CHAPTER 1: INTRODUCTION

1. INTRODUCTION TO THE STUDY

In an attempt to meet the Millennium Development Goal 5 (MDG 5) of improving maternal health by reducing the maternal mortality ratio by three quarters by 2015 (Target 5A), South Africa made maternal death notification mandatory and established a National Committee on Confidential Enquiries into Maternal Deaths (NCCEMD) in November 1997 (National Department of Health. 1998). Despite these efforts, maternal mortality ratio is increasing in South Africa (Blaauw & Penn-Kekana, 2010).

An increasing maternal mortality significantly drops the Gross Domestic Product, hence reducing maternal mortality has a potential to improve the economic returns in that particular country (Kirigia, Oluwole & Mwabu, et al., 2006).Prevention of maternal deaths also benefits child health as preventing the death of a mother is an important intervention for child survival (Filippi, Ronsmans & Campbell, et al., 2006). These statements put the subject of maternal morbidity and mortality in the centre of this study, which is concerned with understanding patients‟ perspectives about factors that have contributed in them having experienced acute, serious maternal morbidities and being at risk of dying (being near-misses) and their opinions on how those could have been prevented.

2. BACKGROUND

Over 500 000 women of reproductive age die from multiple causes each year worldwide. Of concern is the fact that more than 99% of these deaths occur in developing countries. In a millennium summit that was held in New York in 2000, maternal health was identified as a major concern by 189 member states which were represented. A commitment was undertaken to reduce the maternal mortality ratio by three quarters between 1990 and 2015 (this has come to be

known as target 5A of Millennium Development Goal no 5, commonly referred to as MDG 5) In spite of the commitment and efforts to reduce maternal mortality, the world is still faced with a high rate of maternal mortality (United Nations Development Programme, 2008).

The NCCEMD makes recommendations every three years to decrease the number of maternal deaths (National Committee for Confidential Enquiries into Maternal Deaths, 1998). These recommendations are largely based on hospital records, assessed by the committee, which comprises of health workers. Although maternal mortality is considered a primary indicator of maternal health, valuable information about causes and contributing factors may be lost if the information is only collected from the health system side (patients‟ records), while information from the patients‟ side is not considered. From Patients‟ side; information collected from both patients and their records may be more reliable than information from a single-source, as it will allow cross-checking between the records and the information received from women. Barriers to effective use of maternal health services may then be better identified and eliminated.

In many cases mortality is the end result of severe morbidities and if intervention is done early there is a high possibility that mortalities may be prevented or reduced. In a retrospective study evaluating the treatment of women with eclampsia, timely referral and optimum management of patients were key in preventing mortality (Thapha, 2008). Identifying women who have suffered severe maternal morbidities and survived (near-misses); and exploring factors that contributed to those morbidities may assist in preventing maternal deaths by strengthening preventive measures.

3. PROBLEM STATEMENT

CEMD contribute to the effort made to decrease maternal deaths by identifying causes of death and suggesting recommendations. Although this is a valuable way of dealing with the problem,

the nature of the methodology used in CEMD does not allow access to information from patients‟ side. Studying maternal deaths only leaves a gap which can be complemented by information from the majority of cases where patients had severe morbidities but managed to survive. Much can be learnt from these patients, their stories, experiences and recommendations. Although CEMD analyses all maternal deaths that occurred in all health facilities; exclusion of women who had serious morbidities may restrict the discussion of what went wrong and how this might be avoided in future, with related strategies that need to be put in place to prevent further deaths. Important information that might strengthen the interventions may be missing in the CEMD report and without it; barriers to effective use of health care may not be adequately identified or addressed.

4. RESEARCH QUESTION

How do women who have suffered near-misses explain their experiences of factors associated with severe maternal morbidities and what recommendations do they have for prevention?

5. JUSTIFICATION

Most studies internationally and in South Africa that have been conducted around the concept of near-misses are only aiming at getting a better understanding or classification of women into near-misses (Mantel, Butchman & Rees, et al., 1998; Souza, et al., 2007). Information from studies of maternal morbidity can be used to complement studies on maternal mortality to inform policy and to recommend changes that may assist to decrease high maternal mortality. There is a need for near-miss studies to complement maternal deaths audit (Souza, Cecatti & Parpenelli, et al., 2007).

To complement the work of the CCEMD, this study gathers information from women in the Eastern Cape who had life-threatening maternal morbidity considered to be „near-misses‟ in

maternal health services. This approach where patients are interviewed allows a focus on the „why" and the „how" questions of what happened prior to, and during, the near-miss event instead of just the „what" question, which is largely tackled by the CEMD.

By bringing together literature about near-misses and maternal mortality and morbidity, on one hand, with literature pertaining to access barriers to reproductive health services on the other, the intention of this study is to situate the phenomenon of near-misses within a wider set of health system concerns about access to reproductive health services, thereby creating a conceptual link between the two.

6. DEFINITIONS OF NEAR-MISSES

A near-miss is a woman who nearly died but survived the complication that occurred during pregnancy, childbirth or within 42 days after delivery or after termination of pregnancy (World Health Organisation, 2009). There is no straightforward way of identifying a near-miss, with some authors focusing on single factors e.g. in a study by Mantel, et al. (1998) where a near-miss was defined as a woman who had severe organ failure; and other authors focusing on multiple causes, for example Souza, et al. (2007) investigated a combination of women who had organ dysfunction and those who had special procedures performed. They argued that women who were admitted in ICU and those who had special procedures like central venous access, echocardiography and invasive mechanical ventilation fell into the category of women who had acute severe morbidity. They found that hospital stay and the number of special procedures performed were significantly higher when the organ dysfunction based criteria were applied (Souza, et al., 2007).

A prospective study by Mantel, et al. (1998) identified near-misses by identifying organ systems that failed. Their study found a high percentage of ICU admissions (80.9%) and among the

special procedures performed the most common were central venous access, echocardiography and invasive mechanical ventilation. They also found that the number of special procedures performed were significantly higher when criteria using the organ-based dysfunction were applied. A systematic review conducted by Minkauskiene, Nadisauskiene & Padaiga, et al. (2004) discovered that different criteria were used in different studies to identify a near-miss but the most common included diseases such as severe haemorrhage, sepsis and hypertensive disorders of pregnancy. Regardless of the definition used, the special procedures performed and organ dysfunction are important issues to consider in near-misses. Information from different criteria identified in the literature, was considered. Related clinical criteria, specific interventions and procedures that have been performed were also used as pointers towards factors that define a near-miss. Pattinson & Hall (2003) argue that there should be a uniform agreement of the definition of a near-miss in areas with similar health care facilities, personnel and medical records.

For the purpose of this study a near-miss was considered to be a woman who had been admitted in ICU, a woman who had a special procedure like central venous access, echocardiography, invasive mechanical ventilation, a woman who had emergency hysterectomy, pulmonary oedema, eclampsia, sepsis, severe hypotension with haemorrhage, severe hypotension with signs of shock, and HELLP Syndrome (haemolysis, elevated liver enzymes and low platelet count) during pregnancy or within six weeks after delivery.

7. AIM OF THE STUDY

The overall aim of the study was to explore patients‟ experiences and perspectives of maternal near-misses and their opinions of how these could have been prevented

8. STUDY OBJECTIVES

- To assess the obstetric history of women who are classified as near-misses (including current pregnancies for those participants who are still pregnant)
- To explore participants‟ perspectives of factors contributing to near-misses (health systems, socio-economic, geographic factors, etc.)
- To explore participants‟ opinions of strategies that may prevent near-misses
- To explore participants‟ perspectives of quality of care and the preventability of severe morbidity in the health system

CHAPTER 2: LITERATURE REVIEW

A search of existing literature around the topics of near-misses, maternal morbidity, maternal mortality and other factors affecting access to, and utilization of, reproductive health service was conducted. Focus was on recent literature not older than 10 years from both South Africa and other countries to avoid outdated medical knowledge but in cases where there was no recent information, older literature was considered. A conceptual framework used by the World Health Organisation (WHO) - the AAAQ framework – was used to structure a review of access-related literature according to the availability, accessibility, acceptability and quality of services. By bringing together literature about near-misses and maternal mortality and morbidity on one hand, with literature pertaining to access barriers to reproductive health services on the other, the intention of this chapter is to situate the phenomenon of near-misses within a wider set of health system concerns about access to reproductive health services, thereby creating a conceptual link between the two.

1. MATERNAL MORTALITY

The big five causes of maternal death as in the previous report on CEMD remain non-pregnancy related infections, complications of hypertension, obstetric haemorrhage, pregnancy related sepsis and pre-existing maternal diseases (National Department of Health, 2009). Complications of hypertension and haemorrhage are some of the conditions included in the criteria for identifying a near-miss in this study.

Most middle and low income countries in the world are not on track to achieve target 5A of MDG 5. The average annual decline is less than 1% when it is supposed to be 5.5%. Eastern Asia is doing better with the average annual decline of 4.2% when Africa has an annual decline of less than 0.1% (World Health Organisation, 2008). Reports from different sources concur that

South Africa is not on track to achieve target 5A of MDG 5, of decreasing by three quarters Maternal Mortality Ratio by 2015. To achieve this goal, South Africa should by the year 2015 have decreased Maternal Mortality Ratio to 38 per 100 000 births. The 4th Report on CEMD reports that there has been a 20.1% increase in the number of deaths reported compared to the previous triennium. While the report states that the increase in Maternal Mortality Ratio may be due to increased notifications (National Department of Health, 2009; Blaauw & Penn-Kekana, 2010) report that there is some concern about the reliability of the data on Maternal Mortality Ratio for South Africa.

2. MATERNAL MORBIDITY

In a study that was conducted in four non-specialist hospitals in rural South Africa measuring causes of severe acute maternal morbidity and assessing the standard of care against management guidelines, approximately 65% of those causes were avoidable and the commonest organ systems involved were cerebral at 42% with the commonest obstetric diagnosis being eclampsia at 39% (Gandhi, Welz & Ronsmans, 2004). Douglas & Redman (1994) also found eclampsia to be a common condition which is responsible for a high proportion of maternal deaths. While prenatal care should allow identification and treatment of potential eclampsia (Partwardhan, 1995) and health care providers sometimes fail to respond to the warning signs evident long before booked women have eclampsia (Mwinyoglee, Amoko & Simelela, et al., 1996), Douglas & Redman (1994) report that eclampsia may occur without being preceded by warning signs.

3. REPRODUCTIVE HEALTH SERVICES AND THE AAAQ FRAMEWORK

Identification of high risk women should be done at the health facility so that they are given education about their medical conditions and are empowered to identify warning signs of serious

morbidity. The South African Constitution acknowledges and affirms the fact that every individual has a right to access health care, reproductive health included (South Africa, 1996). It is therefore important that reproductive health services are accessible to all women in need of the service.

According to Thiede, Akweongo & McIntyre (2007), accessibility of health services is multi-dimensional and comprises of different elements and should be assessed as such. Thiede, et al. (2007) define the three arms of access as availability, affordability and acceptability and they see them as interrelated elements that cannot be separated from each other. They define access as a form of interaction between the health system and the user of the service and their household. The WHO AAAQ Framework, a framework used in this study within the reproductive health cycle, emphasizes the importance of availability, accessibility, acceptability and quality of health services for the benefit of those who utilize them (Hunt & de Mesquita, 2010). Availability, accessibility, acceptability and quality of reproductive health services are serious issues that can contribute in lending consumers of health services in the near-miss situation. The focus of this study is more on the household, or demand side, as it attempts to establish factors that lend reproductive health consumers in the near-miss situation.

3.1 Availability of reproductive health services

Availability refers to availability for public consumption of adequate essential goods and services for health services (Hunt & de Mesquita, 2010). It also asserts that services should be accessed at the correct place and at the correct time whenever they are needed. It can be measured by the distance from the household to the facility, the availability of transport from the household to the facility, the availability of emergency or after-hours service, availability of staff, supplies and equipment and the interplay between the type of service and the needs of the

community (Thiede, et al., 2007). The WHO AAAQ Framework does not see availability as the responsibility of the Department of Health only but rather include other areas like the quality of roads leading to where the health facility is (Thiede, et al., 2007; Hunt & de Mesquita, 2010).

3.1.1 Availability of resources

In some instances, as was found in a study that was conducted in Mafikeng-Mmbabatho District in South Africa; although the physical distance may not be an issue, factors like the inadequacy of resources may be a problem and may limit use of those facilities (Pretorious & Greeff, 2004). This may discourage or prevent women from using the facilities and may be a limitation to the staff who want to render service of high standard.

3.1.2 Availability of after hour services

Most clinics only open during the day from 07h00 to 16h00 -a time when most women of reproductive age are either at school or working. These clinics close during the weekend causing a problem in cases when women would like to go to the clinic for reproductive health services and not miss going to work or school. In a study conducted by Nwokolo, McOwan & Hennebry, et al. (2002), young people wanted the clinics to run more frequently than they usually did and preferred to have the clinics open after school. In some cases, although the clinic is open patients are expected to come to the clinic in the morning. Adolescents using reproductive health services report that they would sometimes stop going to the clinic than to face angry nurses who would scold them for coming after school (Wood and Jewkes, 2006).

3.2 Accessibility of reproductive health services

Health services have to be physically and economically accessible to everyone without any form of discrimination (Hunt & de Mesquita, 2010). This includes being able to receive health information that can help prevent morbidity and mortality. Affordability of services, as means to access does not only consider service fees (something that uninsured pregnant South African women are exempt from), it also covers a number of issues like transport to the health facility and lost income as some women may have to leave their work. Families may also have to borrow money, sell their important assets or cut down on their important expenditure to afford health services (Gilson & McIntyre, 2005). Thiede, et al. (2007) also consider the availability of assets that can be easily translated to cash should the need arise to influence affordability. They also argue that affordability should also not be treated as a one size fits all as there is a vast difference in the income different people are taking home. This study intends to assess other forms of affordability like transport costs; not only in terms of service fees.

3.2.1 Distance and routes to health facilities

The Department of Health (DoH) has identified the need to have health facilities closer to the community as stated in the Alma Ata Declaration that primary health; as the first contact to health system should bring health care as close as possible to where people live (Dennill, King & Swanepoel, 1998). Having the health services brought closer to the households would not serve any purpose if the roads between those households and that health facility could not be travelled. In some cases where the services are not adequately close to the community, the DoH makes mobile health units available (Dennill, et al., 1998). The challenge with the mobile services is that they do not come as often as they may be needed by the community, leaving people stranded on some days.

Hamilton, Perlman & de Souza (1987) suggest that it is not only the presence or absence of the service that matters but also how far they are from where people live. Their study compared a group of women that booked for their deliveries early and regularly attended the antenatal clinic with those who did not book. They discovered that those who were not booked were poorer and of a low socioeconomic status and that the reasons that they did not attend the antenatal clinic was because of the expenses involved and that the mothers usually stayed outside the area during pregnancy (Hamilton, et al., 1987).

3.2.2Payment of user-fees

In its commitment and efforts to enhance equity and accessibility of health services in communities which were previously underprivileged, South Africa defied the option that most countries were taking in the early-1990s,and the state removed user fees on all maternal health services and for children less than 6 years of age in 1994 (Gilson & McIntyre, 2005).

3.3 Acceptability of services

Health services must be acceptable in terms of not only being respectful of medical ethics but also being gender sensitive and culturally appropriate (Hunt & de Mesquita, 2010). Acceptability is associated with the nature and the quality of the service rendered as perceived by the individual or the communities utilizing that service (Thiede, et al., 2007). The service may be seen as unacceptable if the health seekers do not receive the respect that they expected to get from the health facility. It therefore becomes important that the providers of health care should measure the degree of fit in terms of the services that they supply and the demand from women‟s side; as consumers of reproductive health services.

3.3.1 Health worker-patient relationship

The treatment that women get at the health facility also determines their future antenatal clinic attendance and their attitude towards health services. Abusive treatment experienced in health facilities may affect patients‟ utilization of health services and result in them not following the recommendations given during the pregnancy-education sessions (Greene, 2004).

In a study conducted in two facilities in Cape Town women reported that some nurses were kind but others were rude and impolite (Jewkes, Abrahams & Mvo, 1998). Most women in both of the facilities studied explained their experiences in health facilities as abusive and that of power, resulting in them attending the antenatal clinic only because of fear of punishment when they come for delivery if they did not book (Jewkes, et al., 1998). In contrast, nurses in the same study did not see their actions as inappropriate. The behaviour of nurses can positively or negatively influence utilization of reproductive health services. In Wood & Jewkes (2006), adolescents would rather stop their use of contraception than face scolding from rude and arrogant nurses. This study suggests that the quality of the interaction that women experience with providers in health facilities influences their interpretation of health services and in turn, their health seeking behaviour; and therefore points to the need for careful supervision of provider-patient interactions.

3.3.2 Culture and acceptability of reproductive health services

Culture also plays a role in the acceptability of health services. It is important that the health care providers be aware of cultural beliefs and practices in their communities so that they can wisely negotiate in terms of any new health practices that they need to introduce. In a study conducted by Mullick, Kunene & Wanjiru (2005), Zulu men whose cultural beliefs, like most Africans, are that family planning, pregnancy and childbirths are exclusively women‟s issues were introduced

to a practice where they had to accompany their partners to reproductive health clinics and to be with them during labour and delivery. Men were more willing to be part of other clinic services but were less willing to be part of their partners‟ labour and delivery. This may be because delivery is seen to be exclusively a women‟s territory which men are not supposed to be part of.

3.4 Quality of Health Services

Health services are to be medically and scientifically appropriate and of good quality (Hunt & de Mesquita, 2010). This will influence the outcome of pregnancy and will also positively influence women‟s health seeking behaviour. As previously stated, in a study by Wood and Jewkes (2006) adolescents who were utilizing reproductive health services ended up not coming for the service because of poor quality treatment they were receiving from nurses. Also, in Jewkes et al. (1998) some women became discouraged and reluctant to come to the health facilities because of poor quality of service characterised by rude and impolite nurses‟ behaviour. They ended up coming for antenatal care only because of fear of punishment when they come for delivery. A policy on Quality in Health Care for South Africa has been developed to ensure that people get high quality health information and that health system errors are prevented as much as possible to influence the health outcomes (National Department of Health, 2007).

4. HEALTH SERVICE UTILIZATION

4.1 Need for health services and health service utilization

Poor people maybe more vulnerable to illness and are at greater risk of poor health outcomes such as morbidity and mortality (Sauerborn & Adams, 1996; Kaye, Mirembe & Aziga, 2003); and cost, household income and women's employment status are some of the factors that can influence antenatal care utilization (Simkhada, Teijlingen & Porter, 2008). Higher levels of health seeking behaviour in richer communities may also be influenced by the fact that many can

afford medical insurance and access to generally well-resourced private facilities, unlike poorer communities who generally rely on public hospitals (Gilson & McIntyre, 2007). The richer urbanised areas in both public and private sector also have a better supply of health professionals compared to poorer rural areas. Contrary to the argument that the private sector may allow people shorter consultation time due to the for-profit nature of their business, in Gilson & McIntyre (2007), people in the lowest income quintile were allowed 5 minutes consultation time or less compared to those in the richest quintile who were given 15 minutes consultation time; possibly because poor people may have been seeking services from public hospitals which were busier than the private facilities.

4.2 Knowledge and health service utilization

Simkhada, et al. (2008) show positive correlation between maternal education, husband's education and utilization of antenatal care services. Educated people also have an added advantage of a better understanding of English; a language commonly used in educational materials in South Africa. Although education is important, antenatal clinic attendance (regardless of education) had a greater positive outcome in Ekwempu (1988) where the perinatal death rate was 44/1000 in booked uneducated women compared to 169/1000 in unbooked uneducated women. Booked uneducated women in this study may have only relied on information given at the clinic as they could not access and understand written information on reproductive health issues. In a study exploring women‟s experiences on use of maternal health services, most women expressed a concern that they were given inadequate information and were as a result unclear about the purpose of antenatal care and the number of antenatal visits required (Gatsinzi & Maharaj, 2008). For the reasons stated above, this study intends to explore antenatal clinic attendance and reproductive health knowledge.

4.3 Socio-cultural practices and health service utilization

It is a cultural practice in many areas that women take care of household chores and this may leave them with little or no time to attend to their health needs. In a study conducted by McCray (2004) where environmental factors and socio-economical factors that influence the use of perinatal health services in rural kwaZulu Natal were explored, daily activities like fetching water had a significantly negative effect on utilization of perinatal health services.

Cultural beliefs and ideas about pregnancy also had an influence on antenatal care use (Simkhada, et al., 2008); which may further have a negative effect on the outcome of pregnancy. Cultural practices that put men in a superior position and undervalue women, having women under strict male control, practices of wife seclusion which restrict women‟s access to medical care, high rate of female illiteracy, marriage at an early age and harmful traditional medical beliefs and practices were some of the factors contributing to maternal mortality (Wall, 1998).

4.4 Social support, community-based care and utilization of services

The involvement of important members of community such as parents and religious leaders is important in generating community involvement and support on reproductive health issues; especially when the users of reproductive health services are young people (Kesterton & Cabral de Mello, 2010). Kesterton & Cabral de Mello (2010) suggest that women‟s reproductive health issues should not only be women‟s concerns; rather, from a health service perspective, other family and community members should also be aware of what comprises good reproductive health and what constitutes an emergency.

Community-based maternity care in rural Bangladesh with low literacy rate proved to be beneficial where posting properly trained midwives at village level with means, supervision and proper back-up system like referral system greatly improved maternal survival and reduced

major causes of death (Fauveau, Stewart & Khan, et al. (1991). A similar study where midwives were posted in villages also showed a substantial 70% decline in direct obstetric deaths in contrast to no change in the control area. The decrease of maternal mortality is attributed to the functioning of the government hospital, where caesarean sections and blood transfusions were available but also, the authors acknowledge that greater use of midwives, referrals and proper transport, and better service conditions had a tremendous contribution to maternal mortality decline (Maine, Akalin & Chakraborty, et al., 1996). A systematic review conducted by Kidney, Winter & Khan, et al. (2009) also concluded that community-level interventions aimed at improving perinatal care practice can contribute to reduced maternal mortality.

5. USE OF FAMILY PLANNING SERVICES

In South Africa, family planning services are free for all age groups and people who do not want to fall pregnant are expected (by the health system) to utilize these services. There may be an association between wanting the pregnancy and use of antenatal care. In a study conducted by Erol, Durusoy, & Ergin, et al. (2010) there was less antenatal care in women with unwanted pregnancies, there was also less iron and vitamin supplementation intake compared to women with wanted pregnancies. Contrary to these findings, in Barrick & Koenig (2008) initiation of care was not delayed in women who reported their pregnancies unplanned. These studies show a conflicting view on whether the desire to fall pregnant or not influences utilization of antenatal care services.

6. ANTENATAL CLINIC ATTENDANCE

Antenatal clinic attendance is important for pregnant women as this is a direct platform where women are given education about their pregnancies, risk factors and the things that they have to do and avoid during pregnancy and when they are in labour. Late (second and third trimester)

antenatal clinic attendance and failure to attend antenatal clinic is one of patient-oriented problems that results in high maternal morbidity and mortality (National Committee on Confidential Enquiries into Maternal Deaths, 2000).

Antenatal clinic attendance is also associated with positive perinatal and neonatal outcomes. In a study conducted in the Black South African population in Durban, 82% of mothers who delivered live babies attended antenatal clinic while 60% of mothers who experienced perinatal death did not attend the antenatal clinic. The study also found that many of the mothers who were at highest risk failed to attend the antenatal clinic (Menown, Archbold & Wills, 1993). Additionally, antenatal booking was associated with higher infant birth weight. Women‟s lack of knowledge about the importance of antenatal care, their perceived health needs, the relationship that they had with nurses, their own financial situation and the availability of transport may also contribute to poor antenatal clinic attendance (Abrahams, Jewkes & Mvo, 2001).

Establishing the expectations of consumers of reproductive health service is important so that the service can be improved to encourage service utilization. In the case of antenatal services, very few studies have attempted to understand what the users of antenatal service want. Butchart, Tancred & Wildman (1999) found that information, support, organization of services, attitudes of the health team, contact with other mothers, practical assistance and other services were important for women in their post-natal period. These needs, although expressed as postnatal needs may indicate that women need support and good care whenever they visit a health facility.

Women view the repeated attendance of antenatal clinic as unnecessary as they do not perceive any significant health threats in pregnancy but only view delivery as a health risk. This results in them only having one visit just to get the antenatal card, seen as something that will allow them access to the clinic when they are in labour (Myer & Harrison, 2003).

7. POSTNATAL CLINIC ATTENDANCE

Postnatal clinic attendance assists in ensuring that there were no unnoticed pregnancy complications; that the woman continues with family planning and that the baby is taken good care of. The reason most women attend antenatal and postnatal clinic is ensuring a healthy mother and a healthy baby (Titaley, Hunter & Heywood, et al., 2010). Postnatal care is also important because symptoms of postnatal depression, puerperal sepsis and other complications that occur after delivery may be noticed during this period.

8. CONCLUSION

The literature above clearly shows the complexity of reproductive health services with regard to their availability and use by women in need. Health system issues and the societal factors form major barriers that warrant immediate attention. Literature shows that reproductive health services are not as accessible as they should be; that involvement of other family members or respected members of the community can contribute to improved practices and health seeking behaviours; and that an improvement in health system management, especially at community level can result in an improvement in Maternal Mortality Ratio. There is, however, no information on perceptions of near-misses in South Africa‟s reproductive health services; leaving a research gap that this study intends to explore. Literature also does not explore women‟s understanding of warning signs for serious morbidities and how women respond to them to prevent near-misses or death. There is also no adequate information on women‟s early identification of their signs of pregnancy and timely attendance of ante-natal care. It is therefore important for each country to guard against known issues that cause complications in reproductive health, put in place preventive measures and deal with these issues as soon as they emerge but also identify issues unique to those particular countries and regions.

CHAPTER 3: MATERIALS AND METHODS

This chapter introduces the reader to the methods followed in identifying the study participants, the participating health facilities, the actual interviews, the way data were analysed and the experiences encountered in terms of conducting this study.

1. STUDY DESIGN

This study is of a qualitative nature and draws on in-depth interviews and field observations. It follows a retrospective format as near-misses were identified after they had occurred and the study went back to identify the contributory factors from the perspective of the women involved. Qualitative design allowed the researcher to study this medical and social phenomenon in situ where both the content and the context were important for making sense of the entire „near miss experience" (Denzin & Lincoln, 2005).

Case studies were chosen because they allow for a research focus on the "why" and the "how", rather than the "what" questions (Yin, 1994); in this study: *why* participants landed in the near-miss situations (the what) from their perspectives and *how* the context (the health system and other social systems, including family, friends and partners, as well as the physical, geographical, political and economic conditions surrounding and influencing the medical event of a near-miss) contributed. Case studies are defined by Yin (1999) as research studies where there is an intense focus on a single phenomenon within its real life context and they work well where the boundary between a phenomenon and its context is not clear. Because a near-miss experience (the phenomenon) is difficult to separate from the context in which it occurs, a case study approach seemed particularly well-suited to this study.

1.1 Definition of a case

When conducting case study work, Yin (1999) warns that the most "difficult step is to define the case" (pp.1214). Case studies can take the form of singular or multiple cases, and cases can exist within cases, depending on where the boundaries are drawn. It is therefore important to carefully and explicitly define „the case". This study comprises a singular case which is „the near-miss experience" from the patient perspective and includes opinions on how it can be prevented or corrected, as well as the actual event and surrounding circumstances, as narrated by women who have been through such an experience".

Yin (1994) defines the unit of analysis within case study research as the source of information which may be the individual or the organisational document; or interactions, dialogues, incidents or settings (Giacomini & Cook, 2000). In this study, the unit of analysis was the stories told by individual women in the ELHC who experienced near-miss incidents. Their stories were collectively built into the case of this study: a near-miss experience from the patient perspective. Having defined the case, a case study protocol was developed to guide the research process from the outset, including study setting, through to recruitment and interviews, and onto the data analysis.

2. SETTING OF THE STUDY

Participants were initially identified and interviewed at the ELHC, a tertiary hospital complex comprising of two hospitals (A and B) 23 km apart. It is in East London, at the Buffalo City sub-district in Amathole District in the Eastern Cape Province in South Africa. Purposive sampling was applied in selecting ELHC because it is a tertiary hospital where most near-misses should be found including those referred from smaller hospitals. Therefore, although ELHC is in Amathole District, near-misses found in the hospital were also from Chris Hani and Ukhahlamba Districts

(districts which do not have a tertiary hospitals) as these areas refer patients to ELHC.

Follow up interviews were conducted in venues chosen by participants themselves, most of which were their homes. However, three who also intended to have second interviews conducted in their homes were interviewed telephonically because they were not staying in their homes anymore and could not make it to a physical venue for a face-to-face interview. The second interviews allowed women to be interviewed in their own environment, allowing a relaxed atmosphere where the researcher could also understand a picture of each participant in a related context, Observation notes were taken to complement the interviews and allow for reflection on the setting and context, as well as the content of the interviews.

3. POPULATION AND SAMPLING

The target population was women who qualified to be defined as near-misses in the Eastern Cape Province and the accessible population was near-misses admitted at ELHC from all areas referring to ELHC at the time of the study. Purposive sampling was used in selecting study participants because only those women fitting the definition of a near-miss were recruited to participate in the study and ELHC was selected because it is a referral hospital where near-misses are likely to be referred. As this was a qualitative study, sampling did not follow a statistical logic but instead followed a conceptual logic and according to a certain purpose, which in this study was to examine the experience of a near-miss from the perspective of women who had personally been through such an experience. Therefore, data were collected until saturation was reached in terms of emerging themes around the near-miss experience, irrespective of the number of participants (Alasuutari, Bichman & Brannen, 2009). As researchers do not have to predetermine the study population in statistical terms (Giacomini & Cook, 2000), near-misses were recruited until the point of saturation was reached after the ninth participant. The point of saturation therefore determined the sample size of nine near-misses.

4. INCLUSION CRITERIA

No consensus had been reached on the criteria for identifying near-misses at the time of this study but the experts in this field are coming up with recommendations of how to bring about consistency on the topic (Souza, et al., 2007). In this study women who were considered eligible were those who met one or more of the following criteria:

women who had been admitted in ICU,

women who had a special procedure like central venous access, echocardiography, invasive mechanical ventilation,

women who had an emergency hysterectomy, pulmonary oedema, eclampsia, sepsis, severe hypotension with haemorrhage, severe hypotension with signs of shock, and HELLP Syndrome (haemolysis, elevated liver enzymes and low platelet count) during pregnancy or within six weeks after delivery were considered near-misses.

5. EXCLUSION CRITERIA

Women who were less than eighteen years old, who were in severe pain or not conscious enough to fully understand that they were participating in a research study were excluded. In one incident, a participant was in severe pain and suffering from the effect of anaesthesia, therefore recruitment was postponed for another day when she was fully conscious and stable enough to enter into the discussion, understanding that she was participating in a research study.

6. DATA COLLECTION

Near-misses were identified by the researcher from the admission books in wards admitting sick pregnant women, women in labour and women who had delivered. Patients‟ records were used to confirm the diagnosis and check if women met the criteria of the near-miss. A poster giving

information on the study and the eligible participants was left in the wards as a reminder to the nursing staff about the study so that they could assist in identifying eligible participants.

Data collection for both phases of the study took place from 1st April to 30th September 2009, with at least three months period between the first and the second interview. Data were collected through two in-depth interviews with each participant, with the first interview taking place at the ELHC and a follow-up interview occurring at participants‟ homes or telephonically (as described in the setting above). Interviews lasted forty five minutes to one hour. A case study protocol; a tool considered by Yin (2004) to be an important aspect of case studies was used to provide prompts to guide the interviewer on which areas to cover during the interviews. Additionally, information was also collected from field observations for triangulation with the interview data because multiple sources of data add methodological rigour to the study (Giacomini & Cook, 2000).

6.1 Content of the interviews

Following the reproductive health cycle, each woman‟s obstetric history and circumstances around each pregnancy and delivery (in cases where women had more than one pregnancy) were explored through the interviews. As target 5B of MDG 5 is to achieve by 2015 universal access to reproductive health, contraception is one of the important indicators for achieving MDG 5 (World Health Organisation, 2008). Taking all pregnancies into consideration helped to compare different situations‟ especially access factors around different pregnancies, and the pregnancy outcome. Interviews also sought participants‟ experiences on factors that contributed to them being near-misses. They further explored patient-centred factors and health system related factors and some recommendations that they thought could improve the health system.

Demographic information was gathered and this provided an idea of geographic location

(defined as rural, urban and peri-urban), the socio-economic status and the type of family that the woman came from. Behavioural patterns and societal and family reactions towards these pregnancies and deliveries were sought. The second interviews were conducted at least 3 months after the first interviews and they followed the same pattern as the first interviews but were also used to fill in the gaps on issues that were not clear during the first interviews.

6.2. Interview Process

6.2.1 Pilot

Interviews were piloted with two participants fitting the definition of a near-miss to test the case study protocol after permission was granted by the Provincial Department of Health and the hospital managers. Those women who participated in the pilot study were not included in the study. The pilot study did not lead to major changes in the case study protocol but the way some of the questions were asked and the flow of the questions was altered.

6.2.2 Recruitment

A total of the first ten eligible patients were recruited. Of those, nine gave written consent to participate and one refused. Additionally, two potential participants fitting the medical definition of a near-miss could not be recruited because they were less than 18 years old.

6.2.3 Saturation

A point of saturation was reached by doing preliminary analysis after each interview, adding new cases until data were fully representative of a full range of constructs (Starks & Trinidad, 2007). Preliminary analysis also assisted in directing the next interviews and coming up with inductive codes.

6.2.4 Data management

The interviews were tape-recorded and transcribed and observation notes were kept. In cases where there was any contradiction between verbal and non-verbal communication, clarity was sought from the participants.

6.3 Trustworthiness (Reliability and validity)

For interpretive research, trustworthiness of the researcher and the research are key in generating research rigour necessary to authenticate credibility of the research study (Gilson, Hanson, Sheikh, et al., 2011). For interpretive research validity is considered to be more of a moral issue taking into consideration how respectful the enquiry was carried, and how persuasively the arguments were developed rather than normative methodological criteria and abstract procedural rules (Angen, 2000).

Qualitative research gives insight about real social and personal experiences and therefore does not aspire to be „objective" or follow a positivist framework (Giacomini & Cook, 2000). Validity in interpretive research is the confidence placed in a study rather than certainty. Angen (2000) suggests that plausibility, relevance and importance of the topic be considered when evaluating a study and that reliability can be achieved by among other things using standardized methods for taking field notes, transcribing taped interviews and having peers review data analysis.

In this study, interviews were piloted with two participants and this assisted with ensuring that the intention of the questions was clearly conveyed and understood in the same way between researcher and participant. To ensure robustness of this study, use of relevant framework and insightful and detailed fieldwork were done in conducting this study (Yin, 1999). During the interviews, an active process of continuously validating information and continuously checking for answers to identify issues for further follow up was followed. In some cases the way

questions were asked was revised in response to the way participants responded to certain questions to guide data collection (Gilson, et al., 2011). Conducting the interviews twice was to ensure validity and credibility of the information that was received from the participants. Second interviews also allowed women time in a relaxed atmosphere to reflect on the service they received. Coding of raw data was also done independently by two people who are from different fields of work (the researcher and the supervisor) to ensure accuracy.

6.4 Reflexivity

Assumptions can influence the interpretation of information received from research participants (Gilson, et al., 2011). Conscious reflexivity, as a way of establishing trustworthiness was introduced into data collection and data analysis as the researcher did not want her prior knowledge and previous experiences to prevent new, perhaps unexpected or different, themes from emerging. Reflexivity refers to sensitivity to the way in which the research and the research process can influence data (Pope, Ziebland & Mays, 2000). As the researcher and interviewer, I took note of issues that could influence my understanding and interpretation of data like my experiences as a health professional and my previous experiences around my own delivery in a public hospital and my experiences of the processes in the reproductive health system. I continuously challenged my thoughts whenever these issues emerged and confirmed with the participant to ensure that I understood what she was saying. This process of reflexivity continued when the audio tapes were listened to. Clarity was then sought on relevant issues during the second interviews. Although reflexivity does not bring about (or aim to bring about) objectivity of data collected, it accounts for the researcher‟s values, beliefs, knowledge and the possible biases (Cutcliffe, 2003).

7. ETHICAL ISSUES

The following research ethics principles were observed:

Permission to conduct the study: Ethics approval was received from the University of Witwatersrand ethics committee (see annexure 4) followed by permission to conduct the study granted by the Eastern Cape Provincial DoH as the study was conducted in the Eastern Cape Province (see annexure 5). ELHC did not find anything unethical about the study and granted permission for the study to be conducted (See annexure 6). Permission to conduct the interviews was also sought from the operational managers of the wards where the women who participated in the study were admitted.

The consent: Prospective participants were informed about the study, given the information sheet to read, allowed time to ask questions and voice out their concerns and were then invited to participate. All participants were informed of their right to refuse to participate in the study or to withdraw at any given point. The information sheet and consent forms were in English and Xhosa (see annexure 2 and 3 respectively) as these were the languages commonly used in the study-area. After the participants‟ concerns and questions were addressed, those who agreed to participate were requested to sign the consent form. A separate consent form was signed to tape record the interviews.

Respect for persons: Patients‟ rights have to be protected as they have diminished autonomy by virtue of being admitted in hospital and under the care of „expert‟ medical staff. In this study, participants were informed of their right to refuse to participate in the study without being prejudiced, their right to refuse answering some questions and to withdraw from the study at any moment without having to justify their actions.

Privacy and confidentiality: Interviews were conducted in closed private rooms and data were

collected by the researcher and no research assistants were used. In one instance where the nurse entered the interview room during the interview, the interview was put on hold for the purpose of privacy. Information given was kept confidential and only the research team was allowed to access it. Participants‟ names were only known to the researcher - names used during data analysis and in the write-up are pseudonyms. A copy of participants‟ names with the matching pseudonyms is kept in a locked file. The taped information is also locked away and will be kept for a period of 5 years before being destroyed.

Freedom from harm: There was no physical harm expected from the study although the interviews were thought to have a potential to evoke negative memories for some participants. During her interactions with the participants, the researcher ensured that the participants were free from harm by observing their reactions to questions and checking with them if the questions were not too sensitive. At that point, they were reminded of their right not to answer questions they were not comfortable with. Women who were in pain and not fully conscious to understand that they are taking part in research were excluded, however if their condition improved they were recruited to participate. Two participants who became emotional during the second interviews were referred for counselling

Justice: Participants were fairly selected on the basis of whether they qualified to be categorized as near-misses. All the participants who were eligible were recruited. The rights to privacy, anonymity and confidentiality have been observed throughout. To protect children and vulnerable groups, participants were women 18 years old or older who were mentally sound and fully conscious at the time they were recruited to participate in the study.

8. DATA ANALYSIS

In analyzing qualitative data from the interviews, a combination of deductive and inductive coding was done. In inductive coding no prior information was used to code; rather coding emerged from the data and was grounded in the narratives of the participants. In deductive coding, „prior" information, that is, theory based on other studies and the researcher"s own medical knowledge and experience as a health professional in the Department of Health was used to assist in coding the findings (Pope, et al., 2000). Integration of data-driven codes with theory-driven codes in a dual inductive-deductive approach allowed for the emergence of themes from data while also acknowledging a wider intellectual framework based on the existing literature (Fereday & Muir-Cochrane, 2006).

Preliminary coding was done independently by the researcher and her supervisor. The initial codes were then compared and a coding framework was agreed upon before the codes were finalised. Mostly deductive coding was influenced by the reports on CEMD and research studies. The four conditions in the AAAQ framework (availability, accessibility, acceptability and quality) were assessed within the reproductive health cycle (see fig. 3.1) as a framework for data analysis. Factors in the cycle were assessed on whether they comply with the framework or not. The reproductive health cycle was used as a device around which women could build their narratives and also to contextualize the near-miss event during data collection and during data analysis. Field notes were also used to strengthen information received or to show contradictions between data collected during interviews and field observations.

Exploring contraception use was used as a starting point towards establishing the decision-making power that women have and their approaches in accessing health services; which may or may not continue into antenatal care. It could also be linked to the outcome of the pregnancy and related-risk factors (for example second, third trimester or no attendance of antenatal care) in the

case that a pregnancy is unwanted; something that theoretically could have been prevented with contraception use. It was also drawn on as an avenue for exploring the access barriers in reproductive health services, as set out in the AAAQ framework.

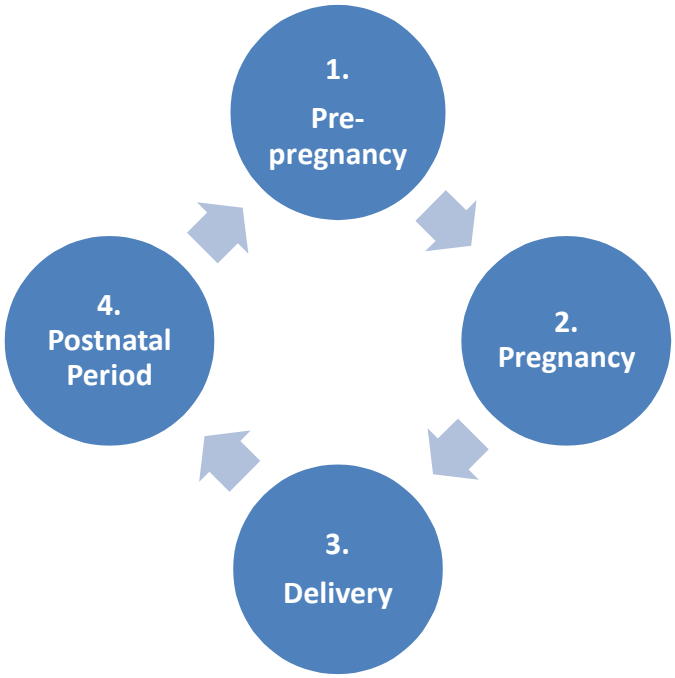

Fig. 3.1: A reproductive health cycle showing the different phases followed in data collection and data analysis

Codes were developed, covering the following:

Demographic characteristics of participants: age, gravidity (number of pregnancies), parity (number of viable babies delivered), educational attainment, home setting (rural or urban), their role at home, age of partner.

Reproductive cycle of the participants:

Pre-pregnancy: Use of contraceptives: Whether the pregnