to maternal deaths were included; to mediate the possible negative feelings associated with this discussion they were placed at the end.

(III) Participant observations. In Nigeria, observations were conducted for one full antenatal clinic day in four primary health centres. A community-based researcher was responsible for observing and recording the field notes during these observations.

(IV) Document review. Community health care providers deliver basic maternal and child health services at the door step in many LMICs (15, 101); however, their training and experience varies widely between countries (102, 103). Systematic reviews of community health worker training curricula, job descriptions, and practice guidelines were conducted in all four countries to determine the community health workers' scope of practice and ability to participate in the CLIP

Trial. In addition, a review was conducted of regional and facility-based policies and guidelines for the management of pre-eclampsia. Finally, any regional or national policies related to community health worker provision of maternal services in country was reviewed and summarized.

Data collection: Quantitative methods

Quantitative methods were employed to determine community health care provider training needs, competence and skills, as well as health care system organization and infrastructural capacity in study areas.

(I) Health facility assessment. Data collection tools for health facility capacity and resource availability were based on the published literature and existing guides related to healthcare system resources and capabilities for maternal, obstetric and neonatal care in the context of developing countries (104, 105). The information collected matches in many areas to the World Health Organization's identified 'service readiness indicators' (106). In addition, facility assessment tools used in Mozambique were informed by the 2012 Service Provision Assessment (SPA) survey (107). The scope of this assessment was to identify the availability of basic, as well as comprehensive emergency obstetric care (CEmOC) facilities, diagnostic services, staffing, working hours, health facility utilization (outpatient/in-patient visits), referral points, cost of care, and maternal mortality. Surveys underwent modifications in each country before translation. All data collection tools underwent pilot testing for content validity review by each country-specific research team and questions were adapted accordingly. Primary, secondary and tertiary level health care facilities were surveyed after obtaining consent on site. In addition, pharmacies were surveyed (where relevant) to identify the availability and cost of essential maternal and newborn commodities. (Table 8, pg 51)

(II) Community health care provider questionnaire. Data were collected through self-administered questionnaires in Pakistan (LHWs), India (ANMs), and Mozambique (APEs). Nigeria did not utilize this data collection method. (Table 9, pg 52)

All community health care providers who were reachable at the time of data collection in the study areas were approached for participation. Some health care providers were on leave or otherwise unreachable at the time of data collection and therefore were not included. Participants were briefed on the questionnaire purpose and general content prior to informed consent. Research staff coordinated with district health authorities and supervisors to recruit community health care providers. Questionnaires were completed and collected on the same day or within a week time, as feasible. Questionnaires were designed to obtain information concerning health worker knowledge and skills to manage pregnant women and to perform home-based treatment for women with pre-eclampsia. Questions used a five-point Likert scale. This format was appropriate for the large sample size and to reflect participants' attitudes. None of the Likert questions were negatively worded. In addition, one open-ended question was included at the end to allow written responses with greater elaboration if desired. Data collection was done in the health facility or home to minimize the required time commitment and maximize convenience. The data collector did not intervene during the questionnaire unless clarification was requested.

(III) Baseline household demographic and health survey. Individual and household level surveys were undertaken in all study areas. The primary objective of this survey was to establish baseline rates of maternal and perinatal mortality and morbidity in study communities to confirm sample size. Second, this survey enabled researchers to beta-test surveillance tools and data management prior to the trial. The key variables on the baseline survey questionnaire included household socio-demographic information, obstetric and general medical history over the previous 12

months. The women of reproductive age, living in the study catchments, and willing to participate in the study were considered eligible for the survey. In Nigeria, Mozambique and Pakistan individual data collection was performed by trained medical and/or research staff. In India, these data were collected prospectively over a 5-month period. (Table 10, pg 53)

Data quality control

Stringent quality control measures were employed at each site. This included field supervisors and senior social scientists who undertook spot visits to observe data collection procedures. Photographs, audio recordings, field site data checks, peer debriefing, real-time data entry, and computer-assisted data analysis were also used to maintain data quality. Reflexivity and data triangulation are widely cited methods of ensuring rigor and quality control in the qualitative research (108, 109). In this study, the data collectors undertook both self and group reflections after FGDs and interviews. These reflections and debriefing were instrumental in contextualizing the data, as well as ensuring a transparent process. Data triangulation between multiple methods of data collection was helpful to validate information from a diverse range of participants.

Project management and oversight were the responsibility of the central CLIP Co-ordinating Centre at the University of British Columbia, in collaboration with the local principal investigators. Collaboration took the form of frequent email communication, teleconferences, and site visits.

Data management and analysis

Qualitative data. Digital voice recorders and hand written field-notes were used to record discussions during focus group discussions and interviews. Analysis was conducted in Sindhi in Pakistan, in English in India and Nigeria, and in a combination of English and Portuguese in

Mozambique. All translations were confirmed by multiple researchers with back-translation of data segments for quality control. Each FGD and interview was assigned a unique identification number, and photographs taken during data collection and reflection notes were attached to transcripts for analysis. The number of data coders varied by country: one in Pakistan, one in India, one in Nigeria, and two in Mozambique. All coded transcripts in India and Nigeria were cross-checked by the local research team to resolve or clarify any misinterpretation of the data. Thematic analysis (combining inductive and deductive approaches) was performed in country by the local country team or analysis was supported by the central trial team, as required. Using deductive reasoning, the results were grouped into predetermined categories of key themes related to the discussion guides. During analysis, inductive reasoning was used to incorporate new and unexpected ideas. This produced a comprehensive analysis structure to reflect the richness and variety of responses. Data were analysed using NVivo 10 software. (Figure 11, pg 59)

Quantitative Data. Data consistency checks were established in the data entry software. Data were double entered in real time, and cleaned prior to analysis. SPSS 19 (IBM, Armonk, NY, USA) Epi Info 7 [CDC, Atlanta, GA, USA], or Stata 13 (Stata Corp. College Station, Texas, USA) were used to calculate frequencies and proportions.

Ethics approval

The CLIP Trial was registered at Clinicaltrials.gov. The Clinical Research Ethics Board of the University of British Columbia, Vancouver Canada, approved the CLIP Trial feasibility work (ETHICS # H12-00132). Institutional ethics approvals were also obtained from all participating sites: Ethics Review Committee at Aga Khan University in Karachi, Pakistan (ERC # 1917-OBS-ERC-11); Health Research Ethics Committee at Olabisi Onabanjo University

Teaching Hospital in Sagamu, Nigeria (ETHICS # 326/431); Bioethics Committee at Manhiça Health Research Centre in Mozambique (ETHICS # CIBS 05/013); and Institutional Ethics Committee at Karnataka Lingayat Education University's Jawaharlal Nehru Medical College in India (ETHICS # MDC/IECHSR/2012-13/A-12).

Discussion

Feasibility studies are critical to understand the context of intervention prior to clinical trials. Such studies enable researchers to capitalize on facilitators, to remediate barriers, and to tailor operational aspects of interventions in advance of the trial (110). Moreover, lessons from feasibility studies are instrumental to guide post-trial program scale-up. It is often argued that interventions shown to have promising results in a trial context are not able to be integrated into existing systems post-trial. Therefore, feasibility assessments, guided by robust methods, play a pivotal role in informing the fate of the trial in terms of implementation and post-trial scale-up. According to Lewin, qualitative research is rarely combined with randomized control trials (RCTs), as it was used in only 23 out of 100 RCTs published in English language during 2001-2003 (111). An exclusively quantitative or qualitative approach cannot appropriately assess the feasibility of a large multi-country community-based clinical trial. A mixed methods design has advantages for validation, contextualization, and triangulation (112).

The mixed method study design used for this study has generated a useful framework which can be employed for future research aiming to evaluate the feasibility of large scale public health interventions. All data collection tools will be made readily available and open access once the primary study results of the trial have been accepted for publication.

The feasibility studies highlight enabling factors including need for community mobilization, awareness raising programs, institutional support, community safety nets for emergency funds, and system integration. Whereas, impeding factors included delays in care seeking, knowledge gaps, lack of trained human resource, cultural myths and misconceptions, high cost of care, and poor health service quality. Lessons learned from this study were used to establish research processes and infrastructure to pave the way for the implementation of the CLIP Trial and post-trial program scale-up should the trial be successful in reducing maternal and perinatal mortality and morbidity. (Figure 12, pg 60)

Findings also informed local investigators, health practitioners, policy makers, and international research partners on the feasibility of implementing a community level package of care to identify, triage and treat women with pre-eclampsia and eclampsia. Combined FGDs for women of reproductive age- and mothers-in-law, husbands- and fathers-in-law may limit generalizability of study results. First, it could possibly impede open dialogue because of potential cultural barriers whereby young people are unlikely to oppose senior members of the family. Second, it could cause social desirability bias whereby participants respond in a manner that was considered favourable by other family members.

Feasibility assessments for community level interventions, particularly those involving task-shifting across diverse regions, require an appropriate theoretical framework and careful selection of research methods. The use of qualitative and quantitative methods increased the data richness to better understand the community contexts. The methodological aspects described in this paper can provide guidance for similar studies in other settings.

Table 6. Distribution of focus group discussions at respective study sites.

Level	Focus groups	Sites				Total
		Mozambique	Nigeria	Pakistan	India	
Community	Women of reproductive age and pregnant women	5	16	19	5	45
	Male and female decision makers (husband/partners, father-in-law, mother-in-law)	10	4	7	6	27
	Opinion/religious leaders or community stakeholders	1	4	-	2	7
	Health committees	1	-	-	-	1
Care providers	Community health care providers	5	7	7	4	23
	Medical officers and obstetricians	-	1	-	1	2
	Nurses and midwives	-	4	-	4	8
	Faith-based care providers	-	1	-	-	1
	Traditional birth attendants	5	4	-	-	9
Total		**27**	**41**	**33**	**22**	**123**

Table 7. Distribution of in-depth interviews at respective study sites.

Level	In-depth informants	Sites				Total
		Mozambique	Nigeria	Pakistan	India	
Policymakers	Opinion leaders, and community stakeholders	-	4	-	-	4
	Head of local government and programme directors	-	7	-	-	7
	Hospital administration and supervisors of community health workers.	3	12	10	-	25
Care providers	Medical doctors, specialist/SOG member, obstetricians, reproductive-child health officers, and private practitioners	5	11	9	12	37
	Traditional birth attendants or traditional healers	5	5	7	-	17
Community	Local NGO representatives	5	-	-	-	5
	Knowledgeable women / matrons	5	-	-	-	5
Total		**23**	**39**	**26**	**12**	**100**

Table 8. Health facilities surveyed.

Facilities surveyed	Sites				Total
	Mozambique	Nigeria	Pakistan	India	
Public primary/secondary health facilities	54	47	14	17	132
Public tertiary care health facilities	2	1	1	2	6
Private secondary/tertiary health facilities	-	16	12	65	93
Laboratories	-	-	25	-	25
Drug stores / Pharmacies	-	-	81	-	81
Total	**56**	**64**	**133**	**84**	**337**

Table 9. Self-administered health care provider questionnaires.

Community health care providers	Country	Numbers
Lady health workers	Pakistan	458
Auxiliary nurse midwives	India	8
Staff nurses	India	2
Agente polivalente elementar	Mozambique	81
Total		**549**

Table 10. Estimated sample size for baseline survey at the community.

Country	Numbers of households/women
Pakistan	88,410 households
Nigeria	32,042 households
India	5189 women
Mozambique	To be determined

Figure 6. Stakeholders of the CLIP feasibility study.

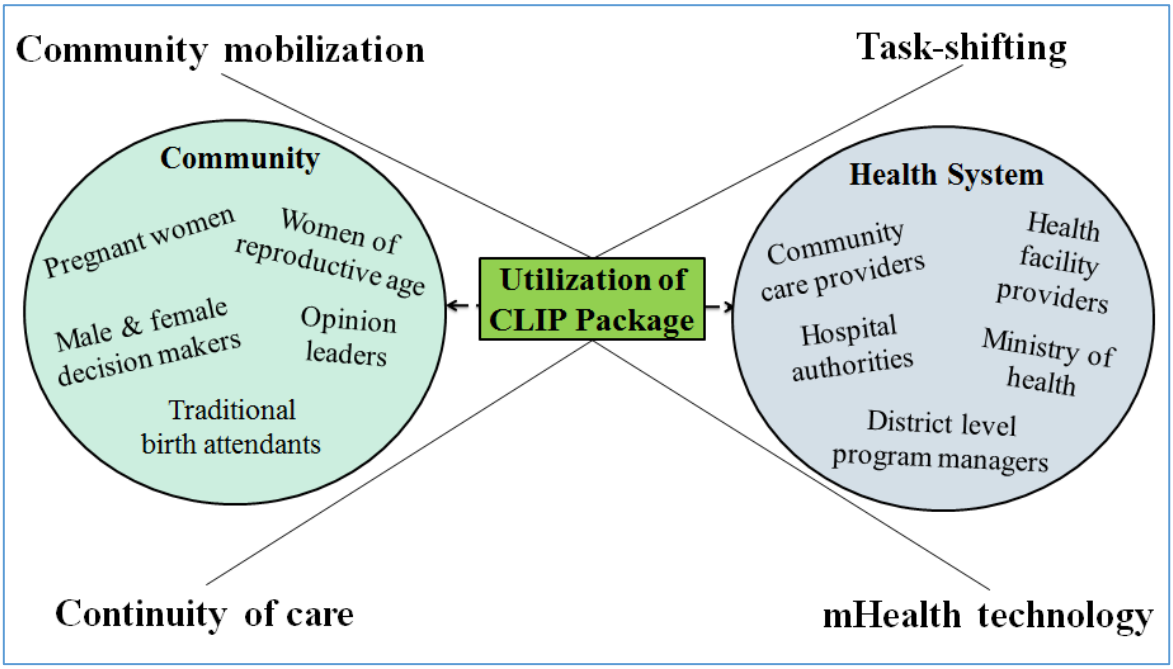


Figure 7. Study site map of Nigeria.

Figure 8. Study site map of Mozambique.

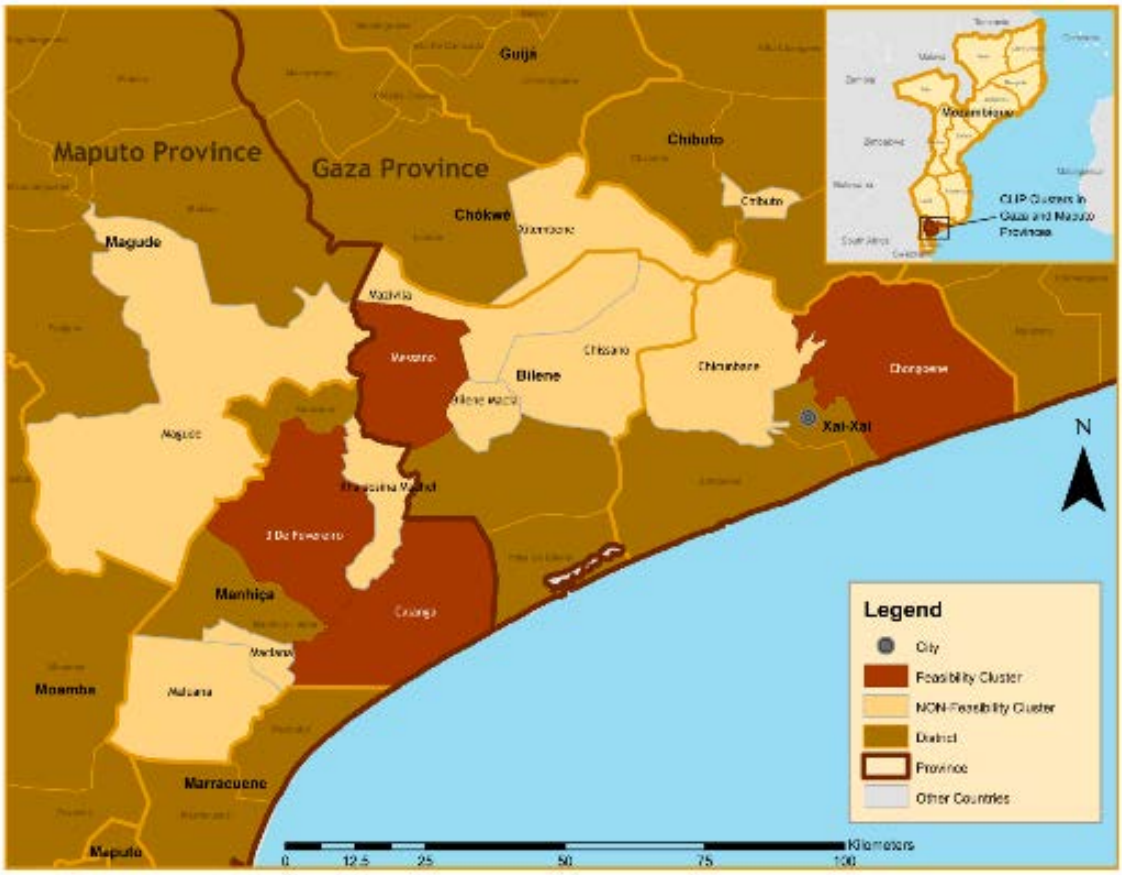


Figure 9. Study site map of Pakistan.

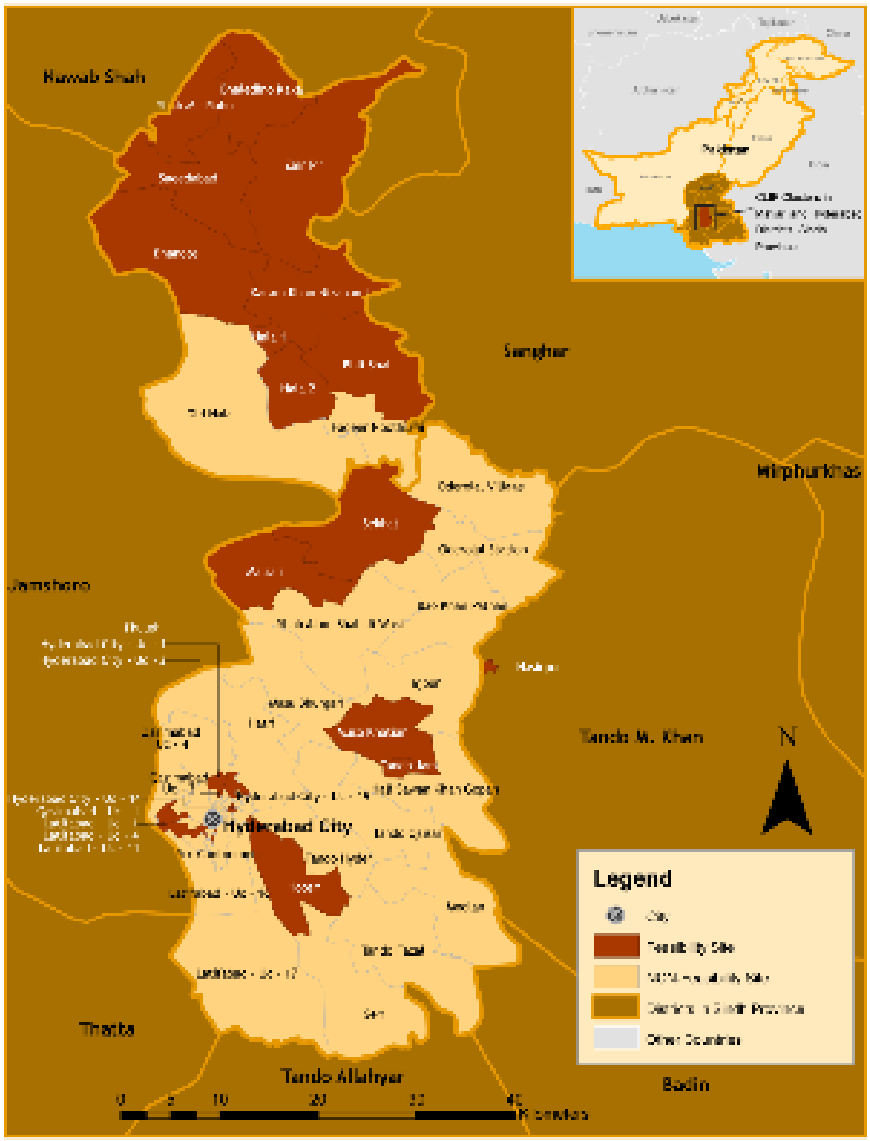


Figure 10. Study site map of India.

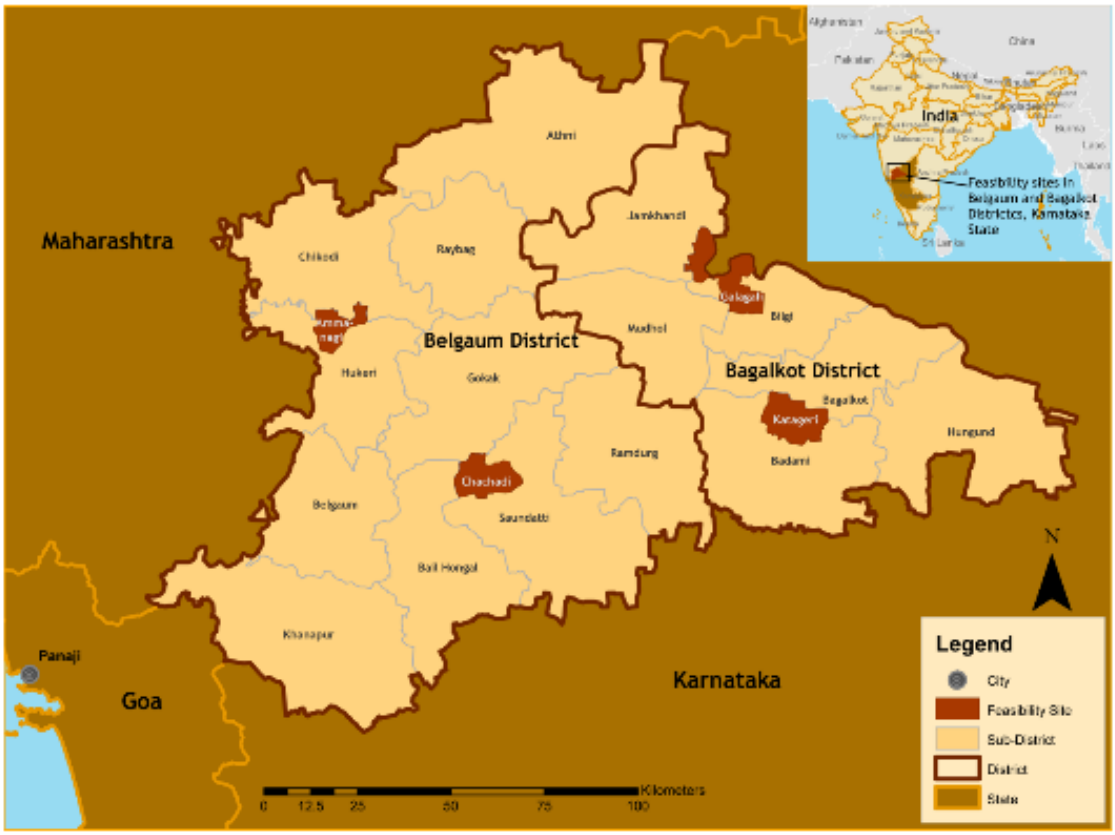


Figure 11. Steps of qualitative data analysis using QSR NVivo-10.

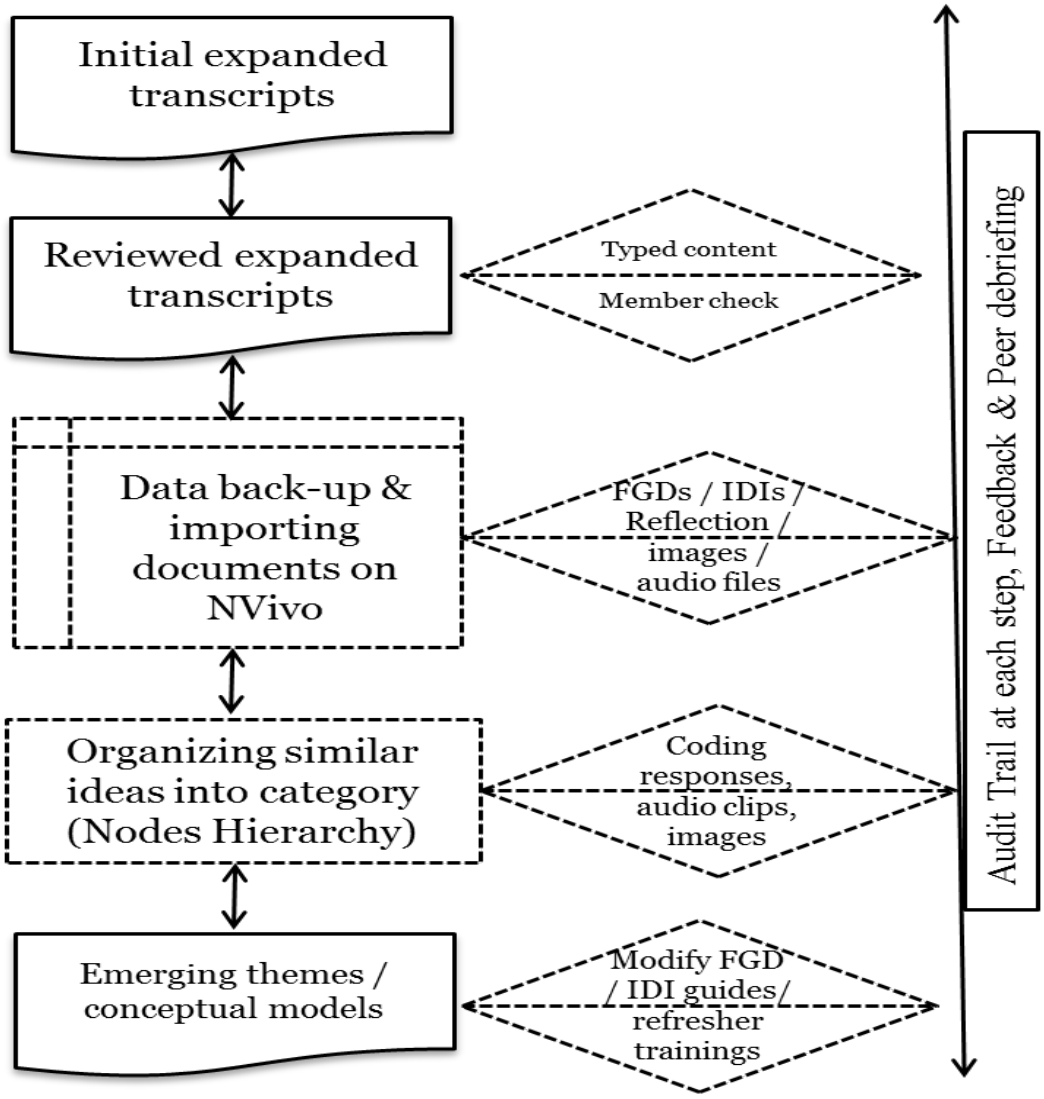
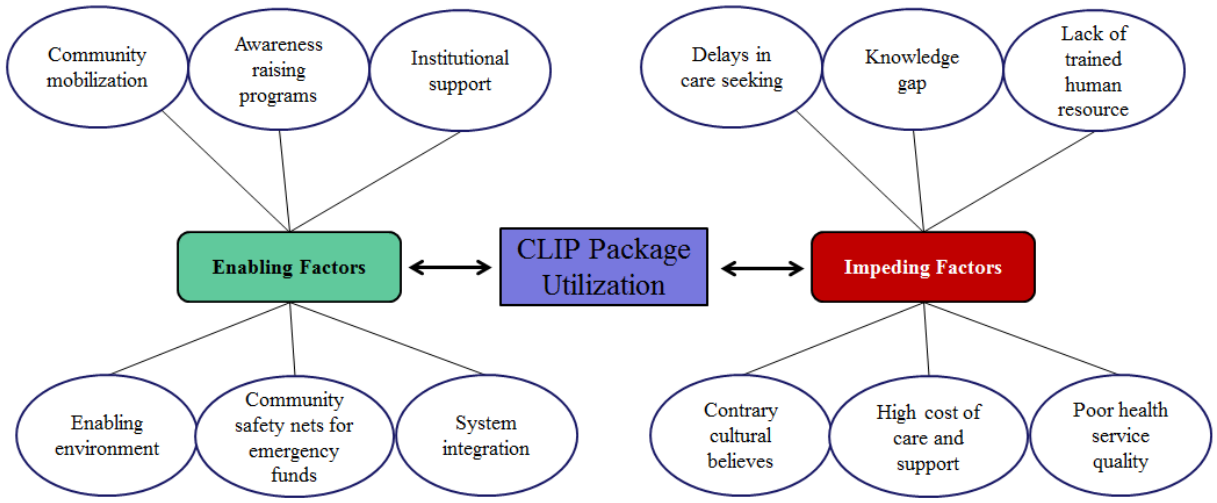


Figure 12. Understanding the context of interventions to maximize the CLIP package utilization.



Chapter 4. Community Perceptions of pre-eclampsia and eclampsia in Ogun State, Nigeria: A qualitative study

Background

Pre-eclampsia is one of the most common complications of pregnancy and continues to be a leading cause of death and disability globally (8). Pre-eclampsia is characterized by new onset of hypertension and proteinuria after 20 weeks gestation (74). It may progress to eclampsia; a potentially lethal complication characterized by convulsions requiring an emergency response (113). The World Health Organization estimates that 14% of all maternal deaths result from the hypertensive disorders of pregnancy (HDP); it is also associated with a high risk of newborn death (8). Nigeria, has one of the highest maternal mortality ratios ranging from 496 to 560 per 100,000 live births (3, 114), as well as a high prevalence of pre-eclampsia and eclampsia of between 2% to 16.7% (115).

Most studies focussing on pre-eclampsia and eclampsia have used a bio-medical model to examine causative factors, prevention and treatment without much attention to local perceptions. This study takes an alternate approach by adopting a perspective that recognizes an interaction of various components of the socio-cultural environment that influence community perceptions (116). The aetiology of pre-eclampsia remains a mystery; the cause and disease pathways are not fully understood (117). There is a gap in knowledge regarding the causes among communities in Northern Nigeria where pre-eclampsia is believed to be caused by *Iska* (spirits) (17). Similarly, Nigerian men have reported that maternal deaths are caused by supernatural spirits, social and economic factors, or poor quality health care services (20). Some Nigerians did not recognize the

signs of pre-eclampsia; however, some women recognized eclampsia and hypertension as potential causes of maternal mortality (18, 95).

The aim of this study was to identify community perceptions of pre-eclampsia and eclampsia in Ogun State, Nigeria. These community understandings were described by the use of local terms, perceived causes, prevention strategies, known outcomes and traditional treatments.

Methods

Description of study sites

The study was undertaken in Nigeria, the country with the largest population in Africa and the 14th largest in land mass (114). More specifically, it was conducted in four (Ogijo, Yewa South, Imeko-Afon and Remo North) Local Government Areas (LGAs) in Ogun State, located in south-western Nigeria. The predominant ethnic group is Yoruba. The health status of the region is reflective of that of most of south-western Nigeria (114). There are high rates of poverty, fertility and mortality (114). See Table 6 for country and cluster characteristics, see Figure 14 (pg 80) for a map of study areas.

Data collection

Data were collected as part of a larger community-based assessment of the acceptability of community-based treatment for pre-eclampsia and eclampsia in Nigeria: a detailed description of these methods is published elsewhere (118). Focus group discussions and in-depth interviews were conducted from 2011-to-2012.

Eight focus groups were held with pregnant women (N=94), eight with new mothers (N=95), four with male decision-makers (N=47), five with community leaders (religious and

representatives of traditional rulers and political groups) (N=56), and three with traditional birth attendants (TBAs) (N=36). In addition, interviews were conducted with the heads of the traditional birth attendants (N=4) and with community leaders (N=5).

Data analysis

All interviews and focus groups were transcribed and translated from local language (Yoruba) to English. These translations were reviewed by study investigators to ensure accuracy, and validated with field notes. Data were analysed using QSR NVivo version 10 software. The analytical framework and coding structure were developed by the study principal investigators (FO, OA) and data analyst (MV); however, for consistency, all coding was performed by one individual (MV). In addition, the nodal structure created and used for coding was subjected to a thorough review process by 5 other authors prior to the commencement of the coding exercise. The majority of themes were identified a priori to represent community perceptions of pre-eclampsia; however, a small number of themes emerged from the data through the coding process and were included at that time. (Figure 15, pg 81)

The Health Research and Ethics Committee of Olabisi Onabanjo University Teaching Hospital, Sagamu, Nigeria (OOUTH/DA/326/431), and the Clinical Research Ethics Board of the University of British Columbia, Vancouver, Canada (H12-00132), approved the study.

Results

Demographic characteristics were collected during focus groups discussions on all 323 participants; for details of participants see Tables 11 (pg 74). Nearly all participants were married; there were very few exceptions to this. Participants were of Islamic, Christian, and local traditional faiths; however, Christianity predominated. Most participants had at least one child

with several having up to 7 children. Educational attainment was highest in one cluster (Ogijo); this may be explained by its proximity to an urban centre. (Table 12, pg 75 and Table 13, pg 77)

Local terms for pre-eclampsia and eclampsia

Based on the descriptions provided by respondents, pre-eclampsia and eclampsia appeared to be a common occurrence in these communities. Although, hypertension and convulsions had few local names that are independent of pregnancy status, there were no local terms in Yoruba for pre-eclampsia.

Hypertension in pregnancy was commonly referred to as "*èjè rírû*" or "*ìfúnpá gígâ*". The term "*ìfúnpá gígâ"* in Yoruba, is a combination of two words: *"ìfúnpá"* signifies the process of strapping the arm during a blood pressure measurement and "*gígâ*" refers to something "elevated" or "high". Thus, "*ìfúnpá gígâ*" as a local term was used to describe hypertension. On the other hand, *"èjè ríru"* provides a succinct description of hypertension; it literally means "*stormy blood"*. This term captures the local perception that hypertension is comparable to a storm within the body.

A number of participants used local terms for general convulsions or convulsions in children to describe eclampsia: "*gìrì"* and *"àìsàn îlè tútù"*. "*Gìrì"* is a common local term used to describe the temporary jerking of the body. *"Àìsàn îlè tútù"* is used to represent seizures, which translates to '*cold-ground illness'*; this indicated the perceived relationship between exposure to cold and seizures. Though these terms imply general convulsions, many also reported the use of '*gìrì âlábôyún'* which is specific to pregnancy and represents eclampsia (See Table 14 (pg 78) for a list of these local names).

Perceived causes of pre-eclampsia and eclampsia

There was a consensus amongst the community regarding what was believed to cause hypertension in pregnancy; most often depressive thoughts and stress were described as the origin.

> *"If the pregnant woman is having depressive thoughts, if she encounters something that is beyond her, and she begins to worry about the issue, a thing like that could cause high blood pressure." [Pregnant Woman]*

The root of these depressive thoughts was most often related to marital or financial worries. This marital conflict included abandonment, teenage pregnancies, unfaithful partners and lack of adequate care by the husband.

> *"It is caused by their husband's bad behaviour, because a lot of men want their wives and not her pregnancy. Some husbands would stop taking care of their wives when they become pregnant." [Community Leader]*

Depressive thoughts were also believed to be associated with a lack of rest which could cause hypertension. Most respondents in this study did not believe that hypertension could have a spiritual origin; however, a small number maintained this belief.

Although a number of possible causes for eclampsia emerged from the focus groups and interviews, the most common were the influences of cold, heredity, diet, and depressive thoughts or stress. There was a strong perception that taking cold food, or drinks during pregnancy can lead to convulsions, as well as the exposure to cold weather. This was by far the most common explanation of convulsions in pregnancy in the community. A pregnant woman demonstrates this belief in the following quote:

"There is a belief that if a pregnant woman frequently sleeps on a cold floor, it could cause convulsion, or if the body is exposed to too much breeze […] and also if there are excessive depressive thoughts…it can lead to convulsion." [Pregnant Woman]

Another explanation was that convulsions during pregnancy could be hereditary.

"Something that I have noticed about 'gìrì' is that some things are hereditary. There are some things that people would say similar thing happened to the father or mother at a time. So things like this would have become hereditary and if this is not treated early it will run from two to three generations and it would become a family problem." [Community Leader]

Similar to the causes of hypertension, development of seizures in pregnancy were seen to be caused by depressive thoughts and stress (See Table 15 (pg 79) for a list of causes mentioned). One male decision-maker shared his view about how depressive thoughts could lead to convulsion:

"If she's under too much stress, she might not sleep and it gets to the point that she finds it difficult to sleep and the health care workers begin to monitor her blood pressure, a thing like this could cause convulsion for an adult and it's the same predicament for a pregnant woman" [Male Decision-Maker]

Similarly, a number of respondents perceived the role of diet to be important in the development of seizures. Poor diet was rarely stated as an independent contributor, but rather a co-factor with marital problems or financial constraints. Apart from the causes mentioned above, the medical conditions thought to be related to eclampsia were anaemia, malaria, urinary tract infections, diabetes, infections, oedema, pre-existing hypertension, and the lack or loss of blood. The possibility of a spiritual origin for convulsions in pregnancy was widely discredited

by the community. Some participants showed comprehension that high blood pressure is a cause of convulsions; however, most did not associate the two conditions.

> *"What causes convulsion is like the other participant explained earlier, if a pregnant woman should have high blood pressure there would be a substance in her urine, there's a way they detect the substance, also if her legs are swollen…blood shortage could cause swollen legs for the pregnant woman, lack of blood in her system could make her legs to swell. If a woman should stress herself too much during pregnancy a thing like this could make her develop high blood pressure, all these factors together would cause convulsion for the pregnant woman and the condition would be out of control. [Community Leader]*

Prevention strategies for pre-eclampsia and eclampsia

Much of the preventive practices mentioned were related to pre-eclampsia and centred on the type and quality of care women received during pregnancy. There were a few mentions of local or traditional practices for prevention of pre-eclampsia aside from dietary suggestions. The role of men in the prevention of pre-eclampsia was widely emphasized, particularly the importance of their emotional and financial support.

> *"If a pregnant woman has a history of convulsion and her husband is aware of her condition her husband could find a person that would be assisting his wife, he would tell the person that "in case my wife convulses, please you would help me assist her" and when they see that the pregnant woman is heavy and she's about to deliver they shouldn't let her be alone, they shouldn't allow her to be alone because it could affect her pregnancy." [New Mother]*

In addition to the role of men, diet was perceived as a significant moderator of high blood pressure. Decreased intake of 'Maggi' – a common food seasoning - and salt were thought to be

appropriate methods for preventing high blood pressure among pregnant women. Other prevention strategies included a public health enlightenment programme on preventive methods of pre-eclampsia and its management at the community level. In addition, the roles of community health workers in expanding knowledge and creating awareness on pre-eclampsia and eclampsia conditions are very crucial.

Outcomes of pre-eclampsia and eclampsia

There was a general perception that pre-eclampsia is severe and could lead to loss of life in pregnancy. This was reinforced by individual experiences of pre-eclampsia. One male decision-maker gave a description of high blood pressure in pregnancy as "a trap".

> *"High blood pressure is like a trap, once it affects a woman, it may be difficult to cure. Sometime it may be hereditary and once a woman has it, she can also transfer it to her unborn baby since they both share the same blood, high blood pressure can lead to the death of women." [Male Decision-Maker]*

Furthermore, a view expressed among a segment of the population showed that "*high blood pressure can affect the brain [and] it can also lead to "gìrì" (convulsions), or "òyì orí" (dizziness).* The term *"òyì orí"* combines two Yoruba words; *"òyì"* literally means *dizziness*, *"orí"* means *head*. Thus, *"òyì orí"* signifies dizziness in the head which could lead to a fatal fall. TBAs described convulsions in pregnancy as a complicated condition. One TBA explained that *"gìrì ipá" (convulsions)* could lead to *"âbísíwín"*, known as puerperal psychosis in biomedical terms. According to new mothers, possible outcomes of pre-eclampsia and eclampsia were premature birth, stillbirth, paralysis, and stroke.

Traditional treatment of pre-eclampsia and eclampsia

Home-based and traditional treatments for pregnancy complications are very common in the region. There were many traditional treatments being used for eclampsia including eating onion, drinking salt solution, and applying Robb to the chest. Robb is a type of balm used for relieving aches and pains among children and adults in addition to its use for treating cold and shivering condition. Other traditional treatment options mentioned were bodily incisions and prayers. According to one woman, "*they could give the pregnant woman onions, they should shred the onions and put in it in her mouth, the aroma of the onions would calm her down, before they take her to the hospital"*. As eclampsia is believed to be caused by exposure to cold, a concoction known as "*oògùn ilè tútù"* meaning *cold ground medicine* is reportedly used. The role of cold-ground-medicine is highlighted in the following quote by a pregnant woman:

> *"If it (convulsion) happens, the woman would be given a local concoction "oògùn ilè tútù" or would be taken to the hospital. But she would usually be given the local concoction until the convulsion subsides." [Pregnant Woman]*

In the treatment of eclampsia, some put salt in the pregnant woman's mouth as it is believed "*salt would dissolve the substance blocking the blood vessels"*. In addition to giving salt, a spoon or '*chewing stick'* is often inserted into the mouth to avoid clenching the teeth. Other types of treatment include asking the woman to lie down on her right side, and then pouring water on her head until she is revived.

> *"They should turn her to her right side and raise her up...that is what I know and that is what I've witnessed, if they pour water on her head and raise her up and put her down gently. Nobody should say a word around her at that moment. If it's just a normal convulsion, she would be revived." [New Mother]*

Lime and hot spices were also reportedly used for treating eclampsia. A TBA described the contents of one of the local concoctions used for eclampsia:

"I use original tobacco leaves… use it with boiling water and soak it with lemon juice, if pregnant woman is convulsing give her one teaspoon, rub it on her eyes and body… it will usually calm her down." [Traditional Birth Attendant]

Some opinion leaders report the use of incisions on the forehead or abdomen of pregnant women for treatment. This was usually combined with other local treatments such as black soap, concoctions, and burnt leaves.

"They treat it in the traditional way, using [herbs], black soap, burnt leaves or make incisions. You would see some pregnant women with many incisions on their heads." [Community Leader]

Among those who patronized prayer houses and spiritualists, different treatment methods were reported: *holy water*. In addition, a special prayer session was reportedly carried out for these women.

Discussion

The findings of this study show that community perceptions of pre-eclampsia and eclampsia in Ogun State differ significantly from biomedical perspectives (17). While the perceived cause of eclampsia in these communities was exposure to cold, biomedical evidence suggest the causal pathway is related to abnormal placentation (119). Divergent community perspectives reported in this study have led to treatment in line with traditional norms and values in Ogun State. Local treatments in these communities have stemmed from the community's understanding of the condition.

In addition, the findings show that respondents do not use specific terms for pre-eclampsia in local language, though hypertension has names that independent of pregnancy status that are used. These results demonstrate limited knowledge and awareness of pre-eclampsia and its associated consequences despite its rating as one of the leading causes of maternal death (2, 8, 74, 120). There was consensus amongst the community on the causes of hypertension, both during and outside pregnancy, with the main cause pointing to psychological factors, particularly depressive thoughts, heredity and stress. There was a similar consensus regarding the cause of eclampsia, the origin reportedly related to an exposure to cold. These findings further show that a knowledge gap exists regarding the causes and progression of symptoms from pre-eclampsia to eclampsia. This lack of awareness underscores the need for a sustained commitment to community sensitization using a combination of approaches that could penetrate social and cultural norms.

There is need for further sensitization of the community members with respect to availability of subsidized health services. The process for sensitization also offers opportunity for education regarding pre-eclampsia and eclampsia. There is a need to promote a strategy that allows community members to intervene using cultural norms to address challenges in care delivery for women with pre-eclampsia and eclampsia. In this sense, this study advocates for a "*cultural intervention"*. As distinct from other forms of intervention, cultural intervention will enable the community to discuss their problems and challenges with the aim of providing solutions to them. The involvement of men in maternal health could be culturally influenced. The role of men in pregnancy and delivery care among African women has gained attention recently, (121, 122) and could be extended to issues related to pre-eclampsia and eclampsia.

This study reveals that there are several local treatments for eclampsia among community members in Ogun state. The use of traditional medicine during pregnancy has been documented elsewhere (123). The desire to have personal control over their health, dissatisfaction with conventional treatments, and concerns about the side effects of medications explain in part the use of herbal remedies during pregnancy (124). The efficacy of local interventions, especially those related to the treatment of eclampsia is either not known or deleterious (i.e placing items between the teeth). The use of traditional treatment has been identified as a source of delay to accessing appropriate health care services and also could be a marker for harmful behaviour (125). The findings from this study provide additional information on local perception and practices that have consequences for the early treatment of pre-eclampsia and eclampsia in Nigeria.

The general perception that psychological distress could be an underlying cause of pre-eclampsia and eclampsia requires further exploration. This study shows that there is a large gap between community perceptions of pre-eclampsia and eclampsia and the biomedical perspective. Sadly, relevant policies, like the National Health Policy in Nigeria, do not take into account community perspectives in framing such policies. As such, these policies are generally disconnected from peoples' experiences, beliefs and local realities.

Strengths and limitations

One of the strengths of this study is the community-based approach, which provided rich insight into perceptions of the diverse population. In addition, the participation of the various stakeholder groups who influence beliefs and attitudes enriched the study findings: pregnant women, opinion leaders, religious leaders, TBAs and male decision-makers. Furthermore, a multi-disciplinary approach brought researchers from various backgrounds to enhance quality in

data collection and the entire study. Notwithstanding, findings from this study may not apply to other ethnic groups represented in Nigeria other than the Yoruba among whom the study was conducted. Another limitation is the inability of the study to provide in details regarding the contents of local medicines in use during pregnancy.

Conclusions

The study illustrates that knowledge of pre-eclampsia and eclampsia are limited amongst communities of Ogun State, Nigeria; there are gaps in knowledge regarding the aetiology and treatment of the conditions. It also highlights the need for a review of maternal health policies in Nigeria with special attention to community roles, specifically the role of men, and the need for health care providers to be equipped with appropriate skills and relevant materials to provide community education and sensitization to improve maternal and perinatal health.

Table 11. Study site characteristics.

Nigeria characteristics	
Population	159,288,426
Size (Km^2)	923, 768
Number of states	36
Number of geopolitical zones	6
Predominant language	Yoruba, Igbo, and Hausa
Predominant religions	Christianity and Islam
Ogun State characteristics	
Population	4,000,000
Size (Km^2)	16,409
Number of local government areas	20
Predominant language	Yoruba
Predominant religion	Christianity
Local Government Area characteristics	
Cumulative population	469,271
Cumulative size (Km^2)	1657
Number of study areas	4/40

Table 12. Focus group discussion characteristics.

#	N participants	Region	**Age (yr)** Median [range]	**Religion** 1 Islam 2 Christian 3 Traditional religion	**N children** Median [range]	**% Married**
Community Leaders						
1	12	Yewa South	52 [27,70]	1= (N=6) 2= (N=6)	5 [0,6]	100%
2	10	Remo North	44 [43,77]	1= (N=3) 2= (N=5) 3= (N=2)	*Not known*	100%
3	12	Remo North	58 [30,85]	*Not known*	*Not known*	100%
4	10	Ogijo	50 [26,71]	1= (N=5) 2= (N=5)	6 [1,9]	100%
5	12	Ogijo	57 [45, 72]	1= (N=3) 2= (N=6) 3= (N=3)	8 [4,10]	100%
6	12	Imeko-Afon	45 [20,55]	1= (N=6) 2= (N=6)	3 [0,10]	100%
Male Decision-Makers						
1	12	Yewa South	38 [27,49]	1= (N=2) 2= (N=10)	3 [1,5]	100%
2	11	Remo North	40 [35,62]	1= (N=4) 2= (N=6) 3= (N=1)	3 [0,9]	100%
3	12	Imeko-Afon	51 [40,60]	1= (N=11) 2= (N=1)	6 [4,10]	100%
New Mothers						
1	12	Yewa South	27 [20,42]	1= (N=6) 2= (N=6)	3 [1,5]	100%
2	12	Yewa South	31 [20,42]	1= (N=4) 2= (N=8)	2 [1,3]	100%
3	12	Remo North	29 [21,39]	1= (N=3) 2= (N=9)	4 [1,6]	100%
4	12	Remo North	28 [21,34]	1= (N=5) 2= (N=7)	2 [1,4]	100%
5	12	Ogijo	31 [26,43]	1= (N=4) 2= (N=8)	3 [1,4]	92%
6	12	Ogijo	29 [22,38]	1= (N=1) 2= (N=11)	2 [1,5]	100%
7	12	Imeko-Afon	30 [16,36]	1= (N=5) 2= (N=7)	3 [1,5]	100%
8	11	Imeko-Afon	30 [18,36]	1= (N=6) 2= (N=5)	3 [1,6]	100%
Pregnant Women						
1	12	Yewa South	26 [20,33]	1= (N=3) 2= (N=9)	1 [0,4]	100%
2	12	Yewa South	26 [20,39]	1= (N=4) 2= (N=8)	3 [1,3]	100%

#	N participants	Region	**Age (yr)** Median [range]	**Religion** 1 Islam 2 Christian 3 Traditional religion	**N children** Median [range]	**% Married**
3	12	Remo North	30 [20,36]	1= (N=1) 2= (N=11)	1 [1,3]	100%
4	12	Remo North	32 [23,40]	1= (N=5) 2= (N=7)	3 [1,5]	100%
5	9	Ogijo	27 [19,34]	1= (N=6) 2= (N=3)	1 [0,2]	100%
6	10	Imeko-Afon	22 [19,26]	1= (N=7) 2= (N=3)	1 [0,4]	100%
7	12	Imeko-Afon	25 [20,30]	1= (N=2) 2= (N=10)	2 [0,4]	100%
Traditional Birth Attendants						
1	12	Yewa South	44 [32,65]	1= (N=7) 1= (N=5)	3 [1,4]	100%
2	12	Remo North	50 [41,77]	1= (N=1) 2= (N=8) 3= (N=2)	5 [3,5]	100%
3	12	Ogijo	40 [25,50]	1= (N=5) 2= (N=6)	4 [0,5]	83%

#	Stakeholder Group	Cluster
1	Head of Traditional Birth Attendants	Sagamu
2	Head of Traditional Birth Attendants	Yewa South
3	Head of Traditional Birth Attendants	Imeko-Afon
4	Head of Traditional Birth Attendants	Remo North
5	Community Leader	Imeko-Afon
6	Male Community Leaders	Imeko-Afon
7	Women Community Leaders	Sagamu
8	Women Community Leaders	Imeko-Afon
9	Women Community Leaders	Remo North

Table 13. Interview characteristics.

Table 14. Local terms for pre-eclampsia and eclampsia.

Local terms for pre-eclampsia		
Ìfúnpá gígâ	Èjè rírû (stormy blood)	
Local terms for eclampsia		
Gìrì âlábôyún (pregnancy related seizure)	Gìrì (Seizure)	Gìrì àgbàlâgbà (Seizure in adults)
Gìrì ipa (stubborn seizure)	Gìrì înú ôyún (pregnancy-related seizure)	Òyì ôrí (dizziness in the head)
Îpá ná (Hot seizure)	Îlè tútù (cold ground)	Òyì ôjú (dizziness in the eyes)

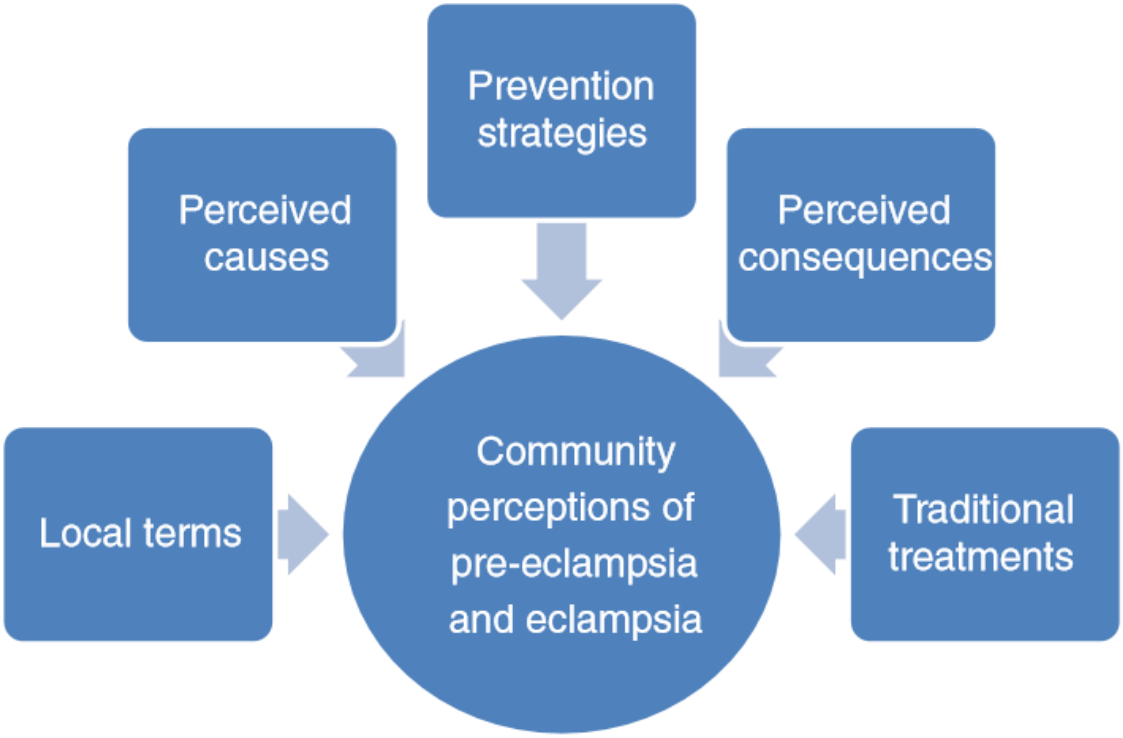
Table 15. Perceived causes of pre-eclampsia and eclampsia.

Perceived causes of pre-eclampsia
Depressive thoughts
Hereditary
Stress
Perceived causes of eclampsia
Prolonged exposure to cold
Hypertension
Anaemia
Malaria
Urinary tract infections
Diabetes
Oedema
Lack or loss of blood
Pre-existing hypertension
Taking cold food or drinks
Sleeping on a cold floor

Figure 14. Map of study sites.

Fig. 1 Map of study sites

Figure 15. Thematic categories used in analysis.



Chapter 5. Community perceptions of pre-eclampsia and eclampsia in southern Mozambique

Background

Improving maternal health is one of the Millennium Development Goals (MDGs) adopted by the international community in 2000. According to MDG5, countries committed to reduce global maternal deaths by three quarters by 2015 (126). Despite the significant gains in terms of reduction, in 2015, an estimated 303,000 maternal deaths will occur globally, representing a decline of only 43% since 1990 (estimated 535,000 maternal deaths) and a similar reduction since the adoption of the MDGs in 2000 (estimated 529,000 deaths) (127), which is far from the target 75% reduction.

Sub-Saharan Africa has the highest maternal mortality ratio (MMR), with 546 deaths per 100,000 live births in 2015 (127). In Mozambique, maternal-newborn health is a public health priority; as it is reflected in recent government investments and policies. The implementation of the National Strategic Plan for the Reduction of Maternal and New Born Mortality since 2000, has led to improvements in access to quality health services including antenatal care, family planning, and the diagnosis and treatment of obstetric complications (128). The MMR in Mozambique has decreased from 1,300 in 1990 (129) to current estimates of 249-480 per 100,000 live births (8). The major direct causes of maternal mortality in Mozambique are obstetric, such as postpartum haemorrhage, rupture of the uterus, and puerperal sepsis, with an increasing role of infectious diseases mainly HIV/AIDS, tuberculosis and malaria (128, 130). Eclampsia has been reported to be the third leading cause of maternal death in the country (128, 131). Effective management of pre-eclampsia and eclampsia is limited to hospital-based

treatment, thus increasing women's probability for severe complications or death due to delays in reaching emergency care (132).

A previous study conducted in Mozambique concluded that 13% of women with eclampsia reported not having had blood pressure monitoring during antenatal care (ANC) (133). This finding highlights the need for improvements in case detection at the primary care level, increased community awareness of the danger signs of eclampsia, as well as prompt referrals. Community-level detection and basic management of pre-eclampsia and eclampsia are needed to effectively address these gaps.

An understanding of community perspectives is crucial to the successful implementation of any community-based intervention. Literature regarding community perceptions of the hypertensive disorders of pregnancy is scarce, particularly in Africa. In a study conducted in Malawi (134) few women were able to correctly identify pre-eclampsia or eclampsia as maternal health problems. Similarly, studies in Nigeria showed limited knowledge of these complications and many misconceptions regarding the causes, as well as regular use of potentially harmful traditional practices (17, 135). In a study on community perceptions of maternal morbidity in Mozambique, pregnant women identified malaria, abdominal, back and body pains as the most important ailments during pregnancy, neither pre-eclampsia nor eclampsia were mentioned (136). There are no previous studies describing community beliefs and practices for pre-eclampsia or eclampsia in Mozambique.

The focus of this article is to document community knowledge, attitudes and beliefs regarding pre-eclampsia and eclampsia in southern Mozambique. A better understanding of community perspectives could be useful for policy makers and health care providers to implement effective strategies to improve maternal health care delivery. These results are equally

important to guide future community-based interventions, and to assess the effectiveness of innovative packages of care to control and mitigate pre-eclampsia and eclampsia.

Methods

Study area

This is an ancillary study of a multinational cluster randomized control trial in Nigeria, Mozambique, Pakistan and India (the Community Level Interventions for Pre-eclampsia trial-CLIP) (NCT01911494) (137). For this qualitative study, four study regions in Mozambique were selected, two from Maputo Province and two from Gaza Province (Figure 16, pg 103). Each study region was equivalent to an Administrative Post (AP), with the exception of Ilha Josina Machel and Calanga administrative posts, which were combined for the purposes of fulfilling the minimal population size for a study cluster within the context of the CLIP trial, and given that they are neighbouring APs. Each region was purposively selected to reflect a variety of socioeconomic and demographic characteristics, such as level of urbanization, population density, distance to a trading centre, and presence of a referral facility.

The Ilha Josina Machel-Calanga region is located in north-east Maputo Province, populated mainly by farmers and fishermen. This area is characterised by extremely poor transportation networks, which further deteriorate due to flooding in the rainy season. Três de Fevereiro is located in the north of Maputo Province, it is intersected by the 1st National Road (the major two-way highway in Mozambique, and the only connection between the northern, central and southern regions of the country) and has reasonable infrastructure such as modern communication networks, some secondary roads, and public services. Most residents of this AP are employed by the Xinavane Sugar Company and other private sugar and rice farms. This area

is an important informal business centre, with a large sector of the young adult male population employed in the mining sector in South Africa**.**

The two regions in Gaza Province were Messano and Chongoene. Messano, in the southwest, has a weak community infrastructure set-up including poor access to the main road. The primary occupation of residents is small-scale farming. Chongoene is a coastal region in northern Gaza. It is the newly appointed district head office, which has led to improvements in commerce, administrative services, tourism, and the agriculture sector.

Most residents of the four regions belong to the Changana ethnic group. The predominant occupation is farming, especially among women. Raising livestock, informal trading, and handicrafts are the other sources of income. Most men migrate to South Africa, Swaziland and other cities in Mozambique for work. Literacy varies between the two provinces with a 22% literacy rate in Maputo and 38% in Gaza, in both cases literacy is lowest among women (137). For more detailed study site characteristics see Table 16 (pg 97).

Data collection

This article is a component of a larger formative study prior to the CLIP trial. While the formative research was based on a mixed methods approach, the present article focuses on the qualitative component, comprised of focus group discussions and in-depth interviews with community stakeholder groups (see Tables 17 (pg 98) and 18 (pg 100) for participant characteristics).

Focus groups were chosen to best capture community members' views, while enabling open discussion between participants. It was difficult to convene focus groups for traditional healers and matrons due to the limited number available; therefore, individual interviews were conducted with these two stakeholder groups.

Data collection took place between September 2013 and May 2014. This process was conducted by a team comprising a Mozambican social scientist and four trained interviewers, all employed by the Manhiça Health Research Centre (CISM). All data collectors were fluent in Portuguese and Changana, the predominant local language.

As part of the rapport-building stage, the first contact was made with the community chief at the Administrative Post level, to obtain permission for data collection. Following this, a neighbourhood was randomly selected for data collection within each AP. Neighbourhood chiefs (known as *secretários dos bairros)* supported the study team in the identification of participants who fulfilled the inclusion criteria for interviews and focus groups. Participants had to belong to one of the following categories: pregnant, partners or husbands of women of reproductive age (WRA), mothers or mothers-in-law of WRA, matrons or traditional birth attendants (TBA), elders and traditional healers. The team made the final selection by verifying the characteristics of the potential participants and the number needed for interviews and focus groups. The *secretários dos bairros* were instructed to identify participants from different *quarteirões* (the set of houses located in the same block within a *bairro*).

Focus groups were conducted either at the *círculos* (the usual community gathering location), or at the community leaders' house, as groups could easily be convened in these locations. A total of 20 focus groups were conducted with an average of 7 (6-14) participants in each session. Groups were homogeneous according to the main inclusion criterion. However, there was heterogeneity within each focus group in terms of age, residence (*quarteirão*), occupation and education, as captured in Table 17 (pg 98). Each discussion lasted for 30 to 80 minutes.

A total of 10 interviews were conducted with community members (traditional healers and matrons). Interviews were conducted one-on-one in the home or workplace of participants, and were 30 to 60 minutes in length.

Data collection instruments served as guides for the discussions, allowing for probing and follow-up questions whenever necessary. These interview and focus group guides had been used in Nigeria, India and Pakistan in the context of the CLIP trial, and were subsequently adapted to the local context during the piloting process in Mozambique. The guides differed slightly according to the stakeholder groups, but in general they touched upon similar themes.

Although the guides were written in Portuguese, data collection was conducted primarily in the Changana local language. The choice of language was determined by participants' preference.

Ethical approval for this study was granted by the CISM Institutional Review Board (CIBS_CISM/08/2013), as well as by the University of British Columbia in Canada (H12-00132).

Data management and analysis

Focus group discussions (FGD) and in-depth interviews (IDI) were digitally recorded using Olympus AS-2400 PC; IDIs and FGDs were transcribed verbatim and translated simultaneously from Changana to Portuguese for analysis at CISM. On site, quality control was ensured by a secondary review of 20% of the transcripts against the audio recordings to confirm accuracy. Two social science researchers coded all the data, which was originally transcribed in Portuguese, in Mozambique. Twenty-six percent of all transcripts were translated into English and re-analysed by an external collaborator from UBC for quality control and to contribute to

interpretation of the data. Data from Ilha Josina Machel and Calanga were analysed separately and subsequently combined for presentation of qualitative findings.

Data saturation was sufficiently met after 20 focus group discussions and 10 individual interviews. Data analysis was performed using NVivo version 10.0 (QSR International Pty.Ltd. 2012). A thematic analysis approach was taken. The coding structure was developed in advance of analysis through collaboration among researchers. Themes were subsequently adjusted and new themes were added as they emerged from the data (Figure 17, pg 104).

Results

Participants' characteristics

Focus group participants were between 18 and 87 years of age. More than half (55%) had completed primary education and the majority were farmers. Sixty-five percent of the participants were married (Table 17, pg 98). Interview participants were male (30%) and female (70%) between 35 and 79 years old, most had completed primary education (80%), and over half (60%) were married (Table 18, pg 100).

Local terminology

The terms "pre-eclampsia" and "eclampsia" were not known to study participants. However, when facilitators further described the presentation of these conditions, participants did recognize them, yet they used alternative local terms. Specifically, pre-eclampsia was referred to as *tensão alta* (high blood pressure) or simply *tensão (*pressure). These were the only terms which were mentioned in Portuguese. The other terms used were in the local dialect, Changana: *mavabjiyambilo*or *mavabjiyatimpfalo* (illness of the heart) and *mavadjiyakuwa* (fainting disease). The Portuguese term used for eclampsia was *epilepsia* (epilepsy) and in

Changanaeclampsia was referred to as *mavabjiyanweti* (illness of the moon), *nhocane* (little snake), *mavabjiyambilo* (illness of the heart), *mavabjiyakuwa* (falling disease), *mavabjiyavatsonguana* (children's illness), *mavabjiyamakulo* (the big illness) and *mavabjiyakudzuka* (illness of scares) (Tables 19 (pg 101) and Table 20 (pg 102)).

Perceived causes

Neither pre-eclampsia nor eclampsia was perceived to be conditions specific to pregnancy. In addition, community participants rarely described a relationship between the two conditions. In these discussions with communities there was limited knowledge of the origin of pre-eclampsia. They most often related pre-eclampsia to marital problems, such as mistreatment by in-laws, strenuous work, excessive thinking or worry, anger, and sadness.

> *"You will get sick if you think a lot, thinking excessively about something and if you talk to yourself inside your heart and if something doesn't go well in your head, all this can lead to that disease."* Mother or mother-in-law, Ilha Josina Machel-Calanga

It was not common to associate pre-eclampsia with lifestyle factors; however, a few participants did believe that diets rich in salt may contribute to the occurrence of pre-eclampsia. During focus groups, all matrons claimed pre-eclampsia was caused by modern ways of living, as the condition was thought to be rare in previous generations (Table 19, pg 101).

Although there were widespread cultural beliefs surrounding convulsions, these were not specific to pregnancy. Seizures of all types were associated with a childhood illness, known as the *mavabjiyanweti* (illness of the moon). This illness is thought to be caused by a small snake (*nhocane*) which lives in the abdomen; it is believed that the phases of the moon can create imbalances in the body, which include growth abnormalities, digestive problems, and ultimately seizures. The 'illness of the moon' is believed to be congenital and continues without appropriate

treatment in childhood. Those who are not treated may suffer in pregnancy, which may affect birth outcomes. Furthermore, seizures are believed to be contagious to children, therefore they are usually sent away when someone is seizing (Table 20, pg 102).

> *"Hum what must be done if you find somebody in this way? In a house where there are children or other people […] this person must be carried away and placed somewhere, and afterwards you must find somebody nearby who knows the rules, then they will be able to help her."* Partner or husband, Ilha Josina Machel-Calanga

Warning signs

Community participants described the warning signs for pre-eclampsia as headache, heart pain, a strong heart-beat, burning sensation in the chest, shortness of breath, loss of speech, weakness, dizziness, fainting, sweating and swollen feet. Many of the warning signs for eclampsia were common with those mentioned for pre-eclampsia. Those warning signs unique to seizures in pregnancy included falling, eyes rolling back and red eyes.

> *"She always feels pain in the heart, or feels her body is weak. When you do hard work while you suffer from this disease, the heart may throb, you may even have dizziness and then faint."* Woman of reproductive age, Ilha Josina Machel-Calanga

Prevention strategies

The majority of participants expressed that early ANC and regular visits to the health facility are the most effective measures to prevent pregnancy complications.

> *"Pregnant women have to go to the hospital while the pregnancy is still small, growing pregnancy while going to the hospital."* Mother or mother-in-law, Três de Fevereiro

The only community-level prevention of seizures discussed was the administration of a medicine that consisted of a mixture of roots prepared in a clay pot *(swimbitana),* which must be

taken daily during childhood to be effective later in life. In addition, there are practices in pregnancy not specific to pre-eclampsia or eclampsia that are followed in order to ensure well-being, such as: avoiding bitter foods and drinks, avoiding strenuous labor, and small lacerations on the breast for the application of traditional powders.

Perceived consequences

The possible outcomes of pre-eclampsia, according to the community were miscarriage, premature delivery and death. Seizures in pregnancy were seen to be dangerous to women and infants because they may cause serious injury, paralysis, or death. These pregnancy complications are thought to be most dangerous before delivery, when pregnant women are more vulnerable, as was mentioned below during a focus group discussion.

> *"Usually it is dangerous during pregnancy, but after birth some things decrease. It is not as if you were pregnant like that woman, and she is ill she will have the same strength as a non-pregnant woman, then one woman that is like that can go wrong"* Partner or husband, Ilha Josina Machel-Calanga

Paralysis of limbs due to falling from a seizure was perceived to be an immediate consequence of eclampsia. In addition, participants described that both mother and infant are vulnerable to death. It was believed that the probability of death is increased as a result of inappropriate behaviours of those surrounding the woman, for instance expressing negative emotions.

> *"Another thing is that when she falls nobody must cry, because if she falls down and does not die but someone cries, she loses strength and dies. The people must be calm and strong."* Partner or husband, Três de Fevereiro

Traditional treatments

Most community members interviewed believed there is no traditional cure for pre-eclampsia or eclampsia; it can only be treated traditionally in childhood. Despite this, if a pregnant woman is unconscious she can be revived by exposing her to strong odours such as dirty shoes or leaves from *mafurreira* (a local wild fruit tree), lemon tree, *maungua-unguana* (a wild plant) or tobacco. Women who suffered seizures in pregnancy were usually taken to the shade or a place that allows her to get fresh air.

Discussion

To the knowledge of the authors, this is the first qualitative study comprehensively describing the local terminology, causes, consequences as well as local preventive and treatment practices for pre-eclampsia and eclampsia by communities in Mozambique. Studies of this nature have been conducted elsewhere, mostly in Malawi, Nigeria and Latin America, where participants were women who had experienced pre-eclampsia, or their close relatives (135, 138, 139). It is, however, important to also understand perceptions of the wider community.

Pre-eclampsia and eclampsia are terms unknown to the communities involved in this study, which is different from findings from one of the above studies, where eclampsia was mentioned by Nigerian women as one of the main causes of maternal mortality (18). Nevertheless, the present study revealed a basic awareness of hypertension and seizures in pregnancy. This finding supports the need to reinforce education regarding pregnancy complications.

Despite the awareness, among some groups, regarding some pre-eclampsia and eclampsia warning signs, they did not view pre-eclampsia or eclampsia as uniquely associated with

pregnancy. This assertion is illustrated by the fact that they are often depicted by the combination of traditional terminologies which do not enclose any reference to “pregnancy” or “pregnant women”. Seizures are generally viewed as a childhood condition, caused by supernatural forces that can persist through adulthood if untreated. Similarly, a study conducted in Nigeria revealed that the origin of pre-eclampsia was related to supernatural causes. However, evil spirits, which were described as such supernatural elements in Nigeria, were not mentioned by participants of this study.

These misconceptions as well as the use of traditional treatments can lead to serious consequences, such as maternal or foetal death, resulting from inadequate or inappropriate treatment. The use of alternative treatment can also increase delays in seeking care at the health facility, decreasing the chances of survival when help is eventually sought at the facility.

Other important perceived underlying factors for pre-eclampsia were social and emotional problems, often associated to gender roles within the household. Similar causes have been reported in Colombia where insufficient antenatal care, familial predisposition, and stress were thought to be responsible for pre-eclampsia (139). It is concerning that in this setting, none of the perceived causes were pregnancy-related; moreover, there was no clear distinction of these conditions in pregnancy from similar conditions outside pregnancy, such as epilepsy or seizures associated to certain childhood disorders. This finding suggests that pregnant women, and those who care for them in the community, may misunderstand the cause seizures and overlook the importance and heightened risk in pregnancy.

Notwithstanding, women were concerned about their vulnerability during pregnancy, as earlier reported in the same setting by Boene *et al* (136), and as evidenced by the range of warning signs and consequences reported in this study. Participants described similar warning

signs for pre-eclampsia and eclampsia, which may further reflect limited familiarity with the conditions.

The serious outcomes discussed for pre-eclampsia and the community´s familiarity with possible consequences reflects a higher perceived severity of the condition in the community.

This study revealed a number of misconceptions rooted in cultural norms that ultimately shape the way people act and react, such as not crying when assisting woman with eclampsia and not approaching pregnant women with eclampsia in order to avoid becoming affected.

Participants did not report any traditional definitive cure or pre-eclampsia or eclampsia, apart from remedies that are used to alleviate seizures. On the contrary, traditional remedies, such as holy water, herbs, concoctions, and charms are commonly used and believed to be effective for these conditions in other African settings (17, 135).

The findings from this study, coupled with the positive tendency of seeking antenatal care in this setting, highlight the opportunity to enhance community based health education in collaboration with maternal health care providers. This qualitative study contributes to the understanding of local beliefs around pre-eclampsia and eclampsia and can support the identification of converging and contrasting views between the local and the biomedical perspectives. This improved understanding can inform the development of more appropriate health promotion messages for pregnant women, their family members and communities. This information can also be used to revisit training curricula for health professionals in the field of maternal health, in order to improve their awareness of sociocultural factors contributing to maternal morbidity and mortality in the regions they serve (140).

Limitations of the study

As with any research there are a number of limitations to these findings. The data were collected in four communities in Maputo and Gaza Provinces; although these results show good representation of the region, results are not generalizable to other settings. Due to translation of the data (between Changana, Portuguese and English), some subtleties of meanings may have been lost; however, strict quality control steps were put in place throughout the transcription, translation, and coding processes to minimize this limitation.

Strengths of the study

Husbands and mothers-in-law are typically those with decision-making power in pregnancy; therefore, it is essential that these views have been explored and included in the findings. In addition, groups of differing ages and educational levels participated; this allowed findings to be applicable to a wider population. Interview facilitators were well trained, equipped with previous qualitative research experience, familiar with the community, and fluent in the local dialect. Relationships with the communities were established prior to data collection by approaching the administrative post chiefs for prior permission. This qualitative study included a substantial sample size with diversity in the types of participants and regions represented. Analysis was conducted as a team with the use of multiple researchers.

Conclusions

In southern Mozambique, the terms pre-eclampsia and eclampsia are not known, but when prompted, the conditions are understood as hypertension and seizures, not necessarily related to pregnancy. Local beliefs regarding the causes of these conditions are not aligned with the biomedical perspective, and instead are associated with supernatural, emotional and social

causes, which may result in inappropriate care-seeking decisions. Effective community-based interventions for the control of pre-eclampsia must be designed and implemented with the aim of increasing awareness of this condition, as well as the associated risks in pregnancy. Appropriate community-based and culturally sensitive educational materials should include information regarding causes, warning signs and consequences of pre-eclampsia and eclampsia. Health professionals serving these communities must be made aware of the local beliefs about pre-eclampsia and eclampsia.

Table 16. Study site characteristics.

Characteristics	Study Regions				
	Ilha Josina Machel	Calanga	Três de Fevereiro	Messano	Chongoene
Population	8591	14,988	46,388	13,400	32,760
Population of women of reproductive age (12-49)	1706	2074	11,694	4825	11,276
Number of villages	2	2	3	3	6
Number of health facilities	1	1	4	2	6
Predominant language	Changana	Changana	Changana	Changana	Changana
Predominant religion	Zion	Zion	Zion	Zion	Zion

Source: Unpublished data from demographic census(2014) and demographic rounds (2015) of the CLIP study

Table 17. Characteristics of focus group discussion participants.

	Stakeholder group	Region	# of Participants	Age (Median)	Marital status	Occupation	Schooling level
1	Women of reproductive age	Ilha Josina Machel*	9	30	Married (9)	Farmer (9)	Never studied (3) Primary (6)
2		Calanga*	3	25	Married (3)	Farmer (3)	Primary (3)
3		Três de Fevereiro	8	23	Married (8)	Farmer (8)	Never studied (1) Primary (4) Secondary (3)
4		Messano	8	28	Married (6) Widow (1) Single (1)	Farmer (7) Nurse (1)	Primary (7) Secondary (1)
5		Chongoene	*Unknown***	*Unknown*	*Unknown*	*Unknown*	*Unknown*
6	Mothers and mothers-in-law	Ilha Josina Machel	12	29	Married (7) Widow (5)	Farmer (12)	Never studied (4) Primary (8)
7		Calanga	12	59	Married (7) Widow (3) Divorced (2)	Farmer (12)	Never studied (1) Primary (11)
8		Três de Fevereiro	*Unknown*	*Unknown*	*Unknown*	*Unknown*	*Unknown*
9		Messano	8	39	Married (5) Widow (1) Single (2)	Farmer (8)	Never studied (6) Primary (2)
10		Chongoene	11	46	Married (3) Widow (1) Single (7)	Housewife (11)	Never studied (3) Primary (8)
11	Partners and husbands	Ilha Josina Machel	12	37	Married (12)	Farmer (12)	Never studied (3) Primary (8) Secondary (1)
12		Calanga	4		Married (4)	Farmer (1) Fisherman (1) Traditional healer (1) Locality chief (1)	Never studied (1) Primary (3)
13		Três de Fevereiro	10	45	Married (10)	Farmer (2) Security (2) Seller (1) Mason (1) Small jobs (2) Gas station clerk (1)	Primary (10)
14		Messano	6	42	Married (6)	Farmer (6)	Primary (6)
15		Chongoene	7	49	Married (3) Single (4)	Farmer 6) Driver (1)	Primary (7)
16	Matrons and traditional birth attendants	Ilha Josina Machel	6	55	Married (3) Widow (3)	Farmer (6)	Never studied (5) Primary (1)
17		Calanga	9	67	Married (3) Widow (4) Divorced (2)	Farmer (9)	Primary (9)
18		Três de Fevereiro	12	65	Married (4) Widow (7) Divorced (1)	Farmer (12)	Never studied (9) Primary (3)
19		Messano	10	43	Married (5) Widow (3) Single (2)	Farmer (8) Teacher (1) Housewife (1)	Never studied (1) Primary (7) Secondary (2)

	Stakeholder group	Region	# of Participants	Age (Median)	Marital status	Occupation	Schooling level
20		Chongoene	9	58	Married (2) Widow (1) Single (6)	Housewife (9)	Never studied (7) Primary (2)

*Despite the fact that these two Administrative Posts were combined into one single cluster, the data was collected separately

** Missing data

Table 18. Characteristics of interview participants.

	Stakeholder Group	Region	Age	Gender	Marital status	Schooling level
1	Traditional Healers	Ilha Josina Machel	61	Male	Married	Primary
2		Calanga	35	Male	Married	Primary
3		Três de Fevereiro	44	Female	Widow	Primary
4		Messano	35	Female	Widow	Primary
5		Chongoene	49	Female	Married	Primary
6	Matrons	Ilha Josina Machel	89	Female	Widow	Primary
7		Calanga	78	Female	Married	Primary
8		Três de Fevereiro	81	Female	Married	Primary
9		Messano	65	Female	Married	Primary
10		Chongoene	49	Female	Single	Primary

Table 19. Local names and perceived causes of pre-eclampsia.

Pre-eclampsia	
Local names	High blood pressure (*tensãoalta*)* Pressure (*tensão*)* Illness of the heart (*mavabjiyambilo* or *mavabjiyatimpfalu*)** Faintingdisease (*doença de desmaiar*)*
Perceived Causes	Mistreatment by the in-laws Marital problems Excessive thinking / worrying Anger Sadness Eating a diet high in salt

*Terms mentioned in Portuguese
**Term mentioned in Changana

Table 20. Local names and perceived causes of eclampsia.

Eclampsia	
Local names	Illness of the moon (*mavabjiyanweti*)** snake illness (*nhocane*)** Illness of the heart (*mavadjiyambilo*)** Falling disease (*doença de cair*)* Children's illness (*mavabjiyavatsonguana*)** Big illness (*mavabjiyamakulo*)** Illness of scares(*mavabjiyakudzuka*)** Epilepsy (*epilepsia*)*
Perceived Causes	Snake (*nhocane*)**

*Terms mentioned in Portuguese

**Terms mentioned in Changana

Figure 16. Map of study areas, southern Mozambique.

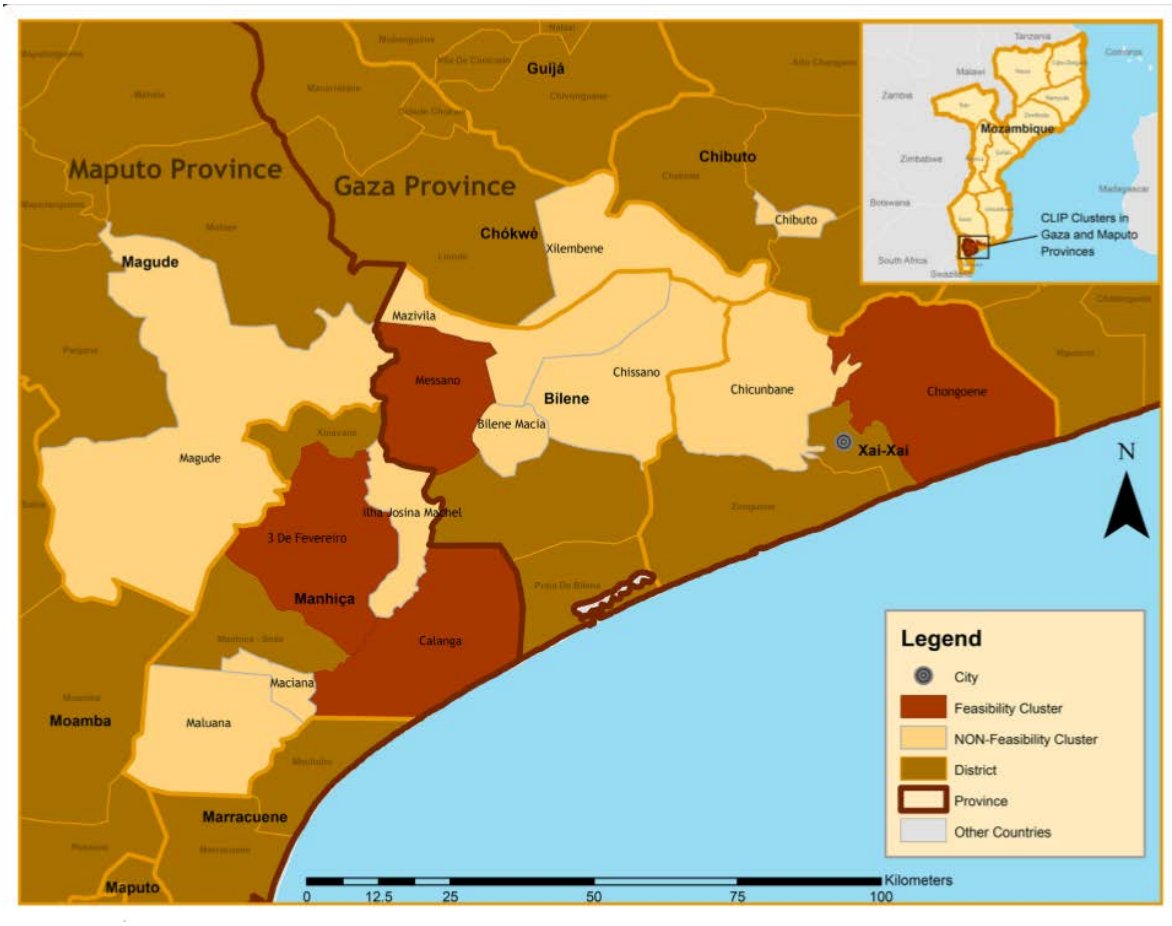


Figure 17. Thematic categories used in analysis.

Chapter 6. Community's perceptions of pre-eclampsia and eclampsia in rural Pakistan: a qualitative study

Background

The hypertensive disorders of pregnancy (HDP), particularly pre-eclampsia and eclampsia are among the top three leading causes of maternal mortality globally (5, 74). Pre-eclampsia is commonly defined as the presence of new hypertension and significant proteinuria during pregnancy (1, 141). The trajectory of the disease can put women at high risk of eclampsia- a serious condition clinically manifested by seizures in the absence of early identification and appropriate management (141). Globally, it is estimated that HDP complicates ten million pregnancies, resulting in 70,000 to 80,000 maternal and 500,000 perinatal deaths annually (142). A landscape analysis revealed the risk of developing pre-eclampsia is seven times greater for women in less developed countries as compared to developed countries (142). Another study from less developed countries reported the odds of a woman dying from pre-eclampsia and eclampsia is 300 times higher than that for a woman in more developed countries (143).

The secondary analysis of the World Health Organization Global Survey on maternal and perinatal health revealed socio-demographic variables (i.e., maternal age > 30 years, and low education attainment), as well as, clinical variables (i.e., chronic hypertension, obesity and severe anemia) as the highest risk factors for pre-eclampsia in low-and-middle income countries (144). Pakistan is the sixth most populous country in the world. A recent systematic analysis of global mortality ranked Pakistan as the country with the third highest burden of maternal, fetal and child mortality (145, 146). According to the Pakistan Demographic and Health Survey 2006-07, the maternal mortality ratio (MMR) was 279 per 100,000 live births (147). There are wide variations

between rural and urban populations; the MMR for Sindh province (which is predominantly rural) was as high as 345-350 per 100,000 live births (148).

Eclampsia is responsible for 34% of maternal deaths in women admitted to a tertiary care hospital in Pakistan (149). Clinical management of pre-eclampsia and eclampsia requires hospitalization; therefore, the magnitude of pre-eclampsia-and eclampsia-related mortality may be higher in rural populations, where there are key barriers to care seeking (60, 94). Previous studies have looked at the prevalence (150), risk factors (151), and clinical management of women with pre-eclampsia and eclampsia in Pakistan (152). Awareness of the cultural aspects is imperative to understand women and their families' perspective about pre-eclampsia.

This study was conducted as part of the formative research of a large community-based research trial - Community Level Interventions for Pre-eclampsia (CLIP Trial) in Sindh province, Pakistan (NCT01911494) (153). The objective of this study was to explore the community's understanding of pre-eclampsia and eclampsia; including local terminology, perceived causes, danger signs, prevention strategies, outcomes, and traditional treatments in the rural settings. The results of this study identify knowledge gaps at community level and can inform development of future communication strategies.

Methods

A qualitative study was undertaken between February to July 2012, as part of a large multi-country study, the detailed methods are described elsewhere (118). This study was conducted in Sindh- the third largest province by area in Pakistan. Two southern districts namely Hyderabad and Matiari were selected. The semi-urban district Hyderabad is located on the east bank of the Indus River, and is the second largest city of Sindh province with a population of

over 1 million (154). Matiari is rural district located 25 kilometers north of Hyderabad with a population of roughly 0.6 million (155). Over 90% of residents are Muslims, Sindhi and Urdu are the main dialects. The literacy rates as compared to other provinces are low (43% for female and 67% for male); and the major industry is agriculture (Table 21, pg 115).

Data were collected through focus group discussions (FGDs) (156), with women of reproductive age (15-49 years), mothers-in-law, husbands, and fathers-in-law. Other studies relevant to maternal health in the rural settings in Pakistan (149) and elsewhere (60), found that men had a key role in decisions pertaining to care seeking. Hence, husbands and fathers-in-law were included in this study to understand their perceptions and belief regarding pre-eclampsia and its prevention and management.

The FGD guides were translated into Sindhi and Urdu languages, and pilot tested for comprehension, cultural sensitivity, and duration. To respect local preferences of participants, FGDs were held separately for women and men at local venues. Data saturation was reached through 26 FGDs (157).

All discussions were transcribed into Sindhi and Urdu languages. Stringent data quality control measures were followed. These included random observations of FGDs, 20% (audit-trial) verification of the content of manual transcripts by audio-recording review, and fortnightly debriefing sessions with moderators and transcribers. In addition, the moderators recoded a self-reflection after each session to describe their thoughts and impressions to better contextualize the data, as well as, to protect against self-bias. A thematic analysis (combining an inductive and deductive approach) was used with the assistance of NVivo version 10 software [QSR, Doncaster Vic, Australia]. All responses were coded to relevant nodes, which were later

categorized into hierarchy of tree-nodes. Subsequently, emerging themes and sub-themes were drawn from the tree nodes. (Figure 17, page 104)

This study received ethical approval from Ethics Review Committee of Aga Khan University (1917-OBS-ERC-11), Karachi Pakistan, National Bioethics Committee of Pakistan and Clinical Research Ethics Board of University of British Columbia, Vancouver Canada (H12-00132).

Results

Twenty-six focus groups were conducted: 19 with women of reproductive age / mothers-in-law; and 7 with husbands/fathers-in-law. (Table 22, pg 116)

The mean age of female participants was 28.5 years, 89% were housewives, and 49% never attended school. The mean age of male participants was 35 years, 92% were self-employed in the agriculture sector, and 37% had never attended school.

Local names and danger signs

A large number of participants, both women and men, had no knowledge of a condition such as pre-eclampsia or eclampsia associated with pregnancy. When asked a direct question if they knew about blood pressure they answered in the affirmative. They believed that even women with normal blood pressure before pregnancy may experience hypertension during pregnancy. Participants used '*Rat jho dabao vadhan*' [Sindhi] to express their understanding of '*high blood pressure*'. Women were asked about symptoms of high blood pressure and they so reported '*mathay-mein-soor', 'chakar', 'ulti-wanghar-mehsoos-thiyan',* and *'kamzoori'* [Sindhi] to represent hypertension in pregnancy. These terms can be translated as headache, dizziness, nausea/vomiting, and weaknesses; all of which are general symptoms associated with pregnancy.

The women's perception about symptoms suggestive of high blood pressure was not related with objective testing of the blood pressure of the women. Women and men reported that they knew about seizures and used the words '*jhatka*' [English translation: *fits*] by majority of participants. Seizures were reported as [in Sindhi] '*khatarnak alaamat*' [English translation: *danger sign*] for mothers and newborns. They were not aware of the association of high blood pressure with seizures.

Perceived causes

Most participants mentioned that [Sindhi] '*ghano-soochanr*', '*pareshani*' [English translation: *excessive thinking* or *stress]* are the most common causes of high blood pressure in pregnancy. Participants ascribed lack of rest, domestic problems [in Sindhi] 'gharelo-pareshani', the burdens of household chores and social responsibilities, as the reasons for maternal stress in pregnancy. One woman described the following:

> *"Blood pressure increases during pregnancy only because of excessive thinking, mental stress and tension about children".*
>
> *Participant 3, FGD 4, woman of reproductive age*

A few participants reported early marriages, anemia and low blood sugar levels as some of the other causes of stress to the mother. A large majority of participants believed that weakness, anemia, and maternal stress were the leading causes of seizures during pregnancy. A few also considered that seizures were supernatural in origin.

Prevention strategies

The predominant perception in this community was that hypertension and seizures in pregnancy were the result of maternal stress; therefore, families should provide support to alleviate stress.

While discussing the roles of household decision makers many women had good relationship with mothers-in-law by receiving emotional support, sharing of household chores, getting help with childcare, and accompanied to health facility in case of emergency. Whereas, the roles of husband and father-in-law were perceived to be more as facilitators: to provide permission, to arrange transport, and to provide financial support. One male decision-maker described this in the following quote:

"The role of husband is critical! After all, the mother and baby are his responsibility. Therefore, it depends on the way he treats his wife, feeds her well, and gives her respect".

Participant 4, FGD 3, male decision-maker

Many also recommended a healthy diet rich in fat, and adequate rest to prevent hypertension and seizures during pregnancy.

Some women complained of their mother-in-law's insensitivity to her problems in pregnancy. A woman described this in the following quote:

"When [she is] sick, [her] mother-in-law thinks that [she is] too weak. She often criticizes and says…don't think, you are the only one pregnant, and no other women have delivered before you".

Participant 1, FGD 6, woman of reproductive age

Perceived severity

The severity of hypertension during pregnancy was mainly recognized with aggravated signs and symptoms. Participants discussed how pregnant woman experienced an '*increasing intensity of headache with dizziness*'; '*inability to do household chores*'; '*feelings of severe weaknesses';* and an *'altered level of consciousness'*.

One-male participant described the severity of hypertension in the following quote:

"She gets seriously ill, [and] cannot work in the house at all".

Participant 9, FGD 2, male decision-maker

Seizures during pregnancy were perceived to be '*a sign for health emergency'*. Many participants mentioned that women must be taken to the health facility, in case of seizures.

Perceived outcomes

All participants believed that hypertension and seizures during pregnancy increased the risk of negative pregnancy outcomes. The main consequences of hypertension and seizures as reported by participants included complications during labor, death of mother, stillbirth, and weakness of the newborn and low birth weight. Likewise, a woman participant revealed as quoted below:

"When mother's blood pressure rises, the vein of the brain can rupture. It can kill the mother and the baby in womb".

Participant 1, FGD 1, woman of reproductive age

Many participants revealed that seizures during pregnancy could lead to unconsciousness, which may result in death. Only a few mentioned post-pregnancy complication of hypertension and seizures, such as delayed development of the baby. A male participant explained this in the following quote:

"If mother is affected by increased pressure and seizures, naturally it will affect baby's health after birth".

Participant 5, FDG 7, male decision-maker

Alternative treatments

Almost all participants reported self-medication for symptoms, such as headache. Although participants did not recall the name of the medication used for managing hypertension during pregnancy, they mentioned [in Sindhi] '*Soor-ji-dawa*' [English translation: *pain killers]*, which were commonly available without prescription. The use of other home remedies, spiritual treatments and alternative medicines were not commonly reported for managing hypertension and seizures during pregnancy. Only a few women of reproductive age [in a rural district] believed in traditional treatments such as '*reciting holy verses, asking mother to drink holy water, [and] massaging with coconut oil*' could be beneficial. Few male decision-makers, also from a rural district, believed home remedies and spiritual treatments could reduce the severity of blood pressure, and manage seizures.

Discussion

Despite substantial global investments to reduce maternal mortality over the past decade, many countries in Sub-Saharan Africa and South Asia have made slow progress towards Millennium Development Goal-5 (158). Cause-specific maternal mortality from pre-eclampsia and eclampsia, albeit alarmingly high, it has received insufficient attention in health policy context (159). In particular early recognition and management at the community level, where many women are dying in less developed countries, has largely been omitted from recent research initiatives (159).

This study contributed to community understandings about pre-eclampsia and eclampsia. These community beliefs included misperceptions regarding danger signs, underlying causes, prevention strategies, outcomes, and management. The literature suggests that the HDP are

commonly misunderstood in less developed countries due to illiteracy, lack of awareness, superstitious beliefs, and poverty (19, 160). Both high blood pressure and seizures were often perceived to be potentially dangerous for mother and baby. Therefore, it is clear that practices for disease prevention and traditional management of pre-eclampsia and eclampsia were deeply rooted in perceptions of disease. Literature also suggests about the delay in recognition of severity, which results in large number of maternal deaths at home or on the way to health facility that could otherwise be averted (161, 162).

Self-medication was reported, as the first choice of treatment for severe headache during pregnancy. Our findings are corroborated with another recent study that also suggested increasing trend of self-medication in Pakistan. It was reported that easy access to over the counter medication and prescription-only medication are main determinant for self-medication in the country (163). However, such contrary practices of self-medication may have serious consequences particularly for pregnant women, who are at risk of developing lethal complications, due to delay of appropriate treatment (164).

Strengths and limitations

This study bridges the knowledge gap for community perceptions surrounding pre-eclampsia and eclampsia in Pakistan. FGDs were scheduled at convenient times and venues to accommodate participants with minimal distractions. Separate sessions for household decision makers (husbands, fathers-in-law, mothers-in-law) were not possible given logistic and resource limitations; as a result, it is possible that some participants did not feel comfortable to actively participate despite encouragement by the moderator. Combined focus groups were held for women of reproductive age and mothers-in-law, therefore some women were hesitant to speak-up. Similarly, group sessions for husbands and fathers-in-law were combined. The combined

focus groups may have impeded open dialogue because potential cultural barrier whereby young people are unlikely to oppose senior members of the community.

Conclusions

This qualitative study provides insights of community's understanding of pre-eclampsia ascribed as general symptoms, and less specific to clinical conditions. There were mixed opinions regarding the causes of the hypertension in pregnancy and a poor understanding regarding the connection between pregnancy, hypertension and seizures.

Community-based participatory health education strategies are highly recommended to address myths and misperceptions about danger signs of pregnancy in Pakistan. Dissemination of knowledge to the wider community would likely challenge traditional beliefs, customs and practices; therefore, behavior change communication would be very useful strategies to implement at community settings. Education should be integrated into training programs for community health workers to improve their knowledge base and facilitate community awareness in rural Pakistan.

Table 21. Study site characteristics.

Pakistan Characteristics	
Population	186,693,907
Area (Km^2)	796,095 km^2
Number of provinces	4 provinces and 4 federal territories
Predominant language	Urdu, Punjabi, Pashto, Sindhi, Saraiki, Balochi, and Kashmiri
Predominant religion	Islam
Sindh Province Characteristics	
Population	42,400,000
Area (Km^2)	140,914 km^2
Number of districts	24
Predominant language	Sindhi, Urdu, Saraiki, Parkari Koli,
Predominant religion	Islam
District Hyderabad, Sindh	
Cumulative population	1,883000
Area (Km^2)	993 km^2
Number of Talukas	04
District Matiari, Sindh	
Cumulative population	615320
Area (Km^2)	1,417 km^2
Number of Talukas	03

Table 22. Site specific distribution of focus group discussions.

Name of district	Stakeholder group	Number of sessions	Number of participants
Matiari	Women of reproductive age and mother in-law	10	89
	Husbands and fathers-in-law	05	49
Hyderabad	Women of reproductive age and mothers-in-law	09	84
	Husbands and fathers-in-law	02	16
Total		**26**	**238**

Figure 18. Map of the study sites.

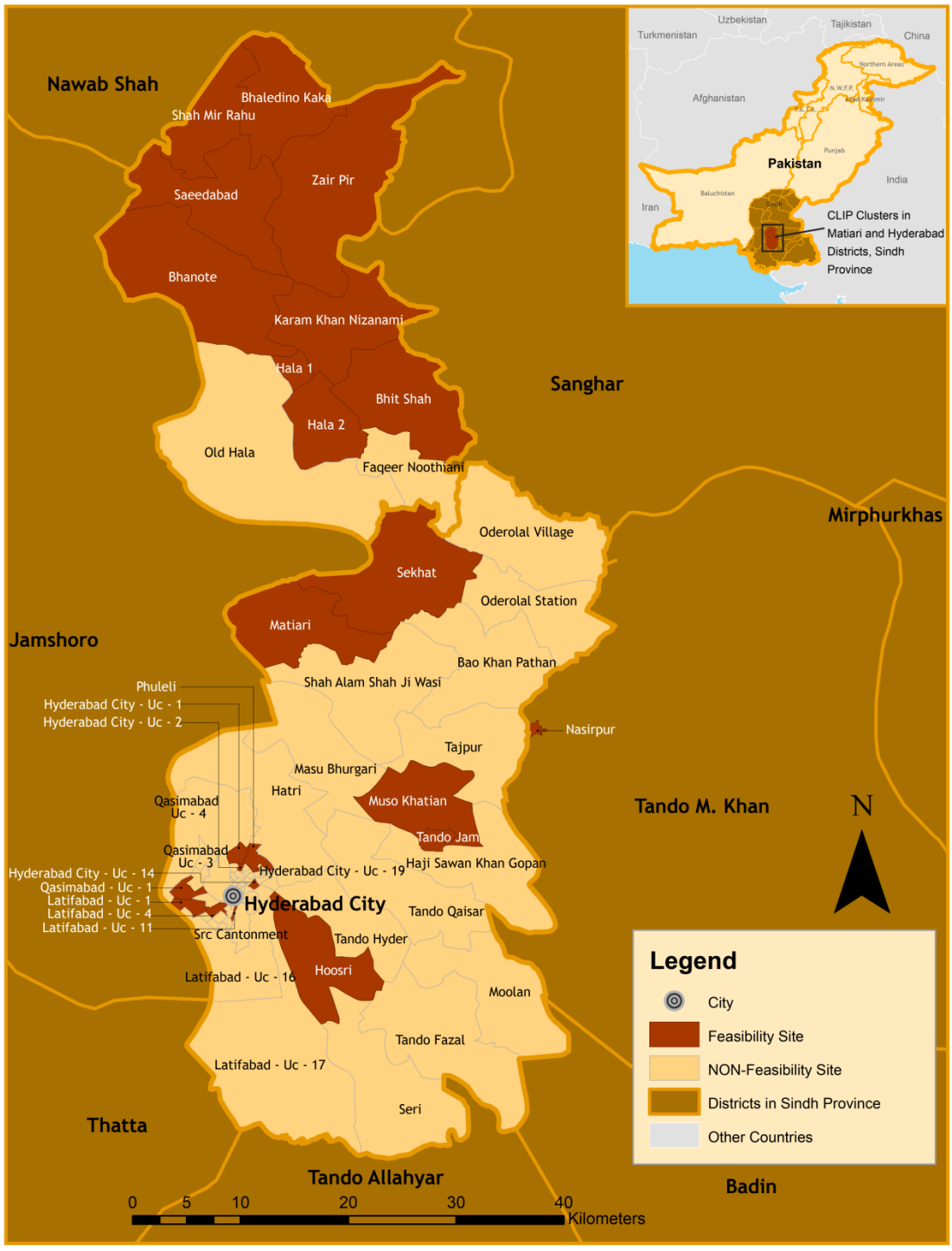
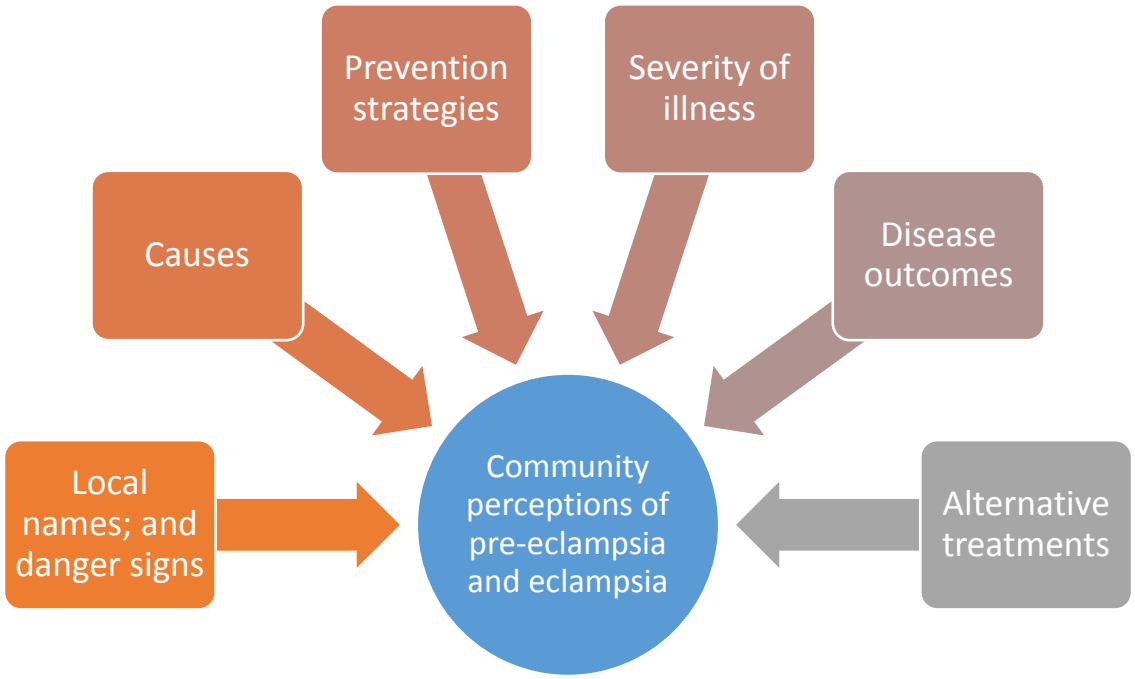


Figure 19. Emerging themes from the focus groups discussions.



Chapter 7. Community perceptions of pre-eclampsia in rural Karnataka State, India: a qualitative study

Background

Reduction of maternal and perinatal mortality is a global priority, particularly in low-and-middle-income countries (LMICs) where more than 99% of these deaths occur. Increasingly, it is recognized that for every woman who dies, up to 25 others suffer a potential life-changing morbidity (165).

India accounts for 17% of all maternal deaths worldwide (8). Since 2004, efforts to lower maternal mortality, such as the National Rural Health Mission (NRHM) (166), have had some success. The latest estimated maternal mortality ratio (MMR) of India is 190- 282/100,000 live births but there is regional variation; the MMR in Karnataka state is below the national average at 144/100,000 live births (3, 167), but it is still the highest in South India. Also, the current MMR has not reached the global Millennium Development Goal 5 of a ¾ reduction in maternal mortality, equivalent to 109/100,000 live births in India (168).

The hypertensive disorders of pregnancy (HDPs) are responsible for ~14% of all maternal deaths, with little change in rates in recent years (5). The most dangerous of the HDPs, pre-eclampsia, is typically defined as the onset of new hypertension with significant proteinuria in pregnancy (1).

While management of pre-eclampsia involves the use of antihypertensive therapy to control blood pressure and steroids to accelerate fetal pulmonary maturity at gestational ages before 34 weeks, the only effective cure is delivery of the placenta (74). Even then, the disease can worsen, or appear for the first time, postpartum. Although the disease can affect almost any

organ in the body, involvement of the brain with seizures, known as eclampsia, poses particular risk for mother and baby.

Maternal deaths and complications in pre-eclampsia (and in general) have been attributed in large part to delays in recognition of illness and in timely transport to facilities for treatment (169). As such, community perceptions of pre-eclampsia and eclampsia are critical to averting maternal morbidity and mortality. The limited literature suggests widespread misconceptions globally regarding presentation, cause, and appropriate treatment of pre-eclampsia (18). Most research has focused on women's perceptions without exploring those of other key decision-makers. For example, in Karnataka State, India, only 13% of pregnant women had accurate knowledge about pre-eclampsia (170). Also, in a systematic review of maternal health interventions in resource limited countries, only 37% of programmes included community-based education and communication (171).

As part of the feasibility work for the Community Level Interventions for Pre-eclampsia (CLIP) (NCT01911494) cluster randomised controlled trial (118), community perceptions of pre-eclampsia and eclampsia in Karnataka State, India were explored. This study aimed to inform implementation of the CLIP intervention, as well as to inform researchers, program managers, health care providers and policy makers about how best to address delays in triage, transport and treatment of women with pre-eclampsia and eclampsia.

Methods

Study area:

This study was conducted in Belgaum and Bagalkot Districts of Karnataka, in South India (Figure 20). Social and health indicators of Karnataka are generally lagging compared

with other southern Indian States. This gap is explained by fragmentation of the social, political and administrative structure, prevailing mismanagement, and a lack of state commitment and leadership regarding maternal health (166, 172). Karnataka shares similar cultural practices with other Indian states, including a strong culture of patriarchy, limited decision-making power for women, early age of marriage, and high fertility rates. The health care infrastructure is often inadequate, particularly in rural areas where access to timely health services is a challenge. For additional study site characteristics see Table 23 (pg 129).

Data collection:

Data were collected as part of a larger study aimed at assessing the feasibility of implementing a community-based treatment package for pre-eclampsia by community health care workers (NCT01911494) (118). A detailed description of the methods has been published (95).

In brief, focus group discussions were conducted to elucidate community views from: community leaders, male and female decision-makers, and women of reproductive age. These groups were chosen as influential members of the community and family, particularly regarding health knowledge and decision-making. Mothers, mothers-in-law and husbands are typically responsible for household decisions and are influential in the beliefs and practices adopted by other household members. Male and female decision-makers were approached for participation when they accompanied women of reproductive age to the health centre. Focus group discussions were conducted with each stakeholder group separately at primary health centres, between January and March 2013. Discussions were in the local language, Kannada, to best promote interaction between community members. A semi-structured guide was used for all discussions, this approach allowed interviewers to tailor questions and probes as needed for

differing groups; open-ended questions promoted free and open discussion among participants. The discussion guide was developed to meet the objectives of this study and had been created to fit the cultural context of South India. Focus group leaders had backgrounds in public health, community medicine or obstetrics. These professional and educational backgrounds made facilitators well-equipped for discussions on this topic, all also underwent study-specific training regarding qualitative data collection. Further meetings were to be scheduled thereafter if data saturation was not reached.

All discussion notes and audio recordings were transcribed verbatim and translated to English for analysis using NVivo 10. Coding was done by one researcher (MV), after which all coded transcripts and thematic associations were cross-checked by the local research team to resolve any discrepancies and reach consensus. Using deductive reasoning, results were grouped into predetermined categories of key themes related to community perceptions of pre-eclampsia (Figure 21, pg 136). Inductive reasoning was used to incorporate new and unexpected ideas. This produced a comprehensive analysis structure to reflect the richness and variety of responses. *A priori*, the following thematic categories were to be explored for pre-eclampsia: local terminology, perceived cause, warning (‘danger’) signs, perceived consequences, and traditional treatments.

This study was approved by ethics review committees at the University of British Columbia, Vancouver Canada (H12-00132) and KLE University, Belgaum India (MDC/IECHSR/2011-12).

Results

There were 14 focus group discussions with 219 individuals: community leaders (3 groups, 27 participants), male decision-makers (2 groups, 19 individuals), female decision-makers (3 groups, 41 individuals), and women of reproductive age (6 groups, 132 individuals). The age of participants ranged from 18 to 65 years, and occupation was generally "agricultural or domestic labour". There were diverse educational backgrounds, some with no formal schooling, particularly in groups of female decision-makers and women of reproductive age, and several with University completion. Most women of reproductive age who participated were pregnant at the time (79%), and over half had at least one child under the age of 5 (66%). (Table 24, pg 130)

Local terminology

Hypertension in pregnancy was referred to as '*BP*' (blood pressure) in all stakeholder groups. In contrast, there were several terms used to describe convulsions in pregnancy or eclampsia (Table 25, pg 132). Most commonly eclampsia was described as '*jhataka'* or '*fits'*. Other terms used were '*lakawa*' and '*ardhangi*' (meaning paralysis) or '*nanju agide*' (meaning infection).

The community members had little understanding of pre-eclampsia or eclampsia as pregnancy complications. Eclampsia was often not differentiated from general convulsive disorders. Some respondents believed pre-eclampsia and eclampsia were related while others were unsure or did not believe this. However, even those who recognized this relationship often did not know the mechanism or direction of the association.

"If blood pressure is high only then fits will occur" [community leader]

Perceived causes

The vast majority of respondents stated that hypertension in pregnancy was due to diet and tension or stress, particularly related to marital conflict or concerns that the fetus may be female. Poor diet was described as those high in salt or sugar and with excess fried and oily foods. Some felt hypertension in pregnancy had medical origins, while others believed the causes to be socio-economic and cultural (Table 26, pg 133). By and large respondents expressed similar understandings of the causes of pre-eclampsia, however, it should be noted that male-decision makers provided the fewest responses, likely related to their lack of familiarity with the condition.

"Those who worry more about their family they will have more BP" [female decision-maker]

"If they have disturbed food habits…like eating less or not eating properly or eating only limited food then they may have weakness and that may cause BP" [woman of reproductive age]

Some gave similar responses for eclampsia; however, anaemia, poor medical adherence, not being immunized against tetanus, and exposure to fire or water in pregnancy were also commonly mentioned. It was described that a lack of regular antenatal attendance and adherence to medical advice and treatment could result in seizures in pregnancy (Table 26, pg 133).

"If they go near water …then they will get fits" [woman of reproductive age]

Danger signs

The most commonly reported signs or symptoms of pre-eclampsia were sweating, fatigue, dizziness-unsteadiness, swelling, anger, and talking too much. Respondents had a more challenging time explaining the danger signs of eclampsia, and often stated signs associated with active convulsions: frothing, shaking, eyes rolling upwards, clenching teeth, and tongue biting.

"I witnessed one woman having fits, I saw that woman in hospital having labour pains and suddenly she had fits. Her hand, leg and body started shaking, became stiff, she bit her tongue, her eyeballs rolled up" [male decision-maker]

Perceived consequences

The most serious and most commonly cited consequences of hypertension or seizures in pregnancy were death of the mother and/or infant. Preterm delivery was also often mentioned. Concerns were raised about the need for Caesarean deliveries by women of reproductive age, which was felt to be highly undesirable. Seizures and heart-related problems were thought to be consequences of pre-eclampsia. Many participants from all groups professed ignorance about the consequences of eclampsia (Table 27, pg 134).

"High BP can endanger the life of a woman; it may lead to death of a woman which in turn is a problem for us" [female decision-maker]

There were differences of opinions regarding the severity of pre-eclampsia and eclampsia, nevertheless many felt these conditions could be fatal.

Traditional treatments

Neither traditional nor home-based remedies were reported for treating hypertension in pregnancy, although a few participants recommended restricting dietary salt. Various home remedies were reported in all focus group discussions for seizures in pregnancy, either during or immediately following a seizure, including providing the 'smell of an onion', placing an iron object or keys in the hand, and squeezing or rubbing the fingers and toes. Many also recommended that an object should be placed between a woman's teeth to avoid biting her tongue. It was noted that the described practices typically do not prevent or delay transfer to hospital.

"For the time being, we should give any iron object in her hand and then we should take her to hospital" [woman of reproductive age]

Discussion

There was very limited understanding of pre-eclampsia and eclampsia in these communities. In the two Districts of rural Karnataka, eclampsia was not differentiated from other convulsive disorders. Most did not realize pre-eclampsia and eclampsia are related, and those who did recognize this relationship often did not know its aetiology or that eclampsia progresses from pre-eclampsia. Local terms exist for hypertension and convulsions, some of which accurately, and others of which inaccurately, describe these conditions. Significant knowledge gaps were evident, particularly regarding warning signs, causes, and outcomes. No traditional remedies were reported for pre-eclampsia; however, there are a number of home-based remedies given to women who experience seizures in pregnancy.

The finding, that women had limited knowledge of pre-eclampsia and the associated signs and symptoms, is consistent with results from Nigeria and Pakistan (19, 95, 138). Other studies, however, have found greater awareness of the condition (17, 18, 61, 173). Attitudes expressed by participants regarding the cause of pre-eclampsia reflect the cultural dynamics with prevalent worry of giving birth to a female child. Pre-eclampsia was linked to exposure to fire or water, a myth that prevailed among many of the participants in the study. Similar to our study, in Nigeria and Brazil, pre-eclampsia was attributed to mental stress or diet, though they also attributed the condition to heredity (18, 174). El-Nafty & Omotara (17) found four common explanations for causes of eclampsia in Nigeria: supernatural causes, malnutrition, heredity, and early age of marriage. In Bangladesh, community members thought eclampsia was due to

exposure to a cold environment, physical weakness from malnutrition, hypertension, lack of tetanus immunization, and supernatural causes (173). Our study findings are also consistent with other study results wherein communities perceive hypertensive disorders of pregnancy to be serious and potentially harmful conditions (61, 134, 173, 174). This high level or perceived severity is likely to influence health care seeking as described by the health belief model and these findings (175).

This study was conducted with a high degree of rigour in close collaboration with local and international experts and with guidance from an international consortium of advisors. These findings represent a comprehensive view of the community's beliefs and practices due to participation with various stakeholders. The study procedures, including training of facilitators, careful translation of guides, and expert guidance all contribute to the strengths of the study.

As many participants were identified through primary health centre networks, women who did not interact with the health system may have been less likely to be included in the sample. The non-probabilistic sampling of this study inhibits the ability generalize findings, as indicated by the consistencies and inconsistencies of our findings with other studies as previously described. The results are further limited by the translation from Kannada to English for analysis, through which some of its meaning may have been lost. Although researchers were not providing direct clinical care to any of the participants, their dual role as researchers and clinicians may have introduced some bias and made participants more likely to respond favourably. Sensitive topics for discussion may have received less open discussion. While those conducting and facilitating the discussions were trained to garner equal input from all, focus group dynamics may have enhanced or hindered dialogue by some members.

Given that this study has identified knowledge gaps, there is a need to increase awareness of, and dispel common myths and misconceptions related to, the HDPs. Education and community engagement initiatives can assist women and communities to recognize the causes, risk factors, and warning signs associated with pre-eclampsia and eclampsia. Health professionals should facilitate dialogue with pregnant women and families in ways that will correct misinterpretations of the disease. To date, much of the education delivered through maternal and child health initiatives have targeted health facilities with limited evidence of the effectiveness (176). Community-based education of diverse groups can reach a wider population. There is mounting evidence of the effectiveness of community and women's groups to improve health outcomes (177, 178). These types of approaches would strengthen the current efforts and mandate of the NRHM which aims at improving maternal and child health particularly for vulnerable populations in rural areas.

Conclusion

Study results clearly indicate a need for further education of the community, moving from a narrow biomedical focus and incorporating the diverse cultural and social factors. Such an approach may positively influence knowledge and practice regarding pre-eclampsia and eclampsia. Greater community education on pre-eclampsia is necessary to achieve effective implementation of research and programmatic initiatives to improve morbidity and mortality.

Table 23. Study site characteristics.

India Characteristics	
Population	1,210,193,444
Size (Km^2)	3,287,590
Number of states	28
Number of union territories	7
Predominant language	Hindi
Predominant religion	Hindu
Literacy rate of women 15-49 years	55%
Karnataka State Characteristics	
Population	61,130,704
Size (Km^2)	191,791
Number of districts	30
Predominant language	Kannada
Predominant religion	Hindu
Literacy rate of women 15-49 years	60%
Site Characteristics	
Cumulative population	86,470
Cumulative size (Km^2)	608
Number of clusters sampled	4
Number of villages	34

Table 24. Focus group characteristics.

#	N participants	Age (yr) Median [range]	Occupation 1 Housewife 2 Labourer 3 Employee 4 Self-employed 5 Other	Child <5yr	Pregnant	Education 1 No formal schooling, cannot read or write 2 No formal schooling, can read and write 3 Primary school incomplete 4 Primary school complete 5 Secondary school incomplete 6 Secondary school complete 7 Pre-university incomplete 8 Pre-university complete 9 University incomplete 10 University complete 11 Postgraduate 12 Don't know	Relationship to woman 1 Husband 2 Father 3 Father-in-law 4 Mother-in-law 5 Mother 6 Other
Community Leaders							
1	7	36 [31,48]	1 = (N=1) 2 = (N=6)	*Not asked*	*Not asked*	1 = (N=1) 6 = (N=1) 8 = (N=2) 10 = (N=3)	*Not asked*
2	10	36 [24,51]	1 = (N=3) 4 = (N=3) 5 = (N=4)	*Not asked*	*Not asked*	1 = (N=1) 3 = (N=1) 4 = (N=1) 5 = (N=1) 6 =(N=3) 8 = (N=1) 9 = (N=1) 10 = (N=1)	*Not asked*
3	10	*Not known*	*Not known*	*Not asked*	*Not asked*	*Not known*	*Not asked*
Male Decision-Makers							
1	8	26 [18,57]	2 = (N=4) 3 = (N=1) 4 = (N=1) 5= (N=2)	*Not Applicable*	*Not Applicable*	1 = (N=4) 3 = (N=2) 6 = (N=2)	1 = (N=4) 3 = (N= 2) 6 = (N=2)
2	11	49 [33,59]	3 = (N=2) 5 = (N=9)	*Not Applicable*	*Not Applicable*	3 = (N=4) 5 = (N=1) 6 = (N=1) 10 = (N=1) 12 = (N=4)	2 = (N=4) 3 = (N=3) 6 = (N=4)
Female Decision-Makers							
1	10	45 [30,60]	1 = (N=9) 2 = (N=1)	*Not Applicable*	*Not Applicable*	1 = (N=8) 4 = (N=2)	4 = (N=6) 5 = (N=2) 6 = (N=2)
2	18	45 [28,65]	1 = (N=5) 3 = (N=1) 4 = (N=1) 5 = (N=11)	*Not Applicable*	*Not Applicable*	1 = (N=3) 2 = (N=1) 3 = (N=1) 12 = (N=13)	*Not Known*
3	13	48	1 = (N=13)	*Not*	*Not*	3 = (N=1)	4 = (N=7)

#	N participants	Age (yr) Median [range]	Occupation 1 Housewife 2 Labourer 3 Employee 4 Self-employed 5 Other	Child <5yr	Pregnant	Education 1 No formal schooling, cannot read or write 2 No formal schooling, can read and write 3 Primary school incomplete 4 Primary school complete 5 Secondary school incomplete 6 Secondary school complete 7 Pre-university incomplete 8 Pre-university complete 9 University incomplete 10 University complete 11 Postgraduate 12 Don't know	Relationship to woman 1 Husband 2 Father 3 Father-in-law 4 Mother-in-law 5 Mother 6 Other
		[30,65]		*Applicable*	*Applicable*	5 = (N=1) 12 = (N=11)	5 = (N=1) 6 (N=5)
Women of Reproductive Age							
1	55	*Not Known*	*Not Known*	*Not Known*	*Not Known*	*Not Known*	*Not Known*
2	16	25 [20,30]	1 = (N=16)	56%	75%	3 = (N=3) 4 = (N=1) 5 = (N=1) 6 = (N=2) 8 = (N=2) 10 = (N=1) 12 = (N=6)	*Not Applicable*
3	14	23 [18,30]	1 = (N=9) 2 = (N=5)	36%	86%	1 = (N=3) 3 = (N=3) 4 = (N=1) 5 = (N=1) 6 = (N=3) 8 = (N=2) 10 = (N=1)	*Not Applicable*
4	17	*Not Known*	1 = (N=17)	88%	100%	*Not Known*	*Not Applicable*
5	14	22 [18,58]	1 = (N=12) 3 = (N=2)	71%	50%	3 = (N=3) 5 = (N=3) 6 = (N=3) 10 = (N=2) 12 = (N=3)	*Not Applicable*
6	16	20 [19,26]	1 = (N=16)	69%	63%	3 = (N=7) 4 = (N=4) 5 = (N=1) 6 = (N=3) 8 = (N=1)	*Not Applicable*

Table 25. Local terms for ‘eclampsia’.

Local terms for ‘eclampsia’		
Jhataka Zataka	Moorcha roga Mala roga	Lakawa
Pepri	Nanju agide	Ghali shaka
Fits	Shatibyani Sete bene	Ardhangi

Table 26. Perceived causes of 'pre-eclampsia' and 'eclampsia'.

Causes of 'pre-eclampsia'	Malnutrition	Martial problems	Stress	Tension
	Changes in body system	Medication side-effect	Poor adherence to medication	Lack of regular check-ups
	Lack of physical activity	Short temper	Poverty	Poor diet
	Home remedies	Reduced blood	Lack of water	Worries related to sex of baby
	Family problems	Anaemia		
Causes of 'eclampsia'	Anaemia	Lack of energy	Hereditary	Blood pressure
	Poor adherence to medication	Malnutrition	Exposure to fire, water or heat	Lack of regular check-ups
	Lack of Tetanus Toxoid vaccination	Tension	Child marriage	Exposure to cold
	Fear			

Table 27. Outcomes for pre-eclampsia and eclampsia.

	Outcomes affecting the mother	**Outcomes affecting the infant**
Pre-eclampsia	Mental imbalance	Stress
	Heart complications	Meconium aspiration
	Delivery complications	Delayed delivery
	Delayed delivery	Death
	Miscarriage	Stunted growth
	Bleeding	
	Death	
	Damage to the uterus	
	Weakness	
	Anaemia	
	Seizures	
	Coma	
	Falls	
	Fatigue	
	Paralysis	
	Brain tumours	
	Swelling	
Eclampsia	Death	Death
	Miscarriage	Injury
	Injury	

Figure 20. Map of study sites, Karnataka State, India.

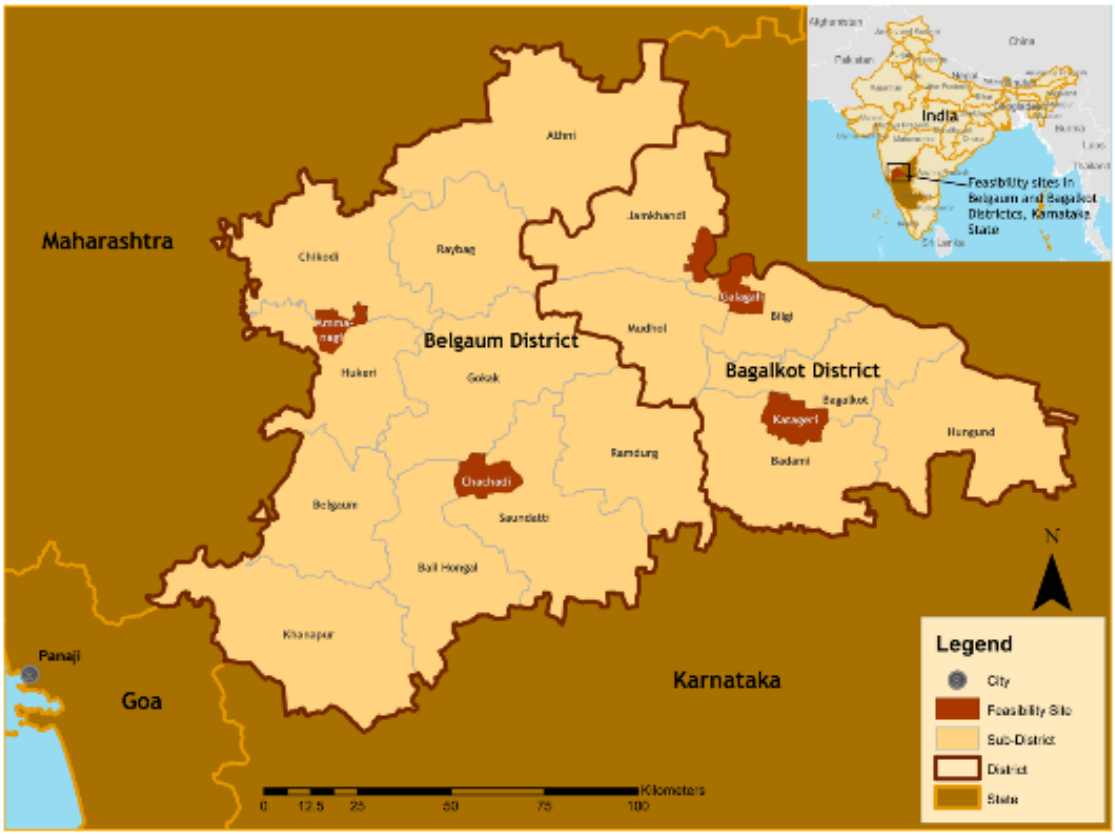
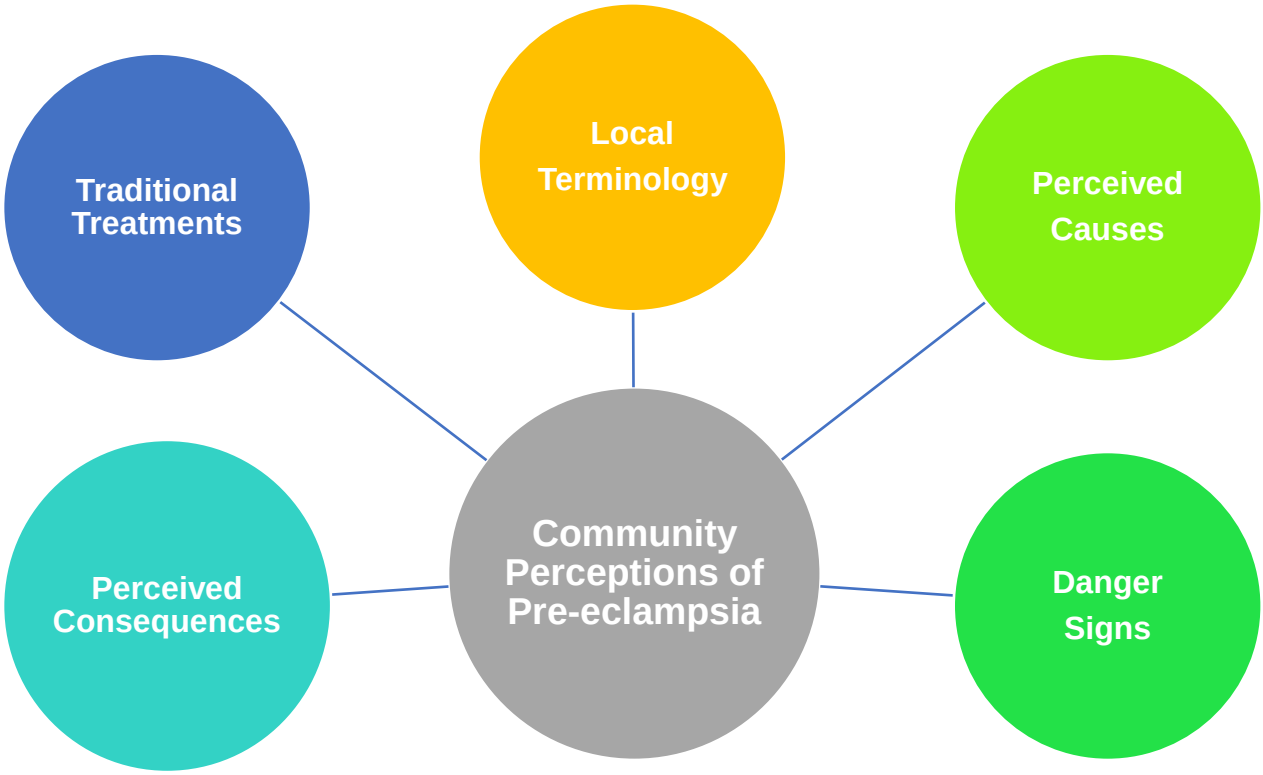


Figure 21. Thematic analysis categories.



What is women's knowledge of the hypertensive disorders of pregnancy when the Community Level Interventions for Pre-eclampsia (CLIP) studies in Nigeria, Mozambique, Pakistan, and India are synthesised from: 1) primary data sources or 2) published findings?

Is there added benefit of a qualitative evidence synthesis from either primary data sources or published findings?

Are there similarities or differences in findings when syntheses are grounded in primary data versus published findings?

Chapter 8. Women's perceptions of the hypertensive disorders of pregnancy in Nigeria, Mozambique, Pakistan and India: A comparison of methods

The synthesis of primary data versus the synthesis of published findings from the Community Level Interventions for Pre-eclampsia (CLIP) Feasibility studies

Background

The purpose of qualitative syntheses is to integrate independent but related qualitative studies (179). This is a relatively new method, starting with the use of meta-ethnography as described by Noblit and Hare in 1988 (180). To date, qualitative evidence syntheses (QES) have by-and-large followed the same basic steps: locating relevant sources, quality assessment, data extraction, and analysis. Qualitative syntheses have become more common, but nevertheless, critiques persist. Sandelowski and others, argue that the process of synthesis can destroy the integrity of qualitative research by summarizing and simplifying complex findings (181). However, it is also reasoned that by combining multiple studies, nuances may become apparent that were otherwise overlooked (181).

In qualitative reviews, the 'data sources' have been representations of studies: academic manuscripts, theses, presentations, newspaper articles, and the like. These sources may vary in the depth and the volume of data they present. However, there has been a considerable push to increase access to primary data. Proponents of 'open data' have identified numerous benefits: increasing the outputs of research, improving transparency, promoting equal access, stimulating innovation, improving sustainability of data, and numerous others (182). Many journals now require open access to datasets prior to publication, and the number of data repositories is quickly growing. Nevertheless, to our knowledge, this is the first QES of original data. With the

recent push for open data, syntheses of primary source may be available in a way it was not before. Both methodologies follow the same basic steps of synthesis – locate relevant sources, quality assessment, data extraction, and analysis – it is only the included sources that differ.

The aim of this study is to determine the level of knowledge that women of reproductive age, pregnant women, and new mothers have regarding the hypertensive disorders of pregnancy (HDPs) in four interrelated studies in Nigeria, Mozambique, Pakistan, and India by way of two methods for qualitative evidence synthesis: (1) synthesis of original transcripts, (2) synthesis of published findings.

Methods

Data for both methods were derived from the four Community Level Interventions for Pre-eclampsia (CLIP) Feasibility studies (118). These four studies were co-ordinated by the University of British Columbia and utilized adaptions of the same protocol and data collection tools, leading to relatively homogenous studies. Nevertheless, field workers were independent, the study settings were vastly different, and the local collaborators had varying levels of qualitative and community-based research experience.

These studies were approved by the Clinical Research Ethics Board of the University of British Columbia, Vancouver, Canada (H12-00132) and by each local ethics committee (OOUTH/DA/326/431, Nigeria; CIBS_CISM/08/2013, Mozambique; MDC/IECHSR/2011-12, India; 1917-Obs-ERC-11, Pakistan). Written informed consent was obtained from each participant and identifiable information was masked to guarantee confidentiality. All quotations provided utilize pseudonyms to mask the identity of participants.

Approach 1 – The synthesis of primary data

Data sources.

For the purposes of this analysis, data from 45 focus groups were included: seven focus groups with pregnant women and new mothers from India, eight focus groups with pregnant women and eight focus groups with new mothers from Nigeria, three focus groups with pregnant women from Mozambique, and nineteen focus groups with pregnant and postpartum women in Pakistan. Focus groups were conducted in their respective local languages: Yoruba in Nigeria, Portuguese and Changana in Mozambique, Sindhi and Urdu in Pakistan, and Kannada and Maharashtra in India. All transcripts were transcribed verbatim and subsequently translated to English were necessary. All translations were conducted by researchers in country with strong language skills and experience with translation.

The SPIDER framework was used to outline the inclusion and exclusion criteria for this qualitative evidence synthesis (QES) (48) (Supplementary Figure 1, pg 229). The syntheses are presented according to the 'Enhancing Transparency in Reporting the Synthesis of Qualitative Research' (ENTREQ) statement (31) (Supplementary Table 6, pg 223).

Quality assessment.

An audit trail was maintained throughout analysis to ensure transparency. NVivo software was used, which maintained an activity log for all modifications during analysis; in addition, memos were used to maintain a record of important analysis decisions. Descriptions were attached to each theme to ensure transparent communication between coders and mutual agreement of theme definitions.

Data extraction.

The use of qualitative software for analysis ensured an audit trail of data extraction and ensured uniformity between sources (183). The use of classifications and attributes allowed a targeted analysis of the studies including relevant study characteristics such as: age, education, number of participants and date (Supplementary Table 7, pg 224).

Approach 2 – The synthesis of published findings

Data sources.

The included studies were selected a priori, therefore, no systematic search or screening was conducted. Nevertheless, the inclusion and exclusion criteria are described by way of the SPIDER framework in Figure 22 (pg 166). This synthesis included the findings from four studies with a shared objective – to determine the feasibility of community interventions for pre-eclampsia – and were conducted in Nigeria, Mozambique, Pakistan, and India. Each study utilized similar methods for focus groups with community women, although procedures were adapted to the local context (24-27). Study details are provided in Table 30 (pg 158).

Quality assessment.

The quality of each study was evaluated using the Critical Appraisal Skills Programme (CASP) checklist. Use of CASP included attribution of a score from 10-30 to reflect strengths and limitations of published findings (Table 31, pg 159). The four studies were of reasonable quality with scores ranging from 26 to 29. Quality assessment was not for the purpose of exclusion but rather to inform the reliability of conclusions drawn and findings presented.

Data extraction.

The data for the purpose of synthesis included the 'findings' extracted from published papers. This text, including quotations and descriptions, was then organized in QSR International NVivo 11 software for coding.

Thematic synthesis

This review utilized thematic synthesis as outlined by Thomas and Harden in 2008 (32). This method urges that results stay close to the primary studies yet provide new ideas and concepts for future use (32). Coding of all data was conducted by one author (MV): a public health researcher and doctoral candidate at the University of British Columbia (co-ordinating centre for the CLIP Trial). To minimize bias, secondary coding was conducted by an independent researcher (DAD) familiar with thematic analysis and NVivo, and who has extensive experience conducting patient research in pre-eclampsia. A random selection of six transcripts, with at least one from each country and participant-type (mothers, pregnant women, women of reproductive age, mothers with children under five), were re-coded and compared at each level of analysis by the secondary coder, for the synthesis of primary data.

Member checking of findings was performed; this involved returning the summary of results to principal investigators and/or coordinators of the primary studies in the respective countries. These individuals were chosen due to their intimate knowledge of the data due to involvement in the study design, data collection and interpretation. These researchers then provided feedback regarding how results corresponded to their experience with primary data collection and analysis. Representatives from the studies in Mozambique and Pakistan reported that all findings described fit with their site. The representative from Nigeria, pointed to numerous findings that reflected the Nigerian CLIP Feasibility experience, however, some results were highlighted as inconsistent with their findings: fire was not a cause mentioned, no discussion of self-medication, diet related to treatment not prevention.

Many of the authors (MV, PvD, DS, KM, RNQ, ZB) participated in the design, conduct, or analysis of one or more of the studies; furthermore, the generation of themes could have been influenced by the authors' familiarity with the data. The views and opinions of the researcher are inextricable from the process of analysis. Trustworthiness can be achieved by having other researchers independently review the synthesis process at each step (184).

Results

Description of study areas

The included studies were conducted from 2012-2014 in four culturally and geographically distinct regions: Nigeria, Mozambique, Pakistan, and India. These were four mixed-methods feasibility studies aimed at assessing the acceptability of community interventions for pre-eclampsia. Comprehensive methodological details can be found in the original publications of the primary studies (24-27, 118). In brief, the study in Nigeria illustrated that knowledge of pre-eclampsia and eclampsia are limited; there were several potentially harmful cultural myths and misconceptions regarding the aetiology and treatment of the conditions. In southern Mozambique, the terms pre-eclampsia and eclampsia were not known, but when prompted, the conditions were understood as hypertension and seizures, not necessarily related to pregnancy. In Nigeria, and to a lesser extent Mozambique, local beliefs were not aligned with the biomedical perspective, and instead are associated with supernatural, emotional and social causes. There were mixed opinions regarding the causes of the hypertension in pregnancy and a poor understanding regarding the connection between pregnancy, hypertension and seizures in Pakistan. In India results clearly indicate a need for further education of the

community, moving from a narrow biomedical focus and incorporating the diverse cultural and social factors.

Description of themes for approach 1 – the synthesis of primary data

The first step in the thematic synthesis was to code all relevant data line-by-line. Each node represented a description of the data included within, and each segment of the raw transcripts was coded to the related first-order theme(s) (nodes). This process included translation of findings across transcripts. In the second step, first-order themes were reviewed and regrouped based on similarities to develop four new related descriptive themes: (1) awareness of hypertension and/or convulsions in pregnancy, (2) the relationship between hypertension and convulsions as well as their connection or lack thereof to the parturient period, (3) personal experiences or the experiences of others, and (4) cultural or historic representations of hypertension and/or convulsions in pregnancy. The third step in the synthesis process was the generation of analytic themes. Unlike the previous two steps, these themes provide further interpretation of the data (Supplementary Figure 2, pg 230).

Inter-rater agreement was assessed through comparison of coded transcripts at all three stages. In cases of disagreement, transcripts were reviewed by both coders until consensus was reached regarding appropriate thematic coding. Discrepancies were found to be primarily related to the style of coding; one reviewer (MV) coded broadly and selected large passages, while the secondary reviewer (DAD) selected narrow sections and did not include the broader context. As both of these methods are acceptable, it was determined that no change to the analysis was required. The four *analytic themes* include:

Theme 1. The influence of personal experiences in making sense of the hypertensive disorders of pregnancy.

Theme 1 reflects both a barrier and facilitator to understanding the HDPs depending on the nature of the experience. Experiential learning was consistently described as the source of knowledge by participants and was far more common than health worker teachings or other sources. Experiences typically reflected personal experiences or those of close relatives, and infrequently folklore maintained for generations by word of mouth:

> *"My husband sells minerals and when I carry too many crates I find it difficult to get up from the bed the following morning, I would be feeling dizzy, when I go to the hospital, they would tell me that my blood pressure is high and I should reduce the work that I do." Adamma – 26-year-old pregnant mother of one from Remo North, Nigeria*
>
> *"Recently I knew a woman who was seven months pregnant and […] they said her BP was very high. At last she lived but the baby died, and it was a male baby. She went for scanning two days before and she was absolutely alright but suddenly the BP was high and the baby died" Navya - woman of reproductive age from Chachadi, India*
>
> *"A pregnant woman convulsed and they rushed her to the hospital, they gave her injections and she eventually died, so convulsions and injections are enemies" Diola – 27-year-old mother of three, Yewa South, Nigeria*

Theme 2. Interpretations of the hypertensive disorders of pregnancy related to the natural environment.

The natural environment was commonly described as influential in the development of hypertension and/or convulsions in pregnancy. The environmental elements felt to be important were fire, water, cold, and heat. Findings demonstrate a prominent perceived association between an exposure to cold and convulsions. In eleven of the focus group discussions in Nigeria, and many elsewhere this relationship was mentioned:

"Cold drinks can cause convulsion" Ileara - 31-year-old mother of one from Yewa South, Nigeria

"If the woman goes near fire or if she carries water" Prisha - woman of reproductive age from Belgaum, India

Theme 3. Interpretations of the hypertensive disorders of pregnancy related to socio-economic factors.

Theme 3 was the most widespread analytic theme across countries and participants. There were very few women who did not mention the role of finances, interpersonal relationships, or psychological health when describing the HDPs (Figure 23, pg 167). There were frequently discussions of disagreements with husbands and in-laws, and at times this included physical violence perpetrated against pregnant women:

"It happens when husbands beat their wives when they are pregnant, […] it also happens because of domestic fights and stress" Fahima - mother from Hala, Pakistan

Stress, worry and depressive tendencies were most commonly reported cause of hypertension in pregnancy. Women in all four sites described the negative impact of stress or anxiety on their health in pregnancy.

"When a pregnant woman is having depressive thoughts, for some women it could occur if the husband neglects them, for others it may be that the pregnancy was by mistake" Lewa - 25-year-old pregnant mother of two from Imeko Afon, Nigeria

In addition, poverty was repeatedly associated with the development of these pregnancy complications:

"Blood pressure increases because of tensions, we also have problems at home, all these problems are there, poverty is also a problem, and then we suffer" Shadi - mother from Sekhat, Pakistan

Manual labour, associated with income generating activities, such as hawking, trading, and agriculture, were also thought to be related to hypertension and convulsions in pregnancy. This was context-dependent due to a varying likelihood for women to engage in manual labour and/or employment in pregnancy.

Theme 4. Interpretations of the hypertensive disorders of pregnancy related to supernatural and mythical factors.

The interpretations of the HDPs were at times related to supernatural and mythical factors in the African context, but less often in India or Pakistan. Nevertheless, many of these discussions, particularly in Nigeria, discredited the influence of supernatural forces:

"It is not every illness that is the result of a spiritual attack, some pregnant women are careless and they would blame it on evildoers" Orisa - 28-year-old Christian mother of two from Yewa South, Nigeria

"High blood pressure can't be caused by spiritual attack" Oriyomi - mother from Yewa South, Nigeria

In Mozambique, there is a prominent myth regarding the cause of convulsions. This myth states that a small snake lives inside the abdomen of the affected individual and causes seizures, and is associated with the moon cycle. This belief was associated with childhood seizures but also extended to the seizures of eclampsia:

"They are identified with the one of children, it is the same disease" Alima - pregnant woman from 3 de Fevereiro, Mozambique

Many explained that the presence or absence of hypertension and convulsions was due to the influence of God, in both the strongly Christian region of Ogun State, Nigeria and the nearly exclusively Muslim region of Pakistan (Figure 24, pg 168).

"Pregnant women should be prayerful" Adeola - 32-year-old mother of four from Imeko-Afon, Nigeria

"We read the Quran over the water and drink that water" Husna - mother from Karo Brohi, Pakistan

For a summary of all themes and associated quotations see Figure 25 (pg 169) and Table 32 (pg 161).

Description of themes for approach 2 – the synthesis of published findings

The first step involved, line-by-line coding of all relevant 'findings' was conducted to determine the first-order themes, many passages were coded to multiple themes. This stage of the process resulted in identification of thirty-three themes. Following this process, second-order themes were developed as a condensed summary of findings; these codes represent the combination of one or more initial themes. Many second-order themes were similar to those provided in the primary publications. These six themes were: causes, danger signs, local terminology, outcomes, connection between hypertension and seizures, and relationship of

conditions with pregnancy and/or the postpartum period. The last stage of the thematic synthesis of published findings was to summarize findings into third-order-analytic themes, which are presented in detail below. This stage included further interpretation of findings; however, interpretation is restricted by the level of detail provided in the publications. This is a subjective process relying on the interpretation and judgment of the analyst. This stage of synthesis is used to go beyond original findings and address the broader research question of the synthesis. The synthesis was used to best describe existing knowledge, gaps in knowledge, and barriers or opportunities for learning regarding the HDPs. The four *analytic themes* include:

Theme 1. Knowledge regarding hypertension or convulsions in pregnancy

It is evident that knowledge of these pregnancy complications (hypertension or seizures) are limited in all four settings. Findings showed a large number of knowledge gaps and misunderstandings, however, a basic level of awareness was present. Awareness of the condition was made evident through the descriptions of danger signs related to hypertension provided by respondents: dizziness, fatigues, headache, and swelling. There also appears to be an acknowledgement of the severity of the condition and the possibility of death for the mother or baby. A familiarity with local terminology, also reflects an awareness of the conditions.

Theme 2. Knowledge gaps regarding hypertension or convulsions in pregnancy

Despite the awareness described in Theme 1 there were widespread knowledge gaps. One recurrent misunderstandings and confusion was the causes of seizures, explanations ranged from supernatural or environmental causes to those related to medical intervention, such as tetanus toxoid vaccination. In addition, most participants did not seem to grasp the link with these conditions (hypertension and seizures) and pregnancy, instead they were often thought to be related to other convulsive disorders outside pregnancy.

Theme 3. Barriers to learning regarding hypertension or convulsions in pregnancy

A number of findings presented in the four studies indicate barriers to education efforts regarding the HDPs. All four studies displayed some beliefs contrary to the biomedical concepts of etiology, pathophysiology, progress, and treatment of the HDPs, such as the association of cold and convulsions in Nigeria (27).

> *"There is a belief that if a pregnant woman frequently sleeps on a cold floor, it could cause convulsion, or if the body is exposed to too much breeze […] and also if there are excessive depressive thoughts…it can lead to a convulsion"* (27)

The use of traditional treatments may delay or substitute evidence-based treatment for the HDPs. The contents of many traditional remedies are unknown and their effects may be harmful. Self-medication was common for hypertension and related symptoms (such as headache) in Pakistan, often women did not know what medication they are taking (25). The misperception that diet and some minor medical conditions cause the onset of hypertension and seizures could lead to ineffective prevention and treatment strategies. Familial relationships, particularly with mothers-in-law in Pakistan, were thought to hinder healthy pregnancies.

> *"When [she is] sick, [her] mother-in-law thinks that [she is] too weak. She often criticized and says…don't think, you are the only one pregnant, and no other women have delivered before"* (25)

In India, the perceived association with the HDPs and caesarean deliveries, which are highly undesirable, may prevent women from accessing timely health care services and necessary preventative antenatal care screening (24).

For a breakdown of all themes see Figure 26 (pg 170).

Discussion

The syntheses outlined above, indicate that culture and context, social learning, and disparities in access to biomedical sources of knowledge have a substantial influence on women's understanding of the HDPs and contribute to the limited knowledge of these conditions among women of reproductive age. The findings showed some considerable differences between countries; however, this is to be expected given that all four countries represent distinct cultural groups. Misconceptions were shown to originate from historical, traditional, or ancestral beliefs and myths related to health and disease, as other research on community understandings of pre-eclampsia have demonstrated (17, 45, 60, 173). In this synthesis, associations between the natural environment and convulsions were found to differing degrees in multiple sites.

Knowledge of the HDPs were profoundly influenced by personal experiences and the experiences of those around them. Some described the limits of their knowledge due to a lack of exposure to the conditions directly. This finding is congruent with Bandura's social learning theory, which posits that knowledge is acquired through experience (41). As such, experiential learning may compound the risk of nulliparous women who are more likely to have higher rates of the HDPs and therefore have had less opportunity for interaction related to hypertension or convulsions. The high frequency of recounted personal experiences may indicate that these complications are relatively common in their communities. These findings emphasize the potential for experience to be used in health education to better communicate the warning signs, causes, and risks of the HDPs, and perhaps other pregnancy complications. Active learning strategies based on Paulo Freire's empowerment education theory, have shown participatory learning of health consequences to be effective (185).

Despite distinct cultural differences, some commonalities were heard from participants between countries. Social factors were deeply intertwined in the perceptions of health and illness in these cultures, particularly the influence of poverty and access to transport and health care services. In addition, representatives from all four countries discussed the importance of familial relationships and the effect of stress on the development of hypertension. There were many mentions of domestic conflict and violence as an important factor in the development of hypertension and/or seizures in pregnancy.

Opportunities for further learning regarding the HDPs were expressed across the four studies. Stress was consistently described to be the cause of hypertension was in all studies. The association between stress signifies a recurrent misconception to be debunked across cultures. Family relations have a central role in the development and severity of the HDPs according to these findings, this may be an opportunity to engage the family in pregnancy-related care which could improve health knowledge and outcomes. This is aligned with situated learning theory, which suggests that learning is inextricable from the social world (42). Some participants emphasized the importance of hypertension and convulsions in pregnancy with regards to deleterious effects on the fetus. Incorporating the risks to the infant may prove to be an alternative avenue to raise the profile of these dangerous conditions.

Strengths and limitations

Both methods for qualitative synthesis presented in Chapter 8 amalgamate data from four distinct international jurisdictions and cultures, providing insight to the beliefs of women in sub-Saharan Africa and South Asia. The four studies are of high and comparable scientific rigor, which allows a similarly rigorous analysis. In addition, the inclusion of relatively homogenous studies allows easy cross-comparison of findings. Access to primary data and the continued

relationships with in-country research teams for support and member checking has strengthened the validity of this analysis. Multiple quality appraisal techniques were also employed: audit trail with use of NVivo qualitative software, secondary independent coder, and member checking. This review and synthesis was presented following the 'Enhancing Transparency in Reporting the Synthesis of Qualitative Research' (ENTREQ) guidelines (Supplementary Table 6 (pg 223) and Supplementary Table 8 (pg 226)) (31).

Despite attention to rigorous scientific strategies, there are inherent limitations to both methods of these qualitative evidence syntheses. This review is limited by the fact that many of the authors also contributed to the primary studies; however, this limitation has been present on other successful and sound reviews and has been counter-balanced by use of a secondary independent coder (186). Both approaches are restricted by the fact that data has been translated from the language of origin, in this process the nuance of some responses may have been lost. The culturally-specific nature of these results makes the findings difficult to generalize to other settings.

A comparison of methods and findings

There are limitations to both approaches described. The review of original transcripts is labour intensive and extremely time consuming; however, the alternative approach is limited by the summarized findings presented in published papers. Manuscripts are constrained by journal regulations and word strict word limits; this is particularly challenging for qualitative studies which require thorough description of the context. It can be challenging to identify which responses are associated with which participants with the limited details published. Manuscripts contain few direct quotes, picked at the discretion of the authors. Furthermore, publications are

subject to the opinions and interpretations of the authors, therefore, it is difficult to know the extent that the findings accurately reflect the experience of participants.

Typically, researchers conducting qualitative synthesis reviews do not have access to the nuanced details available in original transcripts, however, this may be changing. Prominent journals and funding agencies are increasingly requiring ‘open data’ when publishing results. Access to original datasets allows a greater level of transparency. This shift to open access databases may facilitate the synthesis of qualitative data in the future.

Sub-group analyses are difficult from published studies as sufficient data or details are not always presented, this is easily conducted from raw data particularly with the help of qualitative software which allow researchers to compare various groups and combinations of characteristics. (For details on differences between methodologies see Table 33 (pg 163) and Table 34 (pg 165)

Conclusion

Knowledge gaps exists amongst women of reproductive age regarding the potentially life-threatening hypertensive disorders of pregnancy across four LMICs. These findings may be used to advocate and inform changes to patient and community health education and health worker training to more appropriately target these gaps.

Table 28. Summary of included studies.

Country	Principal investigators	Year of data collection		Location	Number of participants	Methods
Nigeria	Adetoro, O.O., Dada, O.A., Oladapo, O.T.	2012	Rural and semi-rural	Primary health centres, DOTS centres, TBA's centre, Oba's palace	Focus groups (N=16) Participants (N=260)	Focus groups
Mozambique	Munguambe, K., Sevene, E., Sacoor, C.	2013	Rural	Community meeting locations (*circulos*), community leader's home, participant's home	Focus groups (N=3) Participants (N=unknown)	Focus groups
Pakistan	Qureshi, R.N., Bhutta, Z.	2012	Rural and semi-rural	Participant's home, rural health centres	Focus groups (N=18) Participants (N=174)	Focus groups
India	Goudar, S., Bellad, M., Mallapur, A.	2013	Rural and semi-rural	Primary health centres	Focus groups (N=7) Participants (N=146)	Focus groups

**DOTS –direct observed treatment short course; TBA – traditional birth attendant; Oba – local king;*

Table 29. Data sources.

Nigeria (n=16)	Mozambique (n=3)	Pakistan (n=19)	India (n=7)
Ogun State	Maputo Province	Sindh Province	Karnataka State
Sagamu (Ogijo)	Ilha Josina	Hala	Chachadi
Focus group with pregnant women (n=2)	Focus group with pregnant women (n=1)	Focus group with mothers (n=3)	Focus group with women of reproductive age (n=3)
Focus group with mothers with children under 5 (n=2)	Calanga	Tando Jam	Ammanagi
Yewa South	Focus group with pregnant women (n=1)	Focus group with mothers (n=1)	Focus group with women of reproductive age (n=1)
Focus group with pregnant women (n=2)	Tres de Fevereiro	Qasimabad	Hosur
Focus group with mothers with children under 5 (n=2)	Focus group with pregnant women (n=1)	Focus group with mothers (n=1)	Focus group with women of reproductive age (n=1)
Imeko-Afon		Hyderabad	Katageri
Focus group with pregnant women (n=2)		Focus group with mothers (n=4)	Focus group with women of reproductive age (n=1)
Focus group with mothers with children under 5 (n=2)		Serkhat	Galagi
Remo North		Focus group with mothers (n=1)	Focus group with women of reproductive age (n=1)
Focus group with pregnant women (n=2)		Latifabad	
Focus group with mothers with children under 5 (n=2)		Focus group with mothers (n=3)	
		Moosa Khatyan	
		Focus group with mothers (n=1)	
		Nasarpur	
		Focus group with mothers (n=1)	

		Hoosri	
		Focus group with mothers (n=1)	
		Saeedabad	
		Focus group with mothers (n=1)	
		Matiari	
		Focus group with mothers (n=1)	
		Bhit Shah	
		Focus group with mothers (n=1)	

Table 30. Data extraction table.

	Study setting	Relevant participants	Relevant study objective(s)	Methods	Themes
1	Ogun State; Nigeria	8 FGDs with pregnant women (n=94); 8 FGDs with new mothers (n=95)	to identify community perceptions of pre-eclampsia and eclampsia	Focus group discussions	Local terms, perceived causes, prevention strategies, outcomes, traditional treatments
2	Maputo Province; southern Mozambique	5 FGD with women of reproductive age (n=28) and 5 FGDs with mothers and mothers-in-law (n=43) *	to describe the community understandings of pre-eclampsia and eclampsia	Focus group discussions	Local terminology perceived causes, warning signs, prevention strategies, perceived consequences, traditional treatments
3	Sindh Province; southern Pakistan	19 FGDs with women of reproductive age and mothers-in-law (n=173)	to explore the community's understanding of pre-eclampsia and eclampsia	Focus group discussions	Local names and danger signs, causes, prevention strategies, severity of illness, disease outcomes, alternative treatments
4	Rural Karnataka State	3 FGDs with female decision-makers (n=41), and 6 FGDs with women of reproductive age (n=132)	to explore community-based understandings of pre-eclampsia and eclampsia	Focus group discussions	Traditional treatments, local terminology, perceived causes, perceived consequences, danger signs

**one focus group did not identify the number of participants*

Table 31. Critical Appraisal Skills Programme (CASP) checklist results.

Nigeria				
		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?		*	
5	Was the data collected in a way that addressed the research issue?		*	
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?	*		
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
			CASP score	*26/30*
Mozambique				
		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?	*		
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?	*		
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?	*		
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
			CASP score	*29/30*
Pakistan				
		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?		*	
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?	*		

9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
			CASP score	*27/30*
India				
		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?			*
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?	*		
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?	*		
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
			CASP Score	*26/30*

Table 32. Summary of themes for the synthesis of primary data.

Initial concepts	Reference	Descriptive themes	Reference	Analytic themes	Reference
Pregnancy complications	*"We can have any problem like diarrhea, vomiting, […] backache or bleeding" (Mother, Hoosri, Pakistan)*	Awareness of hypertension and/ or convulsions as a complication of pregnancy	*"We don't usually experience that (convulsions) of adult here" (20-year old nulliparous woman, Yewa-South, Nigeria)* *"Yes it may become high and it can happen with anybody" (Mother in Hoosri, Pakistan)*	Influence of experience on understanding the HDPs	*"Using myself as an example I find it difficult to sleep at night […], so if I've not been able to sleep well for about two consecutive nights my blood pressure would rise" (24-year-old pregnant mother of two, Remo North, Nigeria)* *"My sister-in-law developed high blood pressure during pregnancy, she developed swelling and then she developed seizures, we tried to bring her back to her senses but she remained unconscious then we borrowed money and tried to take her to the hospital but she died on her way to the hospital" (Mother, Matiari, Pakistan)*
Awareness of convulsions in pregnancy	*"They don't have that here" (30-year-old mother of 6, Imeko-Afon, Nigeria)* *"We have not seen seizures and we don't know about it" (Mother in Nasarpur, Pakistan)*				
Awareness of hypertension in pregnancy	*"Yes [blood pressure] could rise" (Mother in Bhale Dino Kaka, Pakistan)* *"Yes, it can go high. It occurs suddenly" (Mother in Latifabad, Pakistan)*				
Causes of convulsions in pregnancy	*"It may be caused by diseases, tension or anxiety"" (Mothers, Latifabad, Pakistan)* *"Due to excess heat, mainly the heat near the oven" (woman of reproductive age, Chachadi, India)*	Relationships Hypertension and convulsions Hypertension or convulsions and pregnancy	*"No they don't have any relationship" (Pregnant woman, Ilha Josina, Mozambique)* *"There is no relation between jahataka [seizures] and high blood pressure" (Pregnant woman, Ammanagi, India)* *"I don't know about this [relationship between high blood pressure and seizures]" (Mother in Saeedabad, Pakistan)*	Interpretations of the HDPs related to elemental factors	*"When you see flames and too much exposure to seeing flames" Pregnant woman, Hosur, India* *"I think salt intake could cause it" 31-year-old mother of two, Imeko-Afon, Nigeria* *"I think cold drinks could cause it, if the pregnant woman takes cold drinks it could cause convulsions for her" (32-year-old pregnant mother of two, Remo North, Nigeria)*
Causes of hypertension in pregnancy	*"Blood pressure comes in because of quarrelling every day at home" (Pregnant woman, 3 de Fevereiro, Mozambique)* *"Stress could cause it… if the pregnant woman does too much work" (32-year-old pregnant woman, Remo North, Nigeria)*				
Outcomes of convulsions in pregnancy	*"A pregnant woman gets unconscious and then she is not able to speak, […] they lose energy to speak" (Mother, Matiari, Pakistan)* *"Women may die because she has jhataka (seizures)" (woman of reproductive age, Chachadi, India)*				
Outcomes of hypertension in pregnancy	*"She can lose her life or give birth and the baby may not survive" (Pregnant woman, Calanga, Mozambique)* *"If the blood pressure is high […] she may be unable to deliver, the baby may not be in a stable condition, […] the baby won't be strong" (25-year-old pregnant mother of four, Imeko-Afon, Nigeria)*	Experiences Personal experiences of hypertension or convulsions in pregnancy Experiences of others with hypertension and/or convulsions in pregnancy	*"We heard you feel your heart paining, beating hard" (Pregnant women, Ilha Josina, Mozambique)* *"I have once had high blood pressure, I developed high blood pressure during pregnancy and they didn't observe it where I was receiving care, it was after my delivery that we discovered" (Mother in Yewa South, Nigeria)* *"I went to the civil hospital and saw there was one woman who knew she had BP in spite of that she delivered at home and after delivery her BP was becoming high and she threw a convulsion, before her relatives brought her to the civil hospital she died on the way, she died due to increased blood pressure" (Woman of reproductive age, Belgaum, India)*	Interpretations of the HDPs related to socio-economic factors	*"Because of improper diet" (Mother, Moosa Khatyan, Pakistan)* *"Other people are always sad and may have conflicts with her husband" (Pregnant woman in 3 de Fevreiro, Mozambique)* *"Excessive worrying that causes high blood pressure" (28-year-old pregnant mother of two, Yewa South, Nigeria)*
Experience of convulsions in pregnancy	*"I have experienced seizures during my pregnancy. I didn't know that was happening at the time, I was completely unconscious, and then my family took me to the doctor's and then they started monitoring the baby's heartbeat and doctors operated on me while I was going through seizures, they rubbed my hands and threw drops of water on my face but I was completely unaware of the situation" (Mother, Matiari,*				

Initial concepts	Reference	Descriptive themes	Reference	Analytic themes	Reference
	Pakistan)				
Experience of hypertension in pregnancy	*"When I was pregnant…the health care workers told me that I ha high blood pressure, that maybe I was worrying about issues" (25-year old mother of one, Remo North, Nigeria)*				
Signs of convulsions in pregnancy	*"[she] falls down and does not speak […] after that she convulses, sometimes she urinates" (pregnant woman, Ilha Josina, Mozambique)* *"The women start shaking […] and froth will come from the mouth" (women of reproductive age, Chachadi, India)*	Traditional, ancestral, historical representations of hypertension and/or convulsions in pregnancy	*"A woman's urine is given to the convulsing woman to drink" (38-year old mother of five, Sagamu, Nigeria)* *"If the woman goes near fire or if she carries water" (Woman of reproductive age in Belgaum, India)* *"We read the Quran over the water and drink the water" (Mother in Nasarpur, Pakistan)*	Interpretations of the HDPs related to supernatural and mythical factors	*"They say that it is the disease of the moon" (Pregnant women in Ilha Josina, Mozambique)* *"A pregnant woman could have a misunderstanding with one of her neighbours, the pregnant woman could go to the church because she could be thinking that the neighbour she fought with could attack her spiritually if she goes back home" (21-year-old mother of one in Remo North, Nigeria)* *"We use spiritual treatment, like we read the holy Quran over the water and drink it" (Mother in Hala, Pakistan)* *"God should not let us encounter it" (31-year-old Muslim mother of two, Yewa South, Nigeria)*
Signs of hypertension in pregnancy	*"Headache, shoulder pain, pain in the sides, skin diseases get exaggerated" (Mother, Sekhat, Pakistan)* *"It can cause dizziness" (25-year old mother of two, Sagamu, Nigeria)*				
Terminology for convulsions in pregnancy	*"They say it is the disease of the moon" (Pregnant woman, Ilha Josina, Mozambique)* *"They call it 'giri'" (30-year old pregnant mother of three, Remo North, Nigeria)* *"All women said 'jhataka'" (pregnant women, Ammanagi, India)*				
Terminology for hypertension in pregnancy	*"We only know it as heart disease" (Pregnant woman, 3 de Fevereiro, Mozambique)* *"Eje riru (stormy blood)" (32-year old nurse/midwife and mother of four, Imeko-Afon, Nigeria)* *"They all call it as BP only" (Women of reproductive age, Chachadi, India)* *"It is called blood pressure" (Mothers, Matiari, Pakistan)*				

Table 33. Differences in methods and findings.

	The synthesis of primary data	The synthesis of published findings
Data sources	Original transcript or other data source (eg. image, recording)	Manuscripts included in synthesis
Quality assessment/ audit procedures	Quality assessment relates specifically to data analysed and analysis process	Quality assessment of study as a whole
Data extraction	Relevant data is extracted through analysis process through review/interpretation of researcher	'findings/results' of studies of interest
First order themes	• Known pregnancy complications • Awareness of convulsions in pregnancy • Awareness of hypertension in pregnancy • Causes of convulsions in pregnancy • Causes of hypertension in pregnancy • Outcomes of convulsions in pregnancy • Outcomes of hypertension in pregnancy • Personal experiences of convulsions in pregnancy • Personal experiences of hypertension in pregnancy • Signs of convulsions in pregnancy • Signs of hypertension in pregnancy • Local terminology for convulsions in pregnancy • Local terminology for hypertension in pregnancy	• Caused by diet • Caused by environmental factors (fire, water, cold, heat) • Caused by other medical conditions • Caused by poor health care seeking behaviours • Caused by poverty • Caused by stress, tension, worries • Caused by supernatural elements • Characterised by anger • Characterised by clenching teeth or tongue bite • Characterised by dizziness • Characterised by excessive talking • Characterised by eyes rolling backward • Characterised by fainting or falling • Characterised by fatigue • Characterised by frothing at mouth • Characterised by headache • Characterised by heart conditions • Characterised by nausea or vomiting • Characterised sweating • Characterised by swelling • Names for seizures • Names for hypertension • No known relationship between hypertension and convulsions • Relationship between hypertension and convulsions • Relationship of hypertension or convulsions with pregnancy • Results in brain conditions • Results in death (mother, infant, miscarriage, stillbirth) • Results in fainting or falling • Results in heart conditions • Results in paralysis • Results in preterm delivery

	The synthesis of primary data	The synthesis of published findings
		• Results in seizures • Results unknown
Second order themes	• Awareness of hypertension or convulsions in pregnancy • Relationships between hypertension and convulsions, and relationship with conditions and pregnancy • Personal experiences and experiences of others • Cultural and historic representations of hypertension or convulsions in pregnancy	• Perceived causes of hypertension or convulsions in pregnancy • Danger signs of hypertension or convulsions in pregnancy • Local terminology of hypertension or convulsions in pregnancy • Perceived outcomes of hypertension or convulsions in pregnancy • Relationships between hypertension and convulsions • Relationship with hypertension and pregnancy or convulsions and pregnancy
Analytic themes	• Influence of experience in understanding the HDPs • Interpretations of the HDPs related to the natural environment • Interpretations of the HDPs related to socio-economic factors • Interpretations of the HDPs related to supernatural or mythical elements	• Barriers to learning regarding hypertension or convulsions in pregnancy • Knowledge gaps regarding hypertension or convulsions in pregnancy • Knowledge of hypertension or convulsions in pregnancy

Table 34. Advantages and disadvantages of synthesis methods.

	The synthesis of primary data	The synthesis of published findings
Advantages	• Access to full detail available in transcripts • Detailed classification of sources is possible during analysis to ease the possibility of greater sub-group analyses • Ability to go beyond primary studies can more easily be achieved as access to a range of data is available • Provides fresh insight to the data • Translation of findings may be possible across diverse methodologies	• Identification of data for extraction is straightforward: 'findings'/'results' • Small amount of data resulting in faster process of analysis
Disadvantages	• Inclusion of transcripts may require translation not previously completed • Quality assessment of studies as a whole may not be appropriate • Appropriate data for extraction requires research interpretation and may vary by analyst • Very time consuming	• Sub-group analyses can be inhibited if data is not presented according to desired sub-groups • New interpretations of findings and theoretical generation is limited by the findings presented for publication • The synthesis (particularly meta-ethnography) of multiple methodologies may not be possible • Can be difficult to identify the data for extractions – key concepts, summaries, quotations • Findings will remain close to primary studies as they are limited to results presented

Figure 22. QES SPIDER framework.

S	**Sample**	• New mothers from Ogun, Nigeria • Pregnant women from Ogun, Nigeria • Pregnant women from Gaza and Maputo, Mozambique • Mothers from Gaza and Maputo, Mozambique • Mothers-in-law from Gaza and Maputo, Mozambique • Women of reproductive age from Sindh, Pakistan • Mothers-in-law from Sindh, Pakistan • Women of reproductive age from Karnataka, India • Mothers form Karnataka, India • Mothers-in-law from Karnataka, India
P I	**Phenomenon of Interest**	• The hypertensive disorders of pregnancy • Pre-eclampsia • Eclampsia • Hypertension in pregnancy • Convulsions in pregnancy
D	**Design**	• Ethnography
E	**Evaluation**	• Knowledge • Awareness • Beliefs • Comprehension • Attitude • Health knowledge
R	**Research type**	• Focus groups • Interviews

Figure 23. Word cloud of the theme 'socio-economic determinants of the hypertensive disorders of pregnancy'.

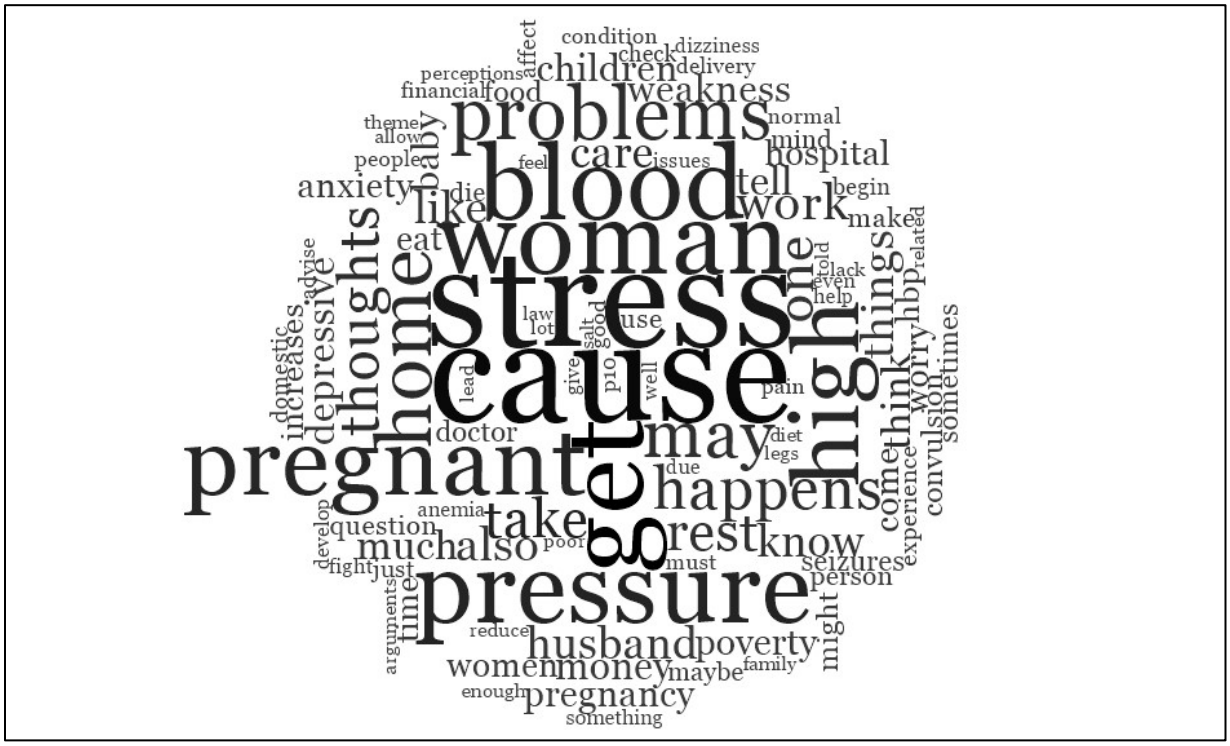


Figure 24. Word tree of all mentions of ‘God’.

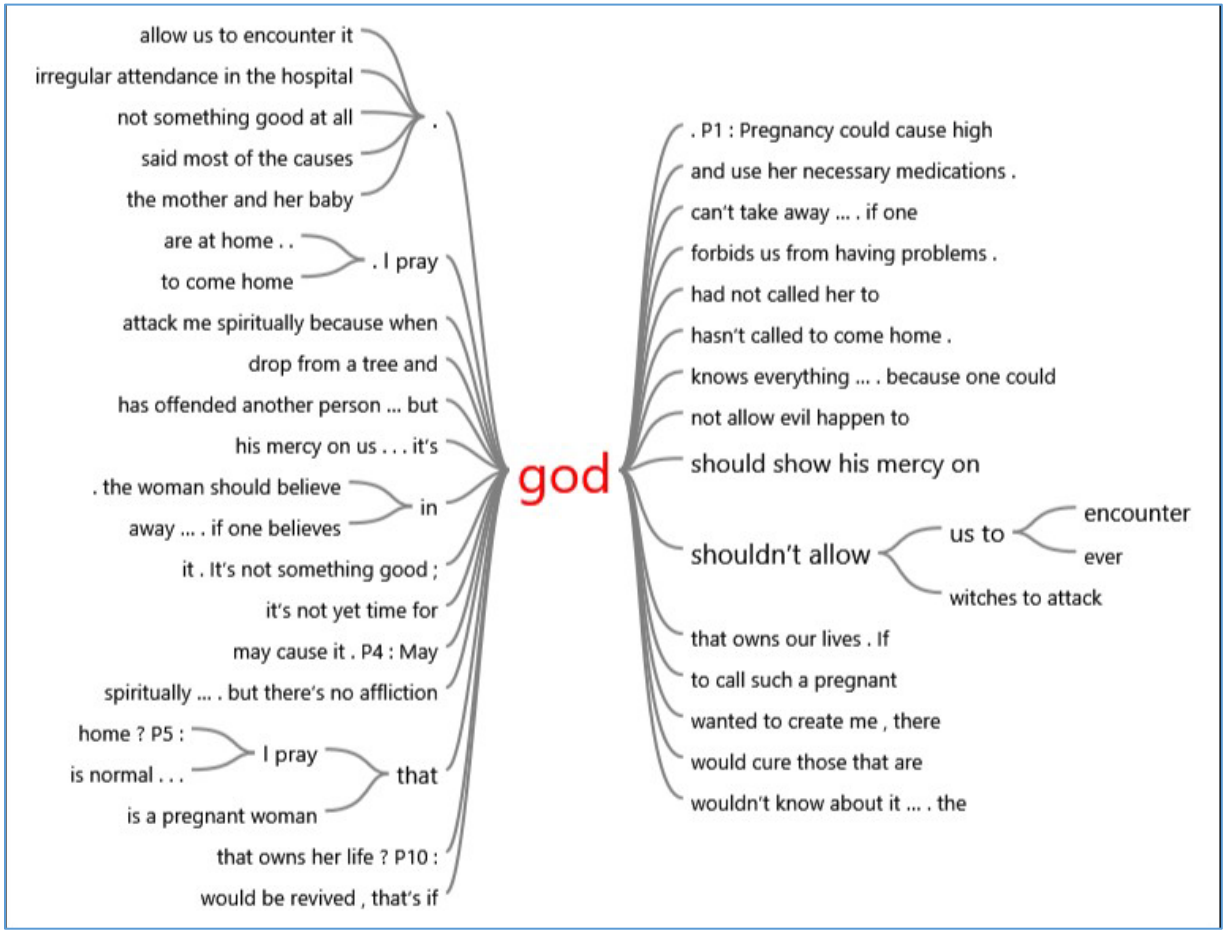


Figure 25. Themes and sub-themes for the synthesis of primary data.

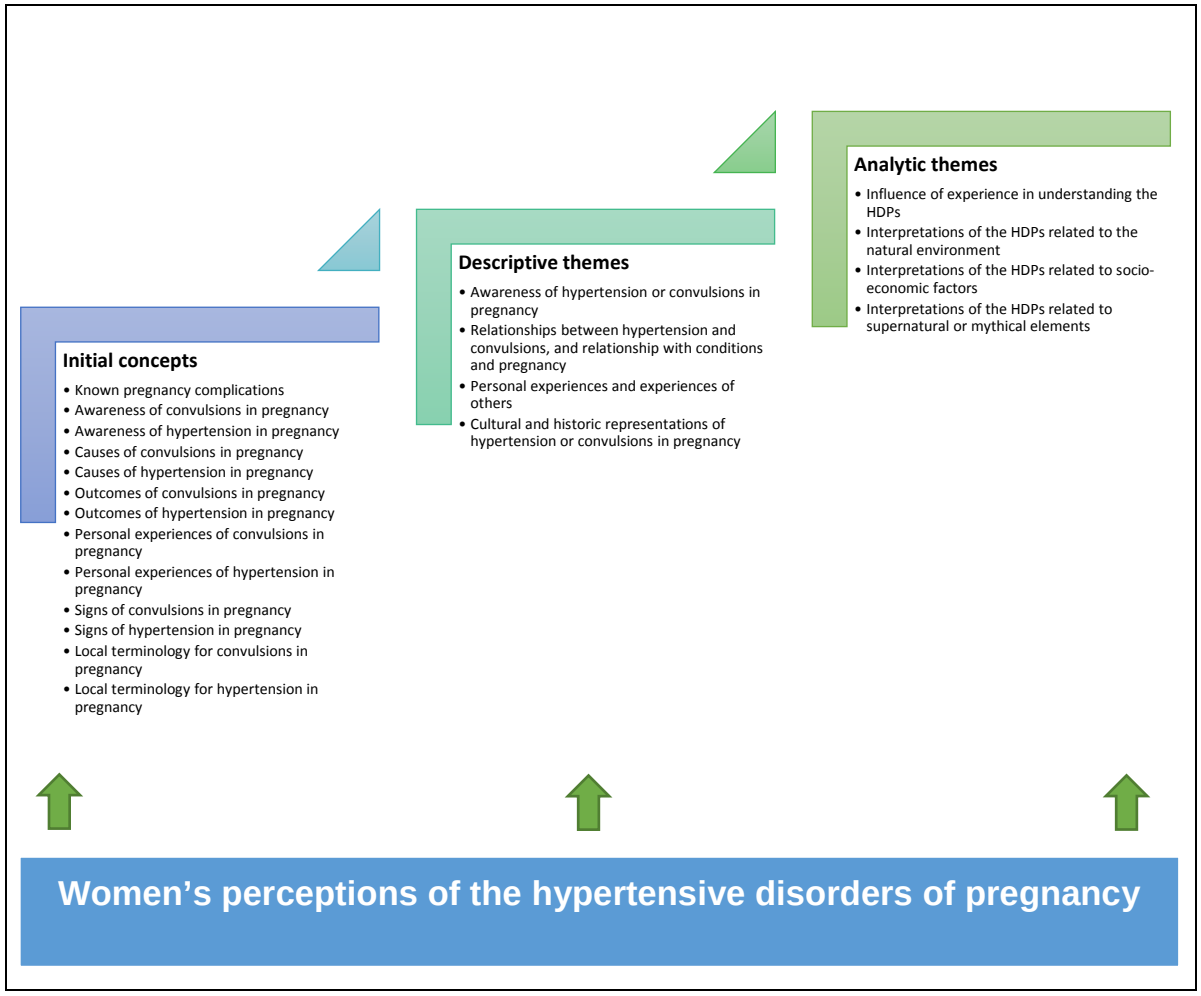


Figure 26. Initial themes, descriptive themes, and analytic themes for the synthesis of published findings.

Chapter 9. Conclusion

Summary of findings

Three primary themes emerged from the qualitative evidence synthesis (QES) of women's knowledge of the hypertensive disorders of pregnancy (HDPs) in Chapter 2: (1) confusion, (2) insufficient information, (3) lifestyle factors. There are widespread knowledge gaps regarding the hypertensive disorders among pregnant women, recently pregnant women and women who may become pregnant. The confusion of the HDPs was related to the complexity and unpredictable nature of the conditions, as well as the quality of information provided. The second analytic theme focused on the quantity of information received, which in some studies was deemed to be insufficient. Finally, the third theme highlighted the role of lifestyle in the hypertensive disorders –diet, weight management and stress. Much of the findings were consistent across regions, nevertheless some differences were found, particularly in relation to Theme 3, where the personal responsibility of women, through diet, exercise, was not reported in LMICs. The CERQual assessment of this synthesis indicates high and moderate confidence in the findings. The confidence could not be deemed 'high' in all cases due to limitations in relevance of some articles and the adequacy detailed findings.

Findings from the CLIP feasibility studies in Nigeria, Mozambique, Pakistan and India are presented in Chapters 4-7. The four related studies found similar themes regarding the knowledge of the HDPs, however, the nature of these findings did differ at times between regions. Findings from Nigeria illustrated that knowledge of pre-eclampsia and eclampsia are limited at the community-level and strongly influenced by traditional myths and beliefs. In southern Mozambique, the terms pre-eclampsia and eclampsia were not known, but when prompted, the conditions were understood as hypertension and seizures, not related to pregnancy.

Similar to Nigeria, local beliefs regarding the causes of the HDPs were not aligned with the biomedical perspective. Pakistan found there were mixed opinions regarding the causes of the hypertension in pregnancy, and as in Mozambique there was a poor understanding of the connection between pregnancy, hypertension and seizures. In India, no traditional remedies were reported for pre-eclampsia; however, home-based treatments were regularly given to women with seizures in pregnancy.

The synthesis of the CLIP feasibility study transcripts resulted in four analytic themes. The first, identified the apparent prominent role of women's personal experiences of the HDPs in their understanding of the conditions. Secondly, the HDPs were consistently associated with the natural environment (heat, cold, fire, water) in all but Mozambique. In data from all four studies the HDPs were believed to be related to socio-economic factors, particularly poverty. Finally, in the data from both African sites (Nigeria and Mozambique) pre-eclampsia and eclampsia were attributed to supernatural and mythical factors, though this belief was not found in Pakistan or India.

The qualitative evidence synthesis of the four CLIP feasibility studies publications yielded three primary findings (themes). The first theme encompassed the knowledge expressed by participants in the four settings. The second theme highlighted the collection of varied gaps and misconceptions of the HDPs. Finally, the synthesis summarized the barriers to acquitting knowledge of the hypertensive disorders in pregnancy. Knowledge gaps exists amongst women of reproductive age regarding the potentially life-threatening hypertensive disorders of pregnancy across the four countries.

The process of synthesis is the same irrespective of data source (transcripts vs 'results' in publications). Quality assessment can take the same form in both methods; however, syntheses

of publications assess the study as a whole, while syntheses of primary data may not have the information necessary to evaluate the study methodology. Due to the significant differences the detail of data sources, the first, second and third order themes are likely to be different. A synthesis of primary data allows analyses of finer detail. Sub-group analyses can be more easily accomplished with access to primary data sources as the 'findings' of published studies restricted by the analyst's interpretation and presentation of the findings.

Advantages of synthesis using primary sources include: access to comprehensive data, the classification of participants/studies is straightforward for sub-group analyses. Syntheses resulting from this method is more likely to present novel findings beyond those provided in the original publications. New insight is possible as analysts do not rely on previous interpretation of data. In addition, translation of themes across methodologies can be more easily achieved. Still there are advantages of the classic synthesis of publications. Relevant findings/data for extraction and synthesis is straightforward and can be replicated by other researchers with similar results. The greatest advantage of this method is its comparable speed, as a result of concise data for analysis.

Implications

The primary purpose of the Community Level Interventions for Pre-eclampsia (CLIP) Feasibility studies, was to determine the appropriateness and practicality of an upcoming cluster randomized control trial of community identification and treatment for pre-eclampsia. The conclusion was made, that a trial such as this would be feasible. Nevertheless, the implementation of the study was informed by the feasibility findings. These results informed the

content of antenatal and community education, as well as identified key stakeholders for engagement.

A number of policy, practice and research recommendations can be drawn from the dissertation presented here. One can conclude, that antenatal education should be delivered at the community and not restricted to facility-based care. The four feasibility studies highlight the important role of the family on perceptions of health and illness. This emphasizes the need to incorporate these influential decision-makers in antenatal activities; husbands, mothers-in-law and religious leaders where possible. Additionally, the inclusion of fetal risks and consequences of the HDPs, may help to raise the profile of the condition and communicate the potential severity.

Furthermore, where available, culturally-specific findings should be used in the development of education regarding the HDPs. This is supported by the fact that many women base their understanding of these conditions on shared cultural beliefs. Health messaging should consider the need to 'debunk' harmful practices related pregnancy. However, in many cases, such practices are innocuous, and many even be beneficial; therefore, they should be assessed on a case-by-case basis.

Personalized health messaging of the HDPs, and other pregnancy complications, should be further explored. Future research to evaluate the success social learning regarding pregnancy and pregnancy complications is needed. This finding presents an avenue for health information communication that is currently underused. The role of social learning should be considered for other conditions, as this source of information may be transferable outside the HDPs.

The comparison of two methods for qualitative syntheses, revealed that the synthesis of primary data is feasible. There is utility in this approach as it allow a deeper and novel

interpretation of the data. This could be used to inform the next level of research questions. Due to the nature of qualitative research, these findings may not be generalizable, nevertheless, they could be considered to inform future research, policy and practice.

Conclusion

This dissertation identifies a wide range of knowledge gaps regarding the HDPs in LMICs. In spite of these gaps, many have some understanding of these conditions, however incorrect at times. Syntheses reveal cultural similarities and distinct differences. These findings suggest a need for targeted community-based efforts to improve awareness and understanding of the HDPs. Culturally-specific findings should be used as a foundation for education, information, communication initiatives to improve maternal health. Study results clearly indicate a need for further education of the community, moving from a narrow biomedical focus and incorporating the diverse cultural and social factors. A comparison of methods highlights the benefits of syntheses from original data, however, challenges in access and labour-intensity remain to be addressed before this approach can be widely adopted.

References

1. World Health Organization. WHO recommendations for prevention and treatment of pre-eclampsia and eclampsia. . 2011.

2. Duley L. The Global Impact of Pre-eclampsia and Eclampsia. Semin Perinatol. 2009 6;33(3):130-7.

3. Kassebaum NJ, Bertozzi-Villa A, Coggeshall MS, Shackelford KA, Steiner C, Heuton KR, et al. Global, regional, and national levels and causes of maternal mortality during 1990–2013: a systematic analysis for the Global Burden of Disease Study 2013. The Lancet. 2014;384(9947):980-1004.

4. Chersich M, Blaauw D, Dumbaugh M, Penn-Kekana L, Thwala S, Bijlmakers L, et al. Mapping of research on maternal health interventions in low-and middle-income countries: a review of 2292 publications between 2000 and 2012. Globalization and Health. 2016;12(1):52.

5. Sibai B, Dekker G, Kupferminc M. Pre-eclampsia. Lancet. 2005 05;365(9461):785-99.

6. Hogan MC, Foreman KJ, Naghavi M, Ahn SY, Wang M, Makela SM, et al. Maternal mortality for 181 countries, 1980–2008: a systematic analysis of progress towards Millennium Development Goal 5. The lancet. 2010;375(9726):1609-23.

7. Graham W, Woodd S, Byass P, Filippi V, Gon G, Virgo S, et al. Diversity and divergence: the dynamic burden of poor maternal health. The Lancet. 2016.

8. World Health Organization. Trends in Maternal Mortality: 1990 to 2013. . 2014.

9. Haukkamaa L, Salminen M, Laivuori H, Leinonen H, Hiilesmaa V, Kaaja R. Risk for subsequent coronary artery disease after preeclampsia. Am J Cardiol. 2004;93(6):805-8.

10. Jordan B. Birth in four cultures: A crosscultural investigation of childbirth in Yucatan, Holland, Sweden, and the United States. Waveland Press; 1992.

11. Maine D, Rosenfield A. The Safe Motherhood Initiative: why has it stalled? Am J Public Health. 1999 Apr;89(4):480-2.

12. Rosato M, Laverack G, Grabman LH, Tripathy P, Nair N, Mwansambo C, et al. Community participation: lessons for maternal, newborn, and child health. The Lancet. 2008;372(9642):962-71.

13. Gilmore B, McAuliffe E. Effectiveness of community health workers delivering preventive interventions for maternal and child health in low-and middle-income countries: a systematic review. BMC Public Health. 2013;13(1):847.

14. Bhutta ZA, Das JK, Rizvi A, Gaffey MF, Walker N, Horton S, et al. Evidence-based interventions for improvement of maternal and child nutrition: what can be done and at what cost? The Lancet. 2013;382(9890):452-77.

15. Haines A, Sanders D, Lehmann U, Rowe AK, Lawn JE, Jan S, et al. Achieving child survival goals: potential contribution of community health workers. The Lancet. 2007;369(9579):2121-31.

16. Rahman A, Malik A, Sikander S, Roberts C, Creed F. Cognitive behaviour therapy-based intervention by community health workers for mothers with depression and their infants in rural Pakistan: a cluster-randomised controlled trial. The Lancet. 2008;372(9642):902-9.

17. el-Nafaty AU, Omotara BA. Perceived causes of eclampsia in four ethnic groups in Borno State, Nigeria. Afr J Reprod Health. 1998 Apr;2(1):20-5.

18. Abdulkarim GM, Kawuwa MB, Kullima A. Community Perception of Maternal Mortality in Northeastern Nigeria. African Journal of Reproductive Health / La Revue Africaine de la Santé Reproductive. 2008 Dec.;12(3):27-34.

19. Hasan I.J. NN. Womens' perceptions regarding obstetric complications and care in a poor fishing community in Karachi. journal of Pakistan Medical Association. 2002;52:148.

20. Lawoyin TO, Lawoyin OOC, Adewole DA. Men's Perception of Maternal Mortality in Nigeria. J Public Health Policy. 2007;28(3):299-318.

21. Kleinman A, Eisenberg L, Good B. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. Focus. 2006.

22. Pachter LM. Culture and clinical care: folk illness beliefs and behaviors and their implications for health care delivery. JAMA. 1994;271(9):690-4.

23. Clift E. Information education and communication: lessons from the past; perspectives for the future. . 2001.

24. Vidler M, Charantimath U, Katageri G, Ramadurg U, Karadiguddi C, Sawchuck D, et al. Community perceptions of pre-eclampsia in rural Karnataka State, India: a qualitative study. Reproductive Health. 2016;13(1):45.

25. Khowaja AR, Qureshi RN, Sheikh S, Zaidi S, Salam R, Sawchuck D, et al. Community's perceptions of pre-eclampsia and eclampsia in Sindh Pakistan: a qualitative study. Reproductive Health. 2016;13(1):39.

26. Boene H, Vidler M, Sacoor C, Nhama A, Nhacolo A, Bique C, et al. Community perceptions of pre-eclampsia and eclampsia in southern Mozambique. Reproductive Health. 2016;13(1):27.

27. Akeju DO, Vidler M, Oladapo OT, Sawchuck D, Qureshi R, von Dadelszen P, et al. Community perceptions of pre-eclampsia and eclampsia in Ogun State, Nigeria: a qualitative study. Reproductive Health. 2016;13(1):17.

28. Bryman A, Bresnen M, Beardsworth A, Keil T. Qualitative research and the study of leadership. Human relations. 1988;41(1):13-29.

29. Popay J, Rogers A, Williams G. Rationale and standards for the systematic review of qualitative literature in health services research. Qual Health Res. 1998 May;8(3):341-51.

30. O'Cathain A, Goode J, Drabble SJ, Thomas KJ, Rudolph A, Hewison J. Getting added value from using qualitative research with randomized controlled trials: a qualitative interview study. Trials. 2014;15(1):1.

31. Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC medical research methodology. 2012;12(1):1.

32. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC medical research methodology. 2008;8(1):1.

33. Seely E.W., RichEdwards J., Lui J., Nicklas J.M., Saxena A., Tsigas E., et al. Risk of future cardiovascular disease in women with prior preeclampsia: A focus group study. BMC Pregnancy and Childbirth. 2013;13(pagination):Arte Number: 240. ate of Pubaton: 21 e 2013.

34. O'Byrne P. Population health and social governance: analyzing the mainstream incorporation of ethnography. Qual Health Res. 2012 Jun;22(6):859-67.

35. Reeves S, Kuper A, Hodges BD. Qualitative research methodologies: ethnography. BMJ. 2008 Aug 7;337:a1020.

36. Pigg SL. On sitting and doing: Ethnography as action in global health. Soc Sci Med. 2013;99:127-34.

37. Grant C, Osanloo A. Understanding, Selecting, and Integrating a Theoretical Framework in Dissertation Research: Creating the Blueprint for Your" House". Administrative Issues Journal: Education, Practice, and Research. 2014;4(2):12-26.

38. Fine M. Working the hyphens. Handbook of qualitative research.Thousand Oaks, CA: Sage. 1994.

39. Cunliffe AL, Karunanayake G. Working within hyphen-spaces in ethnographic research implications for research identities and practice. Organ Res Methods. 2013;16(3):364-92.

40. Twyman C, Morrison J, Sporton D. The final fifth: Autobiography, reflexivity and interpretation in cross

41. Bandura A, Walters RH. Social learning theory. . 1977.

42. Lave J. Situating learning in communities of practice. Perspectives on socially shared cognition. 1991;2:63-82.

43. Dunn L. Theories of learning. Learning and Teaching Briefing Papers Series, Oxford Centre for Staff and Learning Development OCSLD, Oxford Brookes University. 2002.

44. Kolb DA, Boyatzis RE, Mainemelis C. Experiential learning theory: Previous research and new directions. Perspectives on thinking, learning, and cognitive styles. 2001;1:227-47.

45. Lima de Souza N., Fernandes Araujo A.C., Dantas de Azevedo G., Bezerra Jeronimo S.M., Barbosa L.M., Lima de Sousa NM. Maternal perception of premature birth and the experience of pre-eclampsia pregnancy. Rev Saude Publica. 2007 Oct 2007;41(5):704-10.

46. Oiyemhonlan B., Udofia E., Punguyire D. Identifying obstetrical emergencies at Kintampo Municipal Hospital: a perspective from pregnant women and nursing midwives. Afr J Reprod Health. 2013 01 Jun 2013;17(2):129-40.

47. Methley AM, Campbell S, Chew-Graham C, McNally R, Cheraghi-Sohi S. PICO, PICOS and SPIDER: a comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews. BMC health services research. 2014;14(1):1.

48. Cooke A, Smith D, Booth A. Beyond PICO: the SPIDER tool for qualitative evidence synthesis. Qual Health Res. 2012 Oct;22(10):1435-43.

49. Dixon-Woods M, Bonas S, Booth A, Jones DR, Miller T, Sutton AJ, et al. How can systematic reviews incorporate qualitative research? A critical perspective. Qualitative research. 2006;6(1):27-44.

50. Finlayson K, Downe S. Why do women not use antenatal services in low-and middle-income countries? A meta-synthesis of qualitative studies. PLoS Med. 2013;10(1):e1001373.

51. Toye F, Seers K, Allcock N, Briggs M, Carr E, Barker K. Meta-ethnography 25 years on: challenges and insights for synthesising a large number of qualitative studies. BMC Med Res Methodol. 2014 Jun 21;14:80,2288-14-80.

52. Dixon-Woods M, Shaw RL, Agarwal S, Smith JA. The problem of appraising qualitative research. Qual Saf Health Care. 2004 Jun;13(3):223-5.

53. 10 questions to help you make sense of qualitative research [Internet].: Milton Keynes Primary Care Trust Milton Keyes; 2002 []. Available from: https://hhs.hud.ac.uk/lqsu/Useful/critap/Qualitative%20Research%20Checklist/CASP-Qualitative-Research-Checklist-31.05.13.pdf.

54. Chuang C.H., Velott D.L., Weisman CS. Exploring knowledge and attitudes related to pregnancy and preconception health in women with chronic medical conditions. Matern Child Health J. 2010 Sep 2010;14(5):713-9.

55. de Azevedo DV, de Araujo,Ana C P F., Clara Costa IC. An analysis of the meanings of pre-eclampsia for pregnant and postpartum women and health professionals in Rio Grande do Norte, Brazil. Midwifery. 2011 Dec;27(6):e182-7.

56. Hoedjes M, Berks D, Vogel I, Franx A, Duvekot JJ, Oenema A, et al. Motivators and barriers to a healthy postpartum lifestyle in women at increased cardiovascular and metabolic risk: a focus-group study. Hypertens Pregnancy. 2012 03;31(1):147,155 9p.

57. Islam KS, Sachchu SA, Sandani R, Bullough C, Siraj N, Dimmock P, et al. Using village theatre to increase knowledge about eclampsia in Bangladesh. Journal of Obstetrics & Gynaecology Research. 2001 Aug;27(4):199-204.

58. Jonkers M., Richters A., Zwart J., Ory F., van Roosmalen J. Severe maternal morbidity among immigrant women in the Netherlands: Patients' perspectives. Reprod Health Matters. 2011 May 2011;19(37):144-53.

59. Kalim N., Anwar I., Khan J., Blum L.S., Moran A.C., Botlero R., et al. Postpartum haemorrhage and eclampsia: differences in knowledge and care-seeking behaviour in two districts of Bangladesh. J Health Popul Nutr. 2009 Apr 2009;27(2):156-69.

60. Osubor K, Fatusi AO, Chiwuzie J. Maternal health-seeking behavior and associated factors in a rural Nigerian community. Matern Child Health J. 2006;10(2):159-69.

61. Kumbani L, McInerney P. The knowledge of obstetric complications among primigravidae in a rural health centre in the district of Blantyre, Malawi. Curationis. 2002;25:43.

62. Brown M, Bell R, Collins C, Waring G, Robson S, Waugh J, et al. Women's perception of future risk following pregnancies complicated by preeclampsia. Hypertension in pregnancy. 2013;32(1):60-73.

63. Atkinson SJ, Farias MF. Perceptions of risk during pregnancy amongst urban women in northeast Brazil. Soc Sci Med. 1995;41(11):1577-86.

64. You W.B., Wolf M., Bailey S.C., Pandit A.U., Waite K.R., Sobel R.M., et al. Factors associated with patient understanding of preeclampsia. Hypertension in Pregnancy. 2012 August 2012;31(3):341-9.

65. Mapp T. Feelings and fears post obstetric emergencies -- 2. BR J MIDWIFERY. 2005 01;13(1):36,40 5p.

66. Fleury C, Parpinelly M, Makuch MY. Development of the mother-child relationship following pre-eclampsia. J REPROD INFANT PSYCHOL. 2010 08;28(3):297,306 10p.

67. Barlow JH, Hainsworth J, Thornton S. Women's experiences of hospitalisation with hypertension during pregnancy: feeling a fraud. J REPROD INFANT PSYCHOL. 2008 08;26(3):157,167 11p.

68. Sandelowski M, Voils CI, Leeman J, Crandell JL. Mapping the mixed methods–mixed research synthesis terrain. Journal of mixed methods research. 2012;6(4):317-31.

69. Gough D, Thomas J, Oliver S. Clarifying differences between review designs and methods. Systematic reviews. 2012;1(1):1.

70. Pembe AB, Urassa DP, Carlstedt A, Lindmark G, Nyström L, Darj E. Rural Tanzanian women's awareness of danger signs of obstetric complications. BMC pregnancy and childbirth. 2009;9(1):1.

71. Kabakyenga JK, Östergren P, Turyakira E, Pettersson KO. Knowledge of obstetric danger signs and birth preparedness practices among women in rural Uganda. Reproductive health. 2011;8(1):1.

72. Safer MP. Making pregnancy safer: the critical role of the skilled attendant. World Health Organization: Geneva. 2004.

73. Chuang CH, Velott DL, Weisman CS. Exploring Knowledge and Attitudes Related to Pregnancy and Preconception Health in Women with Chronic Medical Conditions. Matern Child Health J. 2010 09;14(5):713,719 7p.

74. Steegers EA, von Dadelszen P, Duvekot JJ, Pijnenborg R. Pre-eclampsia. The Lancet. 2010;376(9741):631-44.

75. Magee LA, Abalos E, von Dadelszen P, Sibai B, Easterling T, Walkinshaw S. How to manage hypertension in pregnancy effectively. Br J Clin Pharmacol. 2011;72(3):394-401.

76. Duley L. Maternal mortality associated with hypertensive disorders of pregnancy in Africa, Asia, Latin America and the Caribbean. BJOG: An International Journal of Obstetrics & Gynaecology. 1992;99(7):547-53.

77. Hezelgrave NL, Duffy SP, Shennan AH. Preventing the preventable: pre-eclampsia and global maternal mortality. Obstetrics, Gynaecology & Reproductive Medicine. 2012;22(6):170-2.

78. Bhutta ZA, Darmstadt GL, Hasan BS, Haws RA. Community-based interventions for improving perinatal and neonatal health outcomes in developing countries: a review of the evidence. Pediatrics. 2005 Feb;115(2 Suppl):519-617.

79. Dunsmuir DT, Payne BA, Cloete G, Petersen CL, Görges M, Lim J, et al. Development of mHealth applications for pre-eclampsia triage. IEEE journal of biomedical and health informatics. 2014;18(6):1857-64.

80. Yen T, Payne B, Qu Z, Hutcheon JA, Lee T, Magee LA, et al. Using clinical symptoms to predict adverse maternal and perinatal outcomes in women with preeclampsia: data from the PIERS (Pre-eclampsia Integrated Estimate of RiSk) study. Journal of Obstetrics and Gynaecology Canada. 2011;33(8):803-9.

81. Rouse DJ, Hauth JC, Nelson KG, Goldenberg RL. The feasibility of a randomized clinical perinatal trial: Maternal magnesium sulfate for the prevention of cerebral palsy. Obstet Gynecol. 1996;175(3):701-5.

82. Korpi-Hyövälti EA, Laaksonen DE, Schwab US, Vanhapiha TH, Vihla KR, Heinonen ST, et al. Feasibility of a lifestyle intervention in early pregnancy to prevent deterioration of glucose tolerance. BMC Public Health. 2011;11(1):179.

83. Burrows RF, Burrows EA. The feasibility of a control population for a randomized control trial of seizure prophylaxis in the hypertensive disorders of pregnancy. Obstet Gynecol. 1995;173(3):929-35.

84. Magee L, Von Dadelszen P, Chan S, Gafni A, Gruslin A, Helewa M, et al. The control of hypertension in pregnancy study pilot trial. BJOG: An International Journal of Obstetrics & Gynaecology. 2007;114(6):770-e20.

85. May CR, Mair F, Finch T, MacFarlane A, Dowrick C, Treweek S, et al. Development of a theory of implementation and integration: Normalization Process Theory. Implementation Science. 2009;4(1):29.

86. May CR, Mair FS, Dowrick CF, Finch TL. Process evaluation for complex interventions in primary care: understanding trials using the normalization process model. BMC Family Practice. 2007;8(1):42.

87. May C, Finch T, Mair F, Ballini L, Dowrick C, Eccles M, et al. Understanding the implementation of complex interventions in health care: the normalization process model. BMC health services research. 2007;7(1):148.

88. Murray E, Treweek S, Pope C, MacFarlane A, Ballini L, Dowrick C, et al. Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. BMC medicine. 2010;8(1):63.

89. Denscombe M. Communities of practice a research paradigm for the mixed methods approach. Journal of mixed methods research. 2008;2(3):270-83.

90. Onwuegbuzie AJ, Leech NL. On becoming a pragmatic researcher: The importance of combining quantitative and qualitative research methodologies. International journal of social research methodology. 2005;8(5):375-87.

91. Creswell JW. Qualitative inquiry and research design: Choosing among five approaches. Sage publications; 2012.

92. Floersch J, Longhofer J, Suskewicz J. The use of ethnography in social work research. 2014.

93. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. Field methods. 2006;18(1):59-82.

94. Safdar S, Inam SNB, Omair A, Ahmed ST. Maternal health care in a rural area of Pakistan. JPMA.The Journal of the Pakistan Medical Association. 2002;52(7):308.

95. Asowa-Omorodion FI. Women's perceptions of the complications of pregnancy and childbirth in two Esan communities, Edo State, Nigeria. Soc Sci Med. 1997 6;44(12):1817-24.

96. Furuta M, Salway S. Women's Position within the Household as a Determinant of Maternal Health Care Use in Nepal. International Family Planning Perspectives. 2006 Mar.;32(1):17-27.

97. Bloom SS, Wypij D, Gupta Md. Dimensions of Women's Autonomy and the Influence on Maternal Health Care Utilization in a North Indian City. Demography. 2001;38(1):67-78.

98. Nordeng H, Havnen GC. Impact of socio -demographic fa
the use of herbal drugs in pregnancy. Acta Obstet Gynecol Scand. 2005;84(1):26-33.

99. Borghi J, Sabina N, Blum LS, Hoque ME, Ronsmans C. Household costs of healthcare during pregnancy, delivery, and the postpartum period: a case study from Matlab, Bangladesh. Journal of Health, Population and Nutrition. 2006:446-55.

100. Britten N. Qualitative interviews in medical research. BMJ. 1995 Jul 22;311(6999):251-3.

101. Lewin SA, Dick J, Pond P, Zwarenstein M, Aja G, van Wyk B, et al. Lay health workers in primary and community health care. The Cochrane database of systematic reviews. 2005(1):CD004015.

102. Love MB, Gardner K, Legion V. Community health workers: who they are and what they do. Health Education & Behavior. 1997;24(4):510-22.

103. Rowe AK, de Savigny D, Lanata CF, Victora CG. How can we achieve and maintain high-quality performance of health workers in low-resource settings? The Lancet. 2005;366(9490):1026-35.

104. World Health Organization. Maternal, newborn, child and adolescent health. Health facility survey: Tool to evaluate the quality of care delivered to sick children attending outpatient facilities. 2003.

105. USAID. 1HHealth facility assessment. 2005.

106. World Health Organization. Service availability and readiness assessment (SARA): an annual monitoring system for service delivery: implementation guide. . 2013.

107. USAID. 1.Service provision assessment. . 2012.

108. Pedler M. Reflexive methodology: New vistas for qualitative research. 2012.

109. Wray N, Markovic M, Manderson L. "Researcher saturation": The impact of data triangulation and intensive-research practices on the researcher and qualitative research process. Qual Health Res. 2007;17(10):1392-402.

110. de Salis I, Tomlin Z, Toerien M, Donovan J. Qualitative research to improve RCT recruitment: issues arising in establishing research collaborations. Contemporary clinical trials. 2008;29(5):663-70.

111. Lewin S, Glenton C, Oxman AD. Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: methodological study. BMJ. 2009 Sep 10;339:b3496.

112. Spillane JP, Pareja AS, Dorner L, Barnes C, May H, Huff J, et al. Mixing methods in randomized controlled trials (RCTs): Validation, contextualization, triangulation, and control. Educational Assessment, Evaluation and Accountability. 2010;22(1):5-28.

113. Packer CS. Biochemical markers and physiological parameters as indices for identifying patients at risk of developing pre-eclampsia. J Hypertens. 2005;23(1):45-6.

114. National Population Commission (NPC) [Nigeria] and ICF International. Nigeria Demographic and Health Survery 2013. 2014.

115. Administering Magnesium Sulfate to Treat Severe Pre-eclampsia and Eclampsia [Internet].; 2009 []. Available from: http://www.popcouncil.org/scripts/tellafriend.asp.

116. Warr PB, Knapper C. The perception of people and events. New York; London: Wiley; 1968.

117. Osungbade KO, Ige OK. Public health perspectives of preeclampsia in developing countries: implication for health system strengthening. Journal of pregnancy. 2011;2011:481095-6.

118. Khowaja AR, Qureshi RN, Sawchuck D, Oladapo OT, Adetoro OO, Orenuga EA, et al. The feasibility of community level interventions for pre-eclampsia in South Asia and Sub-Saharan Africa: A mixed-methods design. Reproductive Health. 2016;13(1):1.

119. Lefèvre G, Berkane S, Etienne J. P1Preeclampsia and oxygen free radicals. Ann Biol Clin. 1997;55:443-50.

120. Elhassan EM, Mirghani OA, Adam I. High maternal mortality and stillbirth in the Wad Medani Hospital, Central Sudan, 2003-2007. Trop Doct. 2009;39(4):238.

121. Clifford Odimegwu, Alfred Adewuyi, Tanwa Odebiyi, Bisi Aina, Yinka Adesina,Olu Olatubara6 and Femi Eniola. Men's Role in Emergency Obstetric Care in Osun State of Nigeria. Afr J Reprod Health. 2006;9(3).

122. Kakaire O, Kaye DK, Osinde MO. Male involvement in birth preparedness and complication readiness for emergency obstetric referrals in rural Uganda. Reproductive health. 2011;8(1):12-.

123. Ologe MO, Aboyeji AP, Ijaiya MA, Adesina KT, Adewara AA, Olarinoye JK. Herbal use among pregnant mothers in Ilorin, Kwra State, Nigeria. Journal of Obstetrics & Gynecology. 2008;28(7):720-1.

124. Low Dog T. The use of botanicals during pregnancy and lactation. Altern Ther Health Med. 2009;15(1):54.

125. Guerrier G, Oluyide B, Keramarou M, Grais RF. Factors associated with severe preeclampsia and eclampsia in Jahun, Nigeria. International journal of women's health. 2013;5:509.

126. World Health Organization. Trends in maternal mortality: 1990 to 2010. 2012.

127. UNICEF, Open Knowledge Repository. Trends in Maternal Mortality: 1990 to 2015. ; 2015.

128. Republic of Mozambique. Report on the Millennium Development Goals. 2005.

129. African Health Observatory. Mozambique Factsheets of Health Statistics. 2016.

130. Menéndez C, Romagosa C, Ismail MR, Carrilho C, Saute F, Osman N, et al. An autopsy study of maternal mortality in Mozambique: the contribution of infectious diseases. PLoS medicine. 2008;5(2):e44.

131. Ministerio da Saude (MISAU), Instituto Nacional de Estatística (INE) e ICF International (ICFI). Mocambique, Inquerito Demografico e de Saude 2011. 2013.

132. Giordano JC, Parpinelli MA, Cecatti JG, Haddad SM, Costa ML, Surita FG, et al. The burden of eclampsia: results from a multicenter study on surveillance of severe maternal morbidity in Brazil. PloS one. 2014;9(5):e97401.

133. Bugalho A, Bacci A, Bergstrom S. Risk factors in Mozambican women with eclampsia: a case-referent study. Afr J Reprod Health. 2001 Aug;5(2):30-5.

134. Rosato M, Mwansambo CW, Kazembe PN, Phiri T, Soko QS, Lewycka S, et al. Women's groups' perceptions of maternal health issues in rural Malawi. The Lancet. 2006;368(9542):1180-8.

135. Adamu A, Ekele B, Tunau K, Hassan M. O13 What causes eclampsia? Perception of relations of patients with eclampsia. International Journal of Gynecology and Obstetrics. 2009;107:S96-.

136. Boene H, González R, Valá A, Rupérez M, Velasco C, Machevo S, et al. Perceptions of Malaria in Pregnancy and Acceptability of Preventive Interventions among Mozambican Pregnant Women: Implications for Effectiveness of Malaria Control in Pregnancy: e86038. PLoS One. 2014;9(2).

137. Recenseamento Geral da População e Habitação [Internet].; 2007 []. Available from: http://www.ine.gov.mz/operacoes-estatisticas/censos/censo-2007/rgph-2007.

138. Souza NLd, Araujo, Ana Cristina Pinheiro Fernandes, Azevedo GDd, Jeronimo SMB, Barbosa LdM, Sousa, Nubia Maria Lima de. Maternal perception of premature birth and the experience of pre-eclampsia pregnancy. Revista de Saude Publica. 2007;41(5):704.

139. Vásquez CL, PulidoAcuña GP, Ruth Alexandra Castiblanco Montañez. Hazard, death and sequels: perception on severe preeclampsia by those who lived it/Peligro, muerte y secuelas: percepción de la preeclampsia severa por quienes la han vivido. Enfermería Global. 2014;13(2):493.

140. Adams V, Miller S, Chertow J, Craig S, Samen A, Varner M. Having a "safe delivery": conflicting views from Tibet. Health Care Women Int. 2005;26(9):821-51.

141. The American College of Obstetricians and Gynaecologists. Hypertension in Pregnancy. 2013.

142. Preeclampsia and Maternal Mortality: a Global Burden [Internet]. []. Available from: http://www.preeclampsia.org/advocacy/archive/332-preeclampsia-and-maternal-mortality-a-global-burden.

143. EngenderHealth. Balancing the Scales: Expanding Treatment for Pregnant Women with Life-Threatening Hypertensive Conditions in Developing Countries. 2007.

144. Bilano VL, Ota E, Ganchimeg T, Mori R, Souza JP. Risk factors of pre-eclampsia/eclampsia and its adverse outcomes in low- and middle-income countries: a WHO secondary analysis. PloS one. 2014;9(3):e91198.

145. Pakistan [Internet].; 2016 []. Available from: https://en.wikipedia.org/wiki/Pakistan.

146. Bhutta ZA, Hafeez A, Rizvi A, Ali N, Khan A, Ahmad F, et al. Reproductive, maternal, newborn, and child health in Pakistan: challenges and opportunities. Lancet (London, England). 2013;381(9884):2207.

147. National Institute of Population Studies. Pakistan Demographic and Health Survey 2006-07. 2008.

148. United Nations Development Programme Pakistan, Government of Sindh. Report on the status of millennium development goals Sindh. 2012.

149. Shah N, Khan NH. Third delay of maternal mortality in a tertiary hospital. Rawal Med J. 2007;32(2):163-7.

150. Riaz S, Habib S, Habib S, Jabeen A. Frequency of maternal mortality and morbidity in pregnancy-induced hypertension. Journal of Ayub Medical College, Abbottabad : JAMC. 2011;23(4):61.

151. Shamsi U, Hatcher J, Shamsi A, Zuberi N, Qadri Z, Saleem S. A multicentre matched case control study of risk factors for preeclampsia in healthy women in Pakistan. BMC Womens Health. 2010;10(1):14-.

152. lkram Butt A. Magnesium Sulphate for Prevention and Treatment of Preeclampsia and Eclampsia in Pakistan.

153. Protocol 13PRT/9313:The Community Level Interventions for Pre-eclampsia (CLIP) Trials: four prospective cluster randomised controlled trials comparing a package of interventions directed towards improving maternal and perinatal outcomes related to pre-eclampsia with current standards of care (NCT01911494) [Internet]. [].

154. District Hyderabad [Internet]. []. Available from: http://www.pwdsindh.gov.pk/districts/hyderabad.htm.

155. District Matiari [Internet]. []. Available from: http://matiari.net/district-matiari-2/.

156. Freeman T. 'Best practice' in focus group research: making sense of different views. J Adv Nurs. 2006;56(5):491-7.

157. Guest G, Bunce A, Johnson L. How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability. Field Methods. 2006;18(1):59-82.

158. Bhutta ZA, Black RE. Global maternal, newborn, and child health--so near and yet so far. N Engl J Med. 2013;369(23):2226.

159. Firoz T, Sanghvi H, Merialdi M, von Dadelszen P. Pre-eclampsia in low and middle income countries. Best Practice & Research Clinical Obstetrics & Gynaecology. 2011;25(4):537-48.

160. Fortney JA, Smith JB. The base of the iceberg: prevalence and perceptions of maternal morbidity in four developing countries. 1997.

161. Koenig MA, Jamil K, Streatfield PK, Saha T, Al-Sabir A, Arifeen SE, et al. Maternal Health and Care-Seeking Behavior in Bangladesh: Findings from a National Survey. International Family Planning Perspectives. 2007;33(2):75-82.

162. Jafarey SN, Korejo R. Social and cultural factors leading to mothers being brought dead to hospital. International Journal of Gynecology and Obstetrics. 1995;50:S97-9.

163. Khan H, Maheen S, Alamgeer GA, Mahmood A, Sarfraz RM, Ashraf Z, et al. Determinants of increasing trend of self-medication in a Pakistani community. Tropical Journal of Pharmaceutical Research. 2014;13(3):437-43.

164. Kowalewski M, Jahn A, Kimatta SS. Why Do At-Risk Mothers Fail to Reach Referral Level? Barriers beyond Distance and Cost. African Journal of Reproductive Health / La Revue Africaine de la Santé Reproductive. 2000;4(1):100-9.

165. Zhang J, Meikle S, Trumble A. Severe Maternal Morbidity Associated with Hypertensive Disorders in Pregnancy in the United States. Hypertension in Pregnancy. 2003;22(2):203-12.

166. Smith SL. Political contexts and maternal health policy: Insights from a comparison of south Indian states. Soc Sci Med. 2014 1;100(0):46-53.

167. Office of the Registrar General, India. Special Bulletin on Maternal Mortality in India (20010-12). New Delhi, India: Office of the Registrar General, India; 2013 Sep.

168. Chatterjee A, Paily V. Achieving Millennium Development Goals 4 and 5 in India. BJOG: An International Journal of Obstetrics & Gynaecology. 2011;118:47-59.

169. Thaddeus S, Maine D. Too far to walk: Maternal mortality in context. Soc Sci Med. 1994;38(8):1091-110.

170. José N, Raddi SA, Kharde S. Assess the Knowledge Regarding Pre-eclampsia and Its Self-care Measures among Antenatal Women Attending Antenatal Outpatient Department of KLES Dr Prabhakar Kore Hospital, Belgaum. Journal of South Asian Federation of Obstetrics & Gynecology. 2010 May;2(2):157-62.

171. Nyamtema AS, Urassa DP, van Roosmalen J. Maternal health interventions in resource limited countries: a systematic review of packages, impacts and factors for change. BMC Pregnancy Childbirth. 2011;11(30).

172. Sudarshan H, Prashanth N. Good governance in health care: the Karnataka experience. The Lancet. 2011 3/5–11;377(9768):790-2.

173. Kalim N, Anwar I, Khan J, Blum LS, Moran AC, Botlero R, et al. Postpartum Haemorrhage and Eclampsia: Differences in Knowledge and Care-seeking Behaviour in Two Districts of Bangladesh. Journal of Health, Population, and Nutrition. 2009;27(2).

174. de Azevedo DV, de Araujo, A. C. P. F., Costa, I. D. C. C., Junior AM. Percepções e sentimentos de gestantes e puérperas sobre a pré-eclâmpsia. Revista de Salud Publica. 2009;11(3):347.

175. Janz NK, Becker MH. The Health Belief Model: a decade later. Health Educ Q. 1984;11(1):1.

176. Costello A, Osrin D, Manandhar D. Reducing maternal and neonatal mortality in the poorest communities. British Medical Journal. 2004;329(7475):1166.

177. Lewycka S, Mwansambo C, Rosato M, Kazembe P, Phiri T, Mganga A, et al. Effect of women's groups and volunteer peer counselling on rates of mortality, morbidity, and health behaviours in mothers and children in rural Malawi (MaiMwana): a factorial, cluster-randomised controlled trial. The Lancet. 2013 5/18–24;381(9879):1721-35.

178. Tripathy P, Nair N, Barnett S, Mahapatra R, Borghi J, Rath S, et al. Effect of a participatory intervention with women's groups on birth outcomes and maternal depression in Jharkhand and Orissa, India: a cluster-randomised controlled trial. The Lancet. 2010 4/3–9;375(9721):1182-92.

179. Walsh D, Downe S. Meta - synthesis metho
Adv Nurs. 2005;50(2):204-11.

180. Noblit GW, Hare RD. Meta-ethnography: Synthesizing qualitative studies. sage; 1988.

181. Sandelowski M, Docherty S, Emden C. Focus on qualitative methods Qualitative metasynthesis: issues and techniques. Research in nursing and health. 1997;20:365-72.

182. Janssen M, Charalabidis Y, Zuiderwijk A. Benefits, adoption barriers and myths of open data and open government. Inf Syst Manage. 2012;29(4):258-68.

183. QSR International Pty Ltd. NVivo qualitative data analysis Software. ; Version 11, 2016.

184. Paterson BL, Thorne S, Dewis M. Adapting to and managing diabetes. Image: The Journal of Nursing Scholarship. 1998;30(1):57-62.

185. Wallerstein N, Bernstein E. Empowerment education: Freire's ideas adapted to health education. Health Education & Behavior. 1988;15(4):379-94.

186. Atkins S, Lewin S, Smith H, Engel M, Fretheim A, Volmink J. Conducting a meta-ethnography of qualitative literature: lessons learnt. BMC medical research methodology. 2008;8(1):1.

Appendices

Supplementary Table 1. Electronic database search details.

Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R)
Search conducted: March 25, 2016

#	Searches	Results
1	(pregnancy or 'pregnant women' or 'postpartum period').mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	839234
2	(attitude or comprehension or 'health knowledge, attitudes, practice' or knowledge or awareness or culture or 'knowledge bases').mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	1485787
3	(pre-eclampsia or eclampsia or 'pregnancy-induced hypertension' or hypertension or seizures or 'blood pressure').mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	771600
4	((('focus groups' or 'qualitative research' or 'anthropology, cultural' or 'surveys) and questionnaires') or interview).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	448078
5	1 and 2 and 3 and 4	88
6	limit 4 to yr="1994 -Current"	76

PsychINFO
Search conducted: March 25, 2016

1	pregnancy or ‘pregnant women’ or ‘postpartum period’	
2	attitude OR comprehension OR ‘health knowledge, attitudes, practice’ OR knowledge OR awareness OR culture OR ‘knowledge bases’	
3	pre-eclampsia OR eclampsia OR ‘pregnancy-induced hypertension’ OR hypertension OR seizures OR ‘blood + pressure’	
4	‘focus groups’ or ‘qualitative research’ or ‘anthropology, cultural’ or ‘Surveys + questionnaires’ or interview	
5	1 and 2 and 3 and 4	16

CINAHL
Search conducted: March 25, 2016
Search terms: (pregnancy or ‘pregnant women’ or ‘postpartum period’) AND (attitude OR comprehension OR ‘health knowledge, attitudes, practice’ OR knowledge OR awareness OR culture OR ‘knowledge bases’) AND (pre-eclampsia OR eclampsia OR ‘pregnancy-induced hypertension’ OR hypertension OR seizures OR ‘blood + pressure’) AND (‘focus groups’ or ‘qualitative research’ or ‘anthropology, cultural’ or ‘Surveys + questionnaires’ or interview)
Limiters - Published Date: 19940101-20151231
Search results: 52

EMBASE
Search conducted: March 26, 2016

#	Searches	Results
1	(pregnancy or pregnant women or postpartum period).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	806762
2	(attitude or comprehension or 'health knowledge, attitudes, practice' or knowledge or awareness or culture or 'knowledge bases').mp. [mp=title, abstract, heading word, drug trade name, original title,	2212798

	device manufacturer, drug manufacturer, device trade name, keyword]	
3	(pre-eclampsia or eclampsia or 'pregnancy-induced hypertension' or hypertension or seizures or 'blood pressure').mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	1103113
4	(focus groups or qualitative research or anthropology cultural or (surveys and questionnaires) or interview).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	280877
5	1 and 2 and 3 and 4	90
6	limit 4 to yr="1994 -Current"	86

LILACS
Search conducted: March 30, 2016
Search results: 4
Search terms: (pregnancy or (pregnant women) or (postpartum period)) AND (attitude OR comprehension OR (health knowledge, attitudes, practice) OR knowledge OR awareness OR culture OR (knowledge bases)) AND (pre-eclampsia OR eclampsia OR (pregnancy-induced hypertension) OR hypertension OR seizures OR (blood pressure)) AND ((focus groups) or (qualitative research) or (anthropology, cultural) or (Surveys questionnaires) or interview)

Sociological Abstracts
Search conducted: March 30, 2016
Search results: 31
Search terms: (pre-eclampsia OR eclampsia OR (pregnancy-induced hypertension) OR (pregnancy* complication*)) AND ((attitude OR comprehension OR (health knowledge, attitudes, practice) OR knowledge OR awareness OR culture OR (knowledge bases)) OR health knowledge attitudes practice)
- limit 1994 →

AJOL
Search conducted: March 30, 2016
Search results: 3
Search terms: (pre-eclampsia OR eclampsia OR (pregnancy-induced hypertension) OR (pregnancy* complication*)) AND ((attitude OR comprehension OR (health knowledge, attitudes, practice) OR knowledge OR awareness OR culture OR (knowledge bases))

Global Health Library
Search conducted: March 30, 2016
Search results: 36
Search terms: (pre-eclampsia OR eclampsia OR (pregnancy-induced hypertension)) AND (attitude OR comprehension OR knowledge OR awareness OR culture OR (health knowledge, attitudes, practice)) AND ((focus groups) or (qualitative research) or (anthropology, cultural) or (Surveys questionnaires) or interview)
- limit 1994 →

DARE
Search conducted: March 30, 2016
Search results: 6 results
Search terms: (attitude OR comprehension OR (health knowledge, attitudes, practice) OR knowledge OR awareness OR culture OR (knowledge bases)) AND (pre-eclampsia OR eclampsia OR (pregnancy-induced hypertension) OR hypertension OR seizures OR (blood pressure)) AND ((focus groups) or (qualitative research) or (anthropology, cultural) or (Surveys questionnaires) or interview)

Supplementary Table 2. Hand-search details.

Key words: (Knowledge OR Culture OR Attitudes OR beliefs OR comprehension) AND Qualitative* AND (pre-eclampsia OR eclampsia OR (pregnancy induced hypertension) OR (hypertensive disorders of pregnancy))		
	Journal	**Search results**
1	BMC Pregnancy and Childbirth	21
2	Reproductive Health	24
3	Social Science and Medicine	62
4	Journal of Advanced Nursing	21
5	Qualitative Heath Research	5
6	Sociology of Health and Illness	13
7	African Journal of Reproductive Health	14
8	Journal of Obstetrics and Gynaecology	29
9	BMC Women's Health	8
10	Maternal and Child Health Journal	34
11	Reproductive Health Matters	22

Supplementary Table 3. Critical Appraisal Skills Programme (CASP) checklist.

Chuang CH, Velott DL, Weisman CS. Exploring knowledge and attitudes related to pregnancy and preconception health in women with chronic medical conditions. Maternal and child health journal. 2010 Sep 1;14(5):713-9.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?	*		
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?	*		
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
Final score = 28				

de Azevedo DV, de Araújo AC, Costa ÍC. An analysis of the meanings of pre-eclampsia for pregnant and postpartum women and health professionals in Rio Grande do Norte, Brazil. Midwifery. 2011 Dec 31;27(6):e182-7.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?		*	
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?		*	
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
Final score = 26				

El-Nafaty AU, Omotara BA. Perceived causes of eclampsia in four ethnic groups in Borno State, Nigeria. African journal of reproductive health. 1998 Apr;2(1):20-5.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?		*	
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?		*	
9	Is there a clear statement of findings?			*
10	How valuable is the research?	*		
Final score = 25				

Hoedjes M, Berks D, Vogel I, Franx A, Duvekot JJ, Oenema A, Steegers EA, Raat H. Motivators and barriers to a healthy postpartum lifestyle in women at increased cardiovascular and metabolic risk: a focus-group study. Hypertension in pregnancy. 2012 Feb 1;31(1):147-55.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?	*		
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?		*	
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
Final score = 27				

Islam KS, Sachchu SA, Sandani R, Bullough C, Siraj N, Dimmock P, Johanson RB. Using village theatre to increase knowledge about eclampsia in Bangladesh. Journal of Obstetrics and Gynaecology Research. 2001 Aug 1;27(4):199-204.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?		*	
5	Was the data collected in a way that addressed the research issue?			
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?		*	
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
Final score = 26				

Jonkers M, Richters A, Zwart J, Öry F, Van Roosmalen J. Severe maternal morbidity among immigrant women in the Netherlands: patients' perspectives. Reproductive Health Matters. 2011 May 31;19(37):144-53.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?			*
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?		*	
9	Is there a clear statement of findings?			*
10	How valuable is the research?	*		
Final score = 23				

Kalim N, Anwar I, Khan J, Blum LS, Moran AC, Botlero R, Koblinsky M. Postpartum haemorrhage and eclampsia: differences in knowledge and care-seeking behaviour in two districts of Bangladesh. Journal of Health, Population and Nutrition. 2009 Apr 1:156-69.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?	*		
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?	*		
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
Final score = 28				

Souza NL, Araújo AC, Azevedo GD, Jerônimo SM, Barbosa LD, Sousa NM. Maternal perception of premature birth and the experience of pre-eclampsia pregnancy. Revista de Saúde Pública. 2007 Oct;41(5):704-10.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?	*		
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?		*	
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
Final score = 28				

Oiyemhonlan B, Udofia E, Punguyire D. Identifying obstetrical emergencies at Kintampo Municipal Hospital: a perspective from pregnant women and nursing midwives. African journal of reproductive health. 2013 Jun 1;17(2):129-40.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?	*		
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?		*	
9	Is there a clear statement of findings?			*
10	How valuable is the research?	*		
Final score = 25				

Seely EW, Rich-Edwards J, Lui J, Nicklas JM, Saxena A, Tsigas E, Levkoff SE. Risk of future cardiovascular disease in women with prior preeclampsia: a focus group study. BMC pregnancy and childbirth. 2013 Dec 21;13(1):240.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?	*		
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?		*	
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
Final score = 27				

You WB, Wolf M, Bailey SC, Pandit AU, Waite KR, Sobel RM, Grobman W. Factors associated with patient understanding of preeclampsia. Hypertension in pregnancy. 2012 Aug 1;31(3):341-9.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?			*
4	Was the recruitment strategy appropriate to the aims of the research?			*
5	Was the data collected in a way that addressed the research issue?			*
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?			*
9	Is there a clear statement of findings?	*		
10	How valuable is the research?		*	
Final score = 19				

Osubor KM, Fatusi AO, Chiwuzie JC. Maternal health-seeking behavior and associated factors in a rural Nigerian community. Maternal and Child Health Journal. 2006 Mar 1;10(2):159-69.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?			*
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?	*		
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?			*
9	Is there a clear statement of findings?			*
10	How valuable is the research?	*		
Final score = 22				

Abdulkarim GM, Kawuwa MB, Kullima A. Community perception of maternal mortality in Northeastern Nigeria. African journal of reproductive health. 2008 Dec 1;12(3).

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?		*	
5	Was the data collected in a way that addressed the research issue?		*	
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?			*
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
Final score = 24				

Kumbani L, Me Inerney P. The knowledge of obstetric complications among primigravidae in a rural health centre in the district of Blantyre, Malawi. Curationis. 2002 Sep 27;25(3):43-54.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?			*
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?		*	
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?			*
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
Final score = 23				

Brown MC, Bell R, Collins C, Waring G, Robson SC, Waugh J, Finch T. Women's perception of future risk following pregnancies complicated by preeclampsia. Hypertension in pregnancy. 2013 Feb 1;32(1):60-73.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?	*		
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?	*		
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
Final score = 28				

Atkinson SJ, Farias MF. Perceptions of risk during pregnancy amongst urban women in northeast Brazil. Social Science & Medicine. 1995 Dec 31;41(11):1577-86.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?			*
2	Is a qualitative methodology appropriate?		*	
3	Was the research design appropriate to address the aims of the research?		*	
4	Was the recruitment strategy appropriate to the aims of the research?		*	
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?		*	
9	Is there a clear statement of findings?			*
10	How valuable is the research?	*		
Final score = 20				

Mapp T. Feelings and fears post obstetric emergencies--2. British Journal of Midwifery. 2005 Jan 1;13(1).

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?		*	
4	Was the recruitment strategy appropriate to the aims of the research?			*
5	Was the data collected in a way that addressed the research issue?		*	
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?		*	
9	Is there a clear statement of findings?			*
10	How valuable is the research?	*		
Final score = 18				

Fleury C, Parpinelly M, Makuch MY. Development of the mother–child relationship following pre-eclampsia. Journal of Reproductive and Infant Psychology. 2010 Aug 1;28(3):297-306.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?	*		
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?	*		
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
Final score = 28				

Barlow JH, Hainsworth J, Thornton S. Women's experiences of hospitalisation with hypertension during pregnancy: feeling a fraud. Journal of Reproductive and Infant Psychology. 2008 Aug 1;26(3):157-67.

		Yes (3)	Can't tell (2)	No (1)
1	Was there a clear statement of the aims of the research?	*		
2	Is a qualitative methodology appropriate?	*		
3	Was the research design appropriate to address the aims of the research?	*		
4	Was the recruitment strategy appropriate to the aims of the research?		*	
5	Was the data collected in a way that addressed the research issue?	*		
6	Has the relationship between researcher and participants been adequately considered?		*	
7	Have ethical issues been taken into consideration?		*	
8	Was the data analysis sufficiently rigorous?	*		
9	Is there a clear statement of findings?	*		
10	How valuable is the research?	*		
Final score = 27				

Supplementary Table 4. CERQual qualitative evidence profile.

Finding	Studies contributing to finding	Methodological limitations	Relevance	Coherence	Adequacy	CERQual confidence	Explanation
Women expressed confusion regarding the hypertensive disorders of pregnancy	Studies: (46, 54, 55, 58, 59, 62-67)	Minor methodological limitations (four studies with minor and two with moderate methodological limitations)	Minor concerns about relevance (partial relevance of studies, many studies focused on women in hospital and/or those with history of pre-eclampsia, studies with focus on knowledge of cardiovascular risks only)	Minor concerns about coherence (findings are consistent within and between studies)	Moderate concerns about adequacy (moderate level of rich data supporting synthesis finding)	**High confidence**	Concerns are present in all categories, nevertheless these are not felt to be significant enough to reduce confidence in this finding. Methodological limitations included studies that quantified results and omitted key methodological details. Partial relevance of included studies as many included hospital-based populations, in some cases only those with history of pre-eclampsia, studies with focus on knowledge of cardiovascular risks only Moderate level of rich data supporting synthesis finding
Women perceived information provided regarding the hypertensive disorders of pregnancy was insufficient	Studies: (33, 45, 54-56, 58, 62, 64, 65, 67)	Moderate methodological limitations (two studies with substantial methodological limitations)	Moderate concerns about relevance (partial relevance of studies, many studies focused on women in hospital and/or	Minor concerns of coherence (findings are consistent within and between studies)	Moderate concerns of adequacy (moderate level of rich data supporting synthesis finding)	**Moderate confidence**	Methodological limitations included studies that quantified results and omitted key methodological details.

Finding	Studies contributing to finding	Methodological limitations	Relevance	Coherence	Adequacy	CERQual confidence	Explanation
			those with history of pre-eclampsia, studies with focus on knowledge of cardiovascular risks only, limited by geographic spread of studies)				
Emphasis on lifestyle and personal responsibility for avoiding the hypertensive disorders of pregnancy	Studies: (18, 54-56, 59, 62, 63, 67)	Minor methodological limitations (included studies were of high quality, two had limited in-depth description of qualitative methods and analysis)	Moderate concerns of relevance (studies did not focus on the causes or management of the hypertensive disorders but it was indirectly addressed in many, limitations in population of inclusion, limited by geographic spread of studies)	Minor concerns of coherence	Moderate concerns of adequacy limited details of findings presented	**Moderate confidence**	

Supplementary Table 5. Sample Focus Group Transcript with New Mothers in Nigeria.

Focus Group Characteristics	
Focus group #	3
Cluster	Yewa South
Stakeholder group	Mothers (with child <5) Group I
Date	20120607
Venue	Traditional Birth Attendant Centre
Start time	15:35
End time	16:30

Participants characteristics						
Participants Number	Age (years)	Level of schooling	Marital Status	Occupation	Religion	Number of children
1	27	Secondary	Married	Trading	Christianity	2
2	20	None	Married	Petty trading	Christianity	3
3	25	Primary	Married	Trading	Christianity	2
4	32	Primary	Married	Trading	Christianity	2
5	27	Secondary	Married	Hair styling	Christianity	3
6	27	Secondary	Married	Fashion designing	Islam	3
7	22	Primary	Married	Petty trading	Islam	2
8	31	Primary	Married	Trading	Islam	1
9	42	Primary	Married	Business	Islam	4
10	30	Secondary	Married	Trading	Christianity	2
11	40	Secondary	Married	Trading	Islam	5
12	25	Primary	Married	Trading	Islam	2

Icebreaker: What does it take to be a mother in this community?

- P4: For someone to be called a mother… when women are pregnant they need to seek treatment at the Traditional Birth Attendant's place regularly…to check ourselves regularly, we should visit the TBA, we need to take medicines from them…all the medicines we receive from them, we need to be using them, so that there would be no complications for us on our day of delivery….and after delivery, we should take the child to the TBA for treatment and we wouldn't have any problems…ever since we've been receiving medicines from them, we have had no problems…and we thank God for that.

- P7: For you to know a real mother…when a pregnant woman delivers, she's supposed to know how to take care of her baby. For instance, we are now in the raining season; when the weather is cold, she should put on cardigan for her child…she shouldn't allow her baby to crawl on the floor in the morning in the cold weather because of convulsion and other illnesses. This season is dangerous. She should take care of her child. She should enroll her child in a school…and when the child is enrolled in a school, she should be checking on her child at the school… to advise her child. She should correct her in the public when the child does something wrong …not that her child would steal and she would call him/her to a corner for correction. She should correct her child always because children of nowadays… God should give them a heart and ears to listen to instructions.
- P5: In addition, when children need something at school, our responsibility is to provide it for them… for them not to look elsewhere…for them not to do what they are not supposed to do.
- P9: A woman must take care of her child; at the time when the child is supposed to eat, she should give her child food….when it rains, the mother is supposed to take care of her child…but there some pregnant women that don't take care of their babies and it's not supposed to be like that.

Moderator: Why don't they take care of their children?

- P9: There some pregnant women, a lot of them that I have seen, it's either that the father and the mother of the child are divorced… and this leads to the child wandering around. How can a man take care of a baby?

Moderator: Is it not possible for a man to take care of a baby?

- P9: What can men really do when it comes to taking care of a child? If the child's mother is not around, what can the man really do to take care of the child? It's the mother that owns the child…we should take care of our children very well.

THEME I: KNOWLEDGE AND PERCEPTIONS / BELIEFS / EXPERIENCES ABOUT COMMON PREGNANCY ASSOCIATED ILLNESSES

Q 1 What are the common pregnancy-related illnesses or complications that you know?

- P9: What I have noticed about pregnant women is that some of them might have typhoid fever…for some, it might be dizziness…some might begin to vomit from the moment they become pregnant; for some, the vomiting wouldn't stop until the fifth month of their pregnancy…for some, they might have a fever…all of a sudden, she would be just be running temperature.
- P11: Some pregnant women might have 'yellow fever' (*used for feverish illness with jaundice*)…I have a friend, when she is pregnant, she can't even lift a plate.

Moderator: What is the reason?

- P11: She would be feeling sick, she's always down with yellow fever…for some pregnant women, it is typhoid fever…but truly for some, it is vomiting; the woman would be vomiting always…for some pregnant women, she might be craving for the food her neighbour is preparing.

Moderator: What is the reason?

- P11: It is the condition she's in at that moment…it's not stealing…it's the condition she's in at the moment and she knows that the condition is just for a while, it's not forever.

Moderator: When we become pregnant, how do we behave to our children, husbands and other family members?

- P12: When we become pregnant, our behavior would change to our husbands, because we become easily irritated…there's nothing they would request us to do that we would be willing to do at that time. The woman would become tired…the woman wouldn't be willing to do anything…the pregnant woman would just be there. God shouldn't allow us to be as if we don't exist. These are the reasons why our attitudes change towards our husbands….our attitudes change…we become easily irritated.
- P1: When women become pregnant, they become easily irritated. Our behavior would change…for us to do anything is a problem; we just struggle to do things…sometimes we just become very tired and we would just try to do things.

Q 2 Why do you think some women develop complications during pregnancy?

- P12: If a pregnant woman doesn't use drugs to treat her illness…for instance, when we go to the hospital and they give us prescribed drugs to use at the hospital and we don't use them. We usually visit the traditional healers…when they give us medicines, we are supposed to use them according to their prescription. For the medicine to work properly, we are supposed to use the drugs according to the prescriptions we are given. If we use the drugs at the right time, we would notice a difference in our body; that our baby is fine.
- P3: A husband who neglects his wife… when pregnant women give birth, their husbands should take care of their babies and also take care of their wives…but when a husband doesn't take care of his wife, he can't take care of the baby…the baby would be become easily irritated….that's the reason why men should take care of their wives.

Moderator: What can cause a husband not to take care of his wife?

- P3: Women should be submissive to their husbands…when women are not submissive; their husbands become easily irritated.

Moderator: Is it the woman's attitude that makes her husband not to take care of her or there are other things that would cause the husband not to take care of his wife?

- P3: Some men might be wandering around; some men might leave the house early in the morning and he wouldn't give his wife money for food and also his children…when the woman wakes up, she would tidy up the house. If her husband's clothes are dirty, the woman would take them and wash them. The man is supposed to give his wife and children money for food.
- P7: Depressive thoughts can cause illness for some pregnant women. When some women become pregnant and there is something they are worrying about, it causes illness for them…it causes high blood pressure for some pregnant women. For instance, when I'm pregnant and I begin to worry about something, I would begin to develop high blood pressure…sometimes when I sit down, I would just feel nauseated and I would go to sleep…when I sleep…. it's either I take milk before sleep… then, I would become better…and when I'm better and I visit the hospital…at the local midwife's, where I have registered, she would give me medicine and I would be fine.

- P7: Not every woman is submissive to their husbands…a woman might have little money and she would be like… "There's nothing my husband can tell me"… and her husband wouldn't want that… "My wife can't become proud because she has some money"… that would cause a fight between the man and the woman. Some men are rascals…it was how they were raised…street boys….when a woman marry them…he is a rascal…before his wife says a word, he would begin to punch her…he doesn't care.
- P6: First, some pregnant women don't use their drugs and it's not good…as we use the drugs prescribed at the hospital, let us also take drugs from the traditional healers…when we do this, I'm sure God will do miracle. Secondly, maybe her husband likes to beat her…before she utters a word, he would quickly give her punches on her face and other areas…it's possible that when she wants to deliver, she might have some complications…this can also cause it.

Moderator: How can punching affect the pregnant woman?

- P6: It would affect a pregnant woman…the woman would begin to worry and if she doesn't worry…maybe he punched her in a delicate area… it would affect the baby.

Q 3 Why do you think some mothers experience high blood pressure during pregnancy?

- Chorus: Depressive thoughts

Q 4 Is there any name or term used in the community to describe high blood pressure (or convulsion) during pregnancy?

- Chorus: There is none.

Q 5 Why do you think some mothers convulse during pregnancy, childbirth or after delivery?

Moderator: What do you think causes convulsion during pregnancy?

- P6: If a pregnant woman doesn't use drugs properly, it causes convulsion…if a pregnant woman doesn't use drugs properly, convulsion wouldn't occur.
- P1: What causes convulsion during pregnancy is when a pregnant woman takes cold drinks…very cold drinks….this is what I think causes it.
- Chorus: Cold weather can cause it.

Q 6 How does high blood pressure during pregnancy affect the mother and her baby?

- P7: When a woman is pregnant and she develops high blood pressure…some pregnant women might develop stroke after delivery…it happened to someone recently…she had a stroke…it could cause paralysis…after delivery, her baby wouldn't be healthy…she might even have a stillbirth….the baby wouldn't be okay.

Moderator: Could high blood pressure occur as a result of repercussion of someone's sins or could it be a spiritual attack?

- Chorus: High blood pressure can't be caused by spiritual attack.

Moderator: How about other illnesses like convulsion and postpartum haemorrhage, could they be caused by spiritual attack?

- P8: Postpartum haemorrhage could occur normally for some pregnant women…but there are some…God shouldn't allow us to encounter it ….maybe when the woman was pregnant, they might have instructed her to use some medicines and she refused.

Moderator: What kind of medicines?

- P8: They might instruct her to use some traditional medicines when she was pregnant….where I usually go to give birth….they usually give us something to use before we deliver and there would be no problem after delivery.

Q 7 How would you feel if you were told you had high blood pressure when you are pregnant?

- P7: It's not a good thing for a pregnant woman to have a high blood pressure…it's not something good at all…the pregnant woman would be running around to find solution to the problem…what type of medicine to use to reduce the high blood pressure…because if her blood pressure is too high…it's not a good thing.

Q 8 What do you think the family of a woman with high blood pressure should do to help her?

- *(Question skipped)*

Q 9 If a pregnant woman is convulsing at home, what do you think should be done to her?

- *(Question skipped)*

THEME II: DELAYS IN CARE SEEKING FOR THE MANAGEMENT OF PREGNANCY-RELATED COMPLICATIONS

Q 1 Where do you normally seek care during pregnancy, labour and after delivery?

- *(Question skipped)*

Q 2 Where do you seek care for complications during pregnancy, delivery and after delivery?

Moderator: If a woman convulses during pregnancy, where do you think she should go to seek care?

- P6: If a pregnant woman convulses….some pregnant women don't take native medicines seriously…if something like that happens, they could take her to the hospital. When they take her to the hospital, they could give her injections. Pregnant women that are familiar with native medicine would be taken to the herbalist for them to be treated with the herbs.
- P5: If a pregnant woman convulses and they take her to hospital, injections can't treat convulsion; it usually works negatively for the patient….but if they take her to the local midwife's place and she gives her herbs and native medicines, the convulsion would be cured….but if a pregnant woman uses the hospital…injections work negatively in the treatment of convulsion sometimes.

Moderator: Have you ever witnessed a case?

- P5: It happens a lot.

Moderator: Please tell us more, how did it happen?

- P5: A pregnant woman convulsed and they rushed her to the hospital….they gave her injections and she eventually died…so convulsion and injections are enemies.

Q 3 Why do you seek care at these places?

Moderator: Why do you seek traditional healers for treatment during pregnancy?

- P7: Some pregnant women might begin to labour in the middle of the night and they wouldn't be able to go to the hospital….and if she goes to the traditional healer, she would also have peace of mind because she had been patronizing there….and it would be a safe delivery.
- P6: The reason why we seek the traditional healers for treatment is because….when we get there…they would be able to give us herbs from time to time… "*Oka Ori*", "*Osi Inu*", "*Erun Inu*" (names of herbs)…they would have treated us with these herbs… "*Ogun Giri*" (convulsion medicine), "*Ogun ile tutu*" (*cold ground medicine*)… they would have treated us with all these medicines during pregnancy…that is the reason why we go to the traditional healer's place and we deliver safely at the place; there is usually no problem.
- P11: It's because of the herbs…there are no herbs in the hospital and we have to try all places because a pregnant woman is in a delicate condition…and during this period, we seek various places…we should use the hospital and also the traditional midwife; so that we can receive enough herbs for our protection.

Q 4 What are the common cultural preferences for seeking care for high blood pressure during pregnancy?

Moderator: What cultural practices or family taboos would hinder us from seeking care for high blood pressure and convulsion during pregnancy and excessive bleeding during childbirth?

- P7: These days, in some hospitals, when we go there for care….they would set a drip for us and give us injections…and when a woman is pregnant, there is a limit to the amount of drip a pregnant woman can take....or if a pregnant woman wants to deliver, she can take drip….but when a woman is pregnant, she is supposed to be taking herbs…she is supposed to take native medicine because when you go to the hospital, they wouldn't give you herbs at the hospital….they prescribe medicine for you and give you injections or drip.

Moderator: Is it the drip that is causing hindrance for you not to seek care at the hospital?

- P7: It's not the drip that is causing hindrance…if a woman is pregnant, she should use hospital medicine and also use native medicine.

Moderator: What can cause hindrance for you to seek care from the nurses and the local midwives?

- P7: There's nothing that can hinder us from seeking care from them.

Moderator: Can the attitudes of the local midwives and nurses cause hindrance for you in seeking care from them?

- P11: It's common in the hospital…they wouldn't attend to you on time and some pregnant women don't want this kind of treatment… that's the reason why they prefer to seek care from the traditional midwives.
- P5: When pregnant women are in labour that's when the nurses would ask them to go for blood test, urine test…and that's the reason why we prefer to seek treatment from the local midwives and deliver our children with them….because the local midwife wouldn't waste our time.
- P6: When a pregnant woman who is in labour goes to the hospital to deliver….the nurses already have the mind set that whatever happens to any patient, they would still get paid at the end of the month…and that's why they waste our time, but at the traditional healer's place, they attend to us immediately we arrive there.

Q 5 What are the common cultural preferences for seeking care for convulsions during pregnancy?

Moderator: What cultural practices or family taboos would hinder us from seeking care for high blood pressure and convulsion during pregnancy and excessive bleeding during childbirth?

- P7: These days, in some hospitals, when we go there for care….they would set a drip for us and give us injections…and when a woman is pregnant, there is a limit to the amount of drip a pregnant woman can take....or if a pregnant woman wants to deliver, she can take drip….but when a woman is pregnant, she is supposed to be taking herbs…she is supposed to take native medicine because when you go to the hospital, they wouldn't give you herbs at the hospital….they prescribe medicine for you and give you injections or drip.

Moderator: Is it the drip that is causing hindrance for you not to seek care at the hospital?

- P7: It's not the drip that is causing hindrance…if a woman is pregnant, she should use hospital medicine and also use native medicine.

Moderator: What can cause hindrance for you to seek care from the nurses and the local midwives?

- P7: There's nothing that can hinder us from seeking care from them.

Moderator: Can the attitudes of the local midwives and nurses cause hindrance for you in seeking care from them?

- P11: It's common in the hospital…they wouldn't attend to you on time and some pregnant women don't want this kind of treatment… that's the reason why they prefer to seek care from the traditional midwives.
- P5: When pregnant women are in labour that's when the nurses would ask them to go for blood test, urine test…and that's the reason why we prefer to seek treatment from the local midwives and deliver our children with them….because the local midwife wouldn't waste our time.
- P6: When a pregnant woman who is in labour goes to the hospital to deliver….the nurses already have the mind set that whatever happens to any patient, they would still get paid at the end of the month…and that's why they waste our time, but at the traditional healer's place, they attend to us immediately we arrive there.

Q 6 What are the cultural preferences for seeking care for excessive bleeding during childbirth?

Moderator: What cultural practices or family taboos would hinder us from seeking care for high blood pressure and convulsion during pregnancy and excessive bleeding during childbirth?

- P7: These days, in some hospitals, when we go there for care….they would set a drip for us and give us injections…and when a woman is pregnant, there is a limit to the amount of drip a pregnant woman can take....or if a pregnant woman wants to deliver, she can take drip….but when a woman is pregnant, she is supposed to be taking herbs…she is supposed to take native medicine because when you go to the hospital, they wouldn't

give you herbs at the hospital….they prescribe medicine for you and give you injections or drip.

Moderator: Is it the drip that is causing hindrance for you not to seek care at the hospital?

- P7: It's not the drip that is causing hindrance…if a woman is pregnant, she should use hospital medicine and also use native medicine.

Moderator: What can cause hindrance for you to seek care from the nurses and the local midwives?

- P7: There's nothing that can hinder us from seeking care from them.

Moderator: Can the attitudes of the local midwives and nurses cause hindrance for you in seeking care from them?

- P11: It's common in the hospital…they wouldn't attend to you on time and some pregnant women don't want this kind of treatment… that's the reason why they prefer to seek care from the traditional midwives.
- P5: When pregnant women are in labour that's when the nurses would ask them to go for blood test, urine test…and that's the reason why we prefer to seek treatment from the local midwives and deliver our children with them….because the local midwife wouldn't waste our time.
- P6: When a pregnant woman who is in labour goes to the hospital to deliver….the nurses already have the mind set that whatever happens to any patient, they would still get paid at the end of the month…and that's why they waste our time, but at the traditional healer's place, they attend to us immediately we arrive there.

Q 7 Under what conditions will you seek medical care and when?

- P7: When a pregnant woman goes to the hospital and they recommend operation for her…it's possible for her to take the same medical condition to the herbalist who wouldn't perform the surgical operation for her…and she would deliver her baby safely.
- P9: A pregnant woman that is about to deliver and has gone to seek treatment in the hospital several times for the same medical condition….and the hospital has given up on the case and they have asked the pregnant woman to seek alternative therapies for her

condition….it's when the pregnant woman seek care at the local midwife's place that she would become well… "It's not their doing, it is God who is helping them".

- P5: The reason why we seek care at the traditional midwife's place is because when a pregnant woman wants to deliver in the hospital, they might tell her that she would need operation before she can deliver; "she can't deliver the baby herself…but we believe in God that when we get to the traditional midwife's place, we would deliver the baby without any operation". For postpartum haemorrhage, when a lot of nurses try to stop the bleeding, God doesn't grant them success; because it is God that grants someone success in treating postpartum haemorrhage….but if it were to be at the local midwife's place, they would have been treating us with some things since the time we became pregnant so that such thing wouldn't occur when we are about to deliver. This is why we prefer to seek care from the local midwife than going to a nurse.

Moderator: How would a local midwife check if a pregnant woman has high blood pressure?

- P5: I didn't mean that it's only the local midwife that can treat high blood pressure and that the nurses can't treat it. The nurses too try… they would test a pregnant woman to know if she has high blood pressure, but the local midwife wouldn't test the pregnant woman to know if she has blood pressure or not….the local midwife would have been treating everything that could cause high blood pressure from the early stage of pregnancy.

Q 8 Who makes the decision regarding where and when you seek care?

- *(Question skipped)*

THEME III: PERCEPTIONS AND BELIEFS REGARDING THE PREVENTION OF PREGNANCY-RELATED COMPLICATIONS AND DEATH

Q 1 What do you think is the role of alternative therapies (e.g. traditional medicine, spiritual treatment) in the treatment of high blood pressure during pregnancy?

(Question skipped)

Q 2 What do you think is the role of alternative therapies (e.g. traditional medicine, spiritual treatment) in the treatment of convulsions during pregnancy?

- *(Question skipped)*

Q 3 What do you think is the role of alternative therapies (traditional medicine, spiritual treatment) in the treatment of excessive bleeding during childbirth?

(Question skipped)

Q 4 What alternative therapies/medicines are being used in your community to treat high blood pressure in pregnancy?

(Question skipped)

Q 5 What alternative therapies/medicines are being used in your community to treat convulsions during pregnancy?

(Question skipped)

Q 5 What alternative therapies/medicines are being used in your community to treat excessive bleeding during childbirth?

(Question skipped)

Q 6 What do you think are the common reasons for death of a pregnant woman?

(Question skipped)

Q 7 What do you think is the role of family members (especially husband; In-laws) in preventing pregnancy-related death?

- P6: If a pregnant woman delivers her baby at the local government hospital and a complication arises…if the nurses have tried their best….they could call her relatives…one of her family members might have something different that could be given to her….but if she delivered her baby at the traditional midwife's place and something like that happens, the traditional midwife already knows what she's going to use to treat the illness.

Moderator: What help can her family members render?

- P6: What the family can do to help her is that when they arrive at the traditional midwife's place and the midwife had diagnosed her illness…. some of the family members could be an herbalist or a native doctor….so a family member can also add to the help of the traditional midwife….and suggest other ways to help the pregnant woman.

Moderator: How about the community members?

- P6: It's risky to announce your medical condition to the whole community.

Moderator: Why is it risky?

- P6: It is risky because it could cost the pregnant woman her life.

Moderator: Can the community members kill the pregnant woman?

- P6: I can't answer that question because you know the hearts of men are deep.

Q 8 What do you think is the role of the community in preventing pregnancy-related death?

- P6: If a pregnant woman delivers her baby at the local government hospital and a complication arises…if the nurses have tried their best….they could call her relatives…one of her family members might have something different that could be given to her….but if she delivered her baby at the traditional midwife's place and something like that happens, the traditional midwife already knows what she's going to use to treat the illness.

Moderator: What help can her family members render?

- P6: What the family can do to help her is that when they arrive at the traditional midwife's place and the midwife had diagnosed her illness…. some of the family members could be an herbalist or a native doctor….so a family member can also add to the help of the traditional midwife….and suggest other ways to help the pregnant woman.

Moderator: How about the community members?

- P6: It's risky to announce your medical condition to the whole community.

Moderator: Why is it risky?

- P6: It is risky because it could cost the pregnant woman her life.

Moderator: Can the community members kill the pregnant woman?

- P6: I can't answer that question because you know the hearts of men are deep.

Q 9 What do you think is the role of health care providers in preventing pregnancy-related death?

- P6: If a pregnant woman delivers her baby at the local government hospital and a complication arises…if the nurses have tried their best….they could call her relatives…one of her family members might have something different that could be given to her….but if she delivered her baby at the traditional midwife's place and something like that happens, the traditional midwife already knows what she's going to use to treat the illness.

Moderator: What help can her family members render?

- P6: What the family can do to help her is that when they arrive at the traditional midwife's place and the midwife had diagnosed her illness…. some of the family members could be an herbalist or a native doctor….so a family member can also add to the help of the traditional midwife….and suggest other ways to help the pregnant woman.

Moderator: How about the community members?

- P6: It's risky to announce your medical condition to the whole community.

Moderator: Why is it risky?

- P6: It is risky because it could cost the pregnant woman her life.

Moderator: Can the community members kill the pregnant woman?

- P6: I can't answer that question because you know the hearts of men are deep.

Q 10 What role do you think home remedies play in the treatment of high blood pressure in pregnancy?

(Question skipped)

Q 11 What role do you think home remedies play in the treatment of convulsions during pregnancy?

(Question skipped)

Q 12 What role do you think home remedies play in the treatment of excessive bleeding during childbirth?

- *(Question skipped)*

Q 13 In this community, please tell me the home remedies that are used in the treatment of hypertension in pregnancy?

(Question skipped)

Q 14 What are the home remedies used in the treatment of convulsions in pregnancy?

(Question skipped)

Q 15 What are the home remedies used in the treatment of excessive bleeding during childbirth?

(Question skipped)

Q 16 How do you think a woman can avoid dying from high blood pressure during pregnancy/ excessive bleeding during childbirth?

(Question skipped)

Q 17 In your opinion, how can families in this community be educated about danger signs in pregnancy?

(Question skipped)

THEME IV: PERCEPTION OF COMMUNITY LEVEL MANAGEMENT OF HIGH BLOOD PRESSURE BY COMMUNITY HEALTH CARE PROVIDERS

Q 1 What health care services have you ever received during pregnancy from health care providers in your home?

Moderator: What kind of home care do you think health care workers can give pregnant woman in the treatment of high blood pressure?

- *(No response)*

Moderator: What is your opinion about health care workers coming to your homes to provide care for us? What is your opinion about a program like that? Is it good or not?

- P9: It would be a very good program.

Moderator: How would the program benefit pregnant women?

- P9: It would be a great privilege because the little care they would give us… when we go to the hospital, they would observe we've had previous care.
- P5: It would be a good thing if the health care workers can come to our homes to provide care for us.....it would be of good benefit for the pregnant women.

Q 2 What is your opinion regarding provision of care by health care providers at the health posts/clinics/centres?

- *(Question skipped)*

Q 3 How confident are you with the services these health workers provide to you?

- *(Question skipped)*

Q 4 What is your opinion regarding home visits for check up/treatment with tablets and injection/referral by health workers when indicated?

- P9: There are some pregnant women who don't like to take injections and there are some that like injection…some pregnant women are skeptical about the injection; that maybe they would administer expired injection to her…that is why some pregnant women don't like to take injections.

Q 5 What would be the effects of home visits and check-ups/treatment on the relationship between you and these health workers?

- P5: There is nothing wrong with a program like that…we wouldn't cross each other's path….I might like something and another pregnant woman might not like the same thing….I might like to take injections and also seek care at the herbalist's place…if I like it like that…I would receive treatment from them….and if a pregnant woman only likes injection…that is what she would seek…she would tell the herbalist that she's not interested in taking herbs….and if a pregnant woman likes to use herbs, if a nurse comes to her home to provide care for her, she would tell the nurse that she's not interested.

Q 6 What would be the effects of home visits and check-ups/treatment on your current perception of the health posts/clinics/centres in your community?

- *(Question skipped)*

Q 7 How acceptable do you think home-based treatment with medicine/injection is to the community in general?

- *(Question skipped)*

Q 8 Do you have any concerns regarding such approach?

- *(Question skipped)*

Q 9 If you were pregnant, what reasons would make you not to permit home visits by health care providers for check up?

Moderator: Would you allow a male health care worker to provide care for you at home?

- P9: "In my room?"… "Is he going to enter my room?"
- P5: It is never going to be possible…. In my own opinion, it wouldn't be possible for a male health care worker to provide care for a pregnant woman at home.

Moderator: Why is it not possible?

- P5: Anything can happen from there…it wouldn't be possible.

Moderator: What other things could jeopardize a program like that?

- P5: If they want male health care workers to provide care for pregnant women at home, then, my husband too would go for nurse training….he should also train as a nurse so that he could treat me.
- P9: Concerning the issue of male health care workers coming to our homes to provide care for us…God shouldn't allow us to encounter a problem that would be too much for us to overcome (prayer)….let's do away with the thought that a male health care worker can't come to our homes to provide care for us…because when we go to the hospital….when we get there… and a man is assigned to deliver us….because all the children I had, I was delivered by a male health care worker… would I then say because I want to avoid a problem or relationship issues with my husband…..that the male health care worker shouldn't deliver me when I wanted to deliver? I don't think that would be possible…whatever anyone intends to do is in her heart.

Q 10 How do you think families can be educated to accept treatment (medicine/ injection/referral) given at home or health facility?

- P9: What we could do is that the first time the male health care worker comes to my house and my husband is not around, if I couldn't reach my husband on the phone, when he comes back home….the health care worker wouldn't care for me that day…I would ask the health care worker to leave and come back on another date…..before he returns, I would have called my husband that "a male health care worker is coming to provide care for me at home"…my husband too must be home on my appointment date….he would wait for the health care worker to arrive…

THEME V: COST OF CARE (DIRECT AND IN-DIRECT) AND PERCEIVED BURDEN OF CARE

Q 1 During pregnancy or delivery you may need to be admitted in the hospital due to some complications (hypertension /convulsions/ bleeding), then costs are incurred, how do you arrange for money to cover the costs?

- P9: A husband that impregnates his wife, does he not know that he ought to be prepared to pay my admission bill?

Moderator: You said something the other time that some men after they've impregnated their wives would leave the home.

- P9: There are some men like that, but for me…I'm not speaking for others…the moment I find out that I'm pregnant…from what I learnt from my mother….the moment I become pregnant… everything we would be doing concerning the pregnancy would be based on an agreement: "do your part and l would do mine"…the moment I become pregnant, everything that would be done concerning the pregnancy would be based on an agreement: "do your part and I would do mine".

Moderator: What are his own parts and your own parts?

- P9: He is supposed to give me to money to go to the hospital…if he gives me….it might not be enough and I would add to it from my own pocket….and on the day of my delivery…when I have delivered in the hospital…. "Your wife has put to bed, they want this amount of money in the hospital….this is how much she has"….he should respond that "they should go to this place or that place to get the balance of the money".

Q 2 What is the total cost of hospital admission (drug, bed and service fee for providers) in your opinion?

- P5: It depends on how long a pregnant woman stays in the hospital before she delivers….when you arrive at the hospital where you want to deliver, they would note the time of your arrival….they would charge you by the minute.

Moderator: How much is it if you spend an hour?

- P5: I don't check the time I delivered, but the hospital staff before they begin to treat the pregnant woman…

Moderator: How much do they bill you?

- P5: It starts from four thousand naira in the hospital… but at the traditional healer's place…their charges are moderate. The traditional healer could charge two thousand naira or two thousand five hundred naira…at most; three thousand naira and their services are good.

Q 3 Who looks after the household chores/children when a woman is admitted to the hospital?

- P5: If a pregnant woman has a grown-up child… and if she doesn't have a grown-up child…as long as she hasn't fought all her neighbours before she left home, they would take care of the house for her before she comes back.

Moderator: How about our husbands; can they take care of the home?

- P5: What if her husband wakes up early to go work…at least, he has to work to be able to feed the family.

Supplementary Table 6. Enhancing Transparency in Reporting the Synthesis of Qualitative (ENTREQ) research framework for the synthesis of primary data.

1	Aim	The aim of this study is to determine the level of knowledge that pregnant women and new mothers have regarding the hypertensive disorders of pregnancy by way of synthesis of original data sets in Nigeria, Mozambique, Pakistan and India.
2	Synthesis methodology	Thematic synthesis to explore the phenomena of hypertension/convulsions in pregnancy and to identify any heterogeneity between groups/cultures.
3	Approach to searching	The sample of studies was determined a priory and as this was not an aggregative review a theoretical sample instead was used (purposive sample)
4	Inclusion criteria	Supplementary Figure 1
5	Data sources	Table 24
6	Electronic search strategy	N/A
7	Study screening methods	N/A
8	Study characteristics	Table 23
9	Study selection results	N/A
10	Rationale for appraisal	To ensure validity of coding results and to provide transparency of synthesis process and findings.
11	Appraisal items	
12	Appraisal process	Audit trail, member checking, secondary independent coder
13	Appraisal results	
14	Data extraction	All data from relevant transcripts
15	Software	QSR International NVivo 11, 2016
16	Number of reviewers	Two: MV and DAD
17	Coding	Line-by-line, descriptive, and analytic (Figure 16 and Table 3)
18	Study comparison	Reciprocal and refutational translation of findings throughout synthesis.
19	Derivation of themes	Inductive and iterative process at all three stages of theme production,
20	Quotations	Provided throughout presentation of synthesis findings, select quotations in Table 25
21	Synthesis output	Figure 16 and Table 25

Supplementary Table 7. Focus group characteristics.

	Country	Date	Group	# of participants	Average age of participants	Length of focus group
1	Mozambique	December 2013	Pregnant women	Unknown	Unknown	30-45 minutes
2	Mozambique	November 2013	Pregnant women	Unknown	Unknown	30-45 minutes
3	Mozambique	November 2013	Pregnant women	Unknown	Unknown	< 30 minutes
4	India	January 2013	Pregnant women	55	Unknown	> 90 minutes
5	Nigeria	June 2012	New mothers	12	28	60-75 minutes
6	Nigeria	June 2012	New mothers	12	28	45-60 minutes
7	Nigeria	June 2012	New mothers	11	29	75-90 minutes
8	Nigeria	June 2012	New mothers	12	30	> 90 minutes
9	Nigeria	June 2012	New mothers	12	29	60-75 minutes
10	Pakistan	February 2012	New mothers	10	Unknown	Unknown
11	Nigeria	June 2012	New mothers	12	Unknown	> 90 minutes
12	Nigeria	June 2012	New mothers	12	Unknown	60-75 minutes
13	Nigeria	June 2012	Pregnant women	12	Unknown	> 90 minutes
14	Nigeria	June 2012	Pregnant women	12	Unknown	75-90 minutes
15	Nigeria	June 2012	Pregnant women	12	Unknown	75-90 minutes
16	Nigeria	June 2012	Pregnant women	12	Unknown	75-90 minutes
17	Nigeria	June 2012	Pregnant women	12	Unknown	> 90 minutes
18	India	February 2013	Pregnant women + new mothers	14	Unknown	60-75 minutes
19	India	February 2013	Pregnant women + new mothers	16	Unknown	60-75 minutes
20	India	February 2013	Pregnant women	17	Unknown	> 90 minutes
21	Pakistan	February 2012	Mothers	9	Unknown	> 90 minutes
22	Pakistan	February 2012	Mothers	8	Unknown	Unknown
23	Pakistan	March 2012	Mothers	8	Unknown	Unknown
24	Pakistan	March 2012	Mothers	8	Unknown	Unknown
25	Pakistan	March 2012	Mothers	8	Unknown	Unknown
26	Pakistan	February 2012	Mothers	9	Unknown	Unknown
27	Pakistan	February 2012	Mothers	12	Unknown	Unknown
28	Pakistan	March 2012	Mothers	9	Unknown	Unknown
29	Pakistan	March 2012	Mothers	9	Unknown	Unknown
30	Pakistan	April 2012	Mothers	11	Unknown	> 90 minutes
31	Pakistan	April 2012	Mothers	9	Unknown	> 90 minutes
32	Pakistan	April 2012	Mothers	9	Unknown	> 90 minutes
33	Pakistan	April 2012	Mothers	8	Unknown	> 90 minutes
34	Pakistan	May 2012	Mothers	10	Unknown	Unknown
35	Pakistan	May 2012	Mothers	8	Unknown	> 90 minutes
36	Pakistan	June 2012	Mothers	10	Unknown	Unknown
37	Pakistan	June 2012	Mothers	8	Unknown	Unknown
38	Pakistan	July 2012	Mothers	11	Unknown	Unknown

	Country	Date	Group	# of participants	Average age of participants	Length of focus group
39	India	February 2013	Pregnant women + new mothers	16	24	75-90 minutes
40	India	February 2013	Pregnant women	14	25	60-75 minutes
41	Nigeria	June 2012	New mothers	12	28	> 90 minutes
42	Nigeria	June 2012	Pregnant women	12	25	> 90 minutes
43	Nigeria	June 2012	Pregnant women	10	22	75-90 minutes
44	India	February 2013	Pregnant women + new mothers	14	23	> 90 minutes
45	Nigeria	June 2012	Pregnant women	12	25	75-90 minutes

Supplementary Table 8. Enhancing Transparency in Reporting the synthesis of Qualitative (ENTREQ) research framework for the synthesis of published findings.

1	Aim	The aim of this study is to determine the level of knowledge that pregnant women and new mothers have regarding the hypertensive disorders of pregnancy by way of synthesis of results found in publications of the CLIP study in Nigeria, Mozambique, Pakistan and India.
2	Synthesis methodology	Thematic synthesis to explore the phenomena of hypertension/convulsions in pregnancy and to identify any heterogeneity between groups/cultures.
3	Approach to searching	The sample of studies was determined a priory and as this was not an aggregative review a theoretical sample instead was used (purposive sample)
4	Inclusion criteria	Figure 17
5	Data sources	Table 23
6	Electronic search strategy	N/A
7	Study screening methods	N/A
8	Study characteristics	See Tables 1 and 2
9	Study selection results	N/A
10	Rationale for appraisal	To ensure validity of coding results and to provide transparency of synthesis process and findings.
11	Appraisal items	Critical Appraisal Skills Programme checklist
12	Appraisal process	Audit trail, member checking, secondary independent coder, Critical Appraisal Skills Programme checklist (Table 27)
13	Appraisal results	No study excluded due to quality appraisal, quality scores provides (Table 27)
14	Data extraction	'Findings'/'Results' section of applicable manuscripts (Table 26)
15	Software	QSR International NVivo 11, 2016
16	Number of reviewers	Two: MV and DAD
17	Coding	Line-by-line, descriptive, and analytic (Figure 18)
18	Study comparison	Reciprocal and refutational translation of findings throughout synthesis.
19	Derivation of themes	Inductive and iterative process at all three stages of theme production,
20	Quotations	Provided throughout presentation of synthesis findings.
21	Synthesis output	Figure 18

Supplementary Table 9. Passages coded by analytic theme and transcript.

	Influence of experience in understandings of the HDP	Interpretations of HDPs related to elemental factors	Interpretations related to socio-economic factors	Interpretations related to supernatural and mythical factors
Moz_Pregnant Women_3 de Fevreiro	0	0	2	4
Moz_Pregnant Women_Ilha Josina	2	0	1	2
In_Pregnant Women_Hosur	2	4	3	0
Nig_New Mothers_Remo North	1	0	8	2
Nig_New Mothers_Imeko Afon	1	6	8	0
Nig_New Mothers_Imeko Afon 2	1	2	5	2
Nig_New Mothers_Yewa South	3	6	15	8
Nig_New Mothers_Yewa South 2	1	1	3	1
Pk_Mothers	0	2	8	0
Nig_New Mothers_Ogijo	1	1	6	0
Nig_New Mothers_Ogijo 2	0	0	3	0
Nig_Pregnant Women_Remo North	0	4	5	3
Nig_Pregnant Women_Yewa South	0	3	8	0
Nig_Pregnant Women_Ogijo	2	0	7	1
Nig_Pregnant Women_Remo North 2	4	5	14	5
Nig_Pregnant Women_Yewa South 2	0	5	4	2
In_Pregnant Women_Belgaum	0	5	4	0
In_Pregnant Women_Galagi	0	4	2	0
In_Pregnant Women_Belgaum 2	0	6	10	0
Pk_Mothers 2	0	4	3	1
Pk_Mothers 3	2	0	4	2
Pk_Mothers 4	0	3	5	5
Pk_Mothers 5	0	5	5	1
Pk_Mothers 6	0	6	5	3
Pk_Mothers 7	0	3	11	0
Pk_Mothers 8	0	3	3	0
Pk_Mothers 9	0	3	7	0
Pk_Mothers 10	1	5	7	2
Pk_Mothers 11	0	6	7	0
Pk_Mothers 12	0	1	7	0
Pk_Mothers 13	0	1	10	0
Pk_Mothers 14	0	2	3	1
Pk_Mothers 15	1	0	5	0
Pk_Mothers 16	1	2	5	0
Pk_Mothers 17	0	0	3	1
Pk_Mothers 18	1	1	5	0
Pk_Mothers 19	0	2	8	0
In_Pregnant Women_Belgaum 3	3	7	7	0
In_Pregnant Women_Chachadi	0	1	4	1
Nig_New Mothers_Remo North 2	1	3	11	1
Nig_Pregnant Women_Imeko Afon	0	3	4	0
Nig_Pregnant Women_Imeko Afon 2	0	1	4	2
In_Pregnant Women_Bagalkot	0	5	6	0
Moz_Pregnant Women_Calanga	0	0	2	2
Nig_Pregnant Women_Ogijo 2	0	1	4	0
Passages coded are represented by colour (red being no passages coded, and the darker green representing the				

	Influence of experience in understandings of the HDP	Interpretations of HDPs related to elemental factors	Interpretations related to socio-economic factors	Interpretations related to supernatural and mythical factors
highest number of passaged coded to the associated theme) *The number of passages coded to each theme by transcript is also represented by the number listed in each cell.*				

Supplementary Figure 1. SPIDER framework.

S	**Sample**	• Pregnant women
		• Postparum women
		  • Mothers with chidlren under five
		  • Recently pregnant women
		  • Nursing mothers
		• Women of reproductive age

P **I**	**Phenomenon of Interest**	• Hypertension in pregnancy • Blood pressure in pregnancy • Pre-eclampsia • Convulsions in pregnancy • Eclampsia
D	**Design**	• Qualitiative • Ethnography
E	**Evaluation**	• Knowledge • Awareness • Perceptions • Beliefs

R	**Research type**	• Qualitative
		  • Focus group transcripts
		  • Focus group field notes
		  • Focus group images (*if applicable)*
		  • Focus group audio recordings (*if necessary*)

Supplementary Figure 2. Coding of analytic themes.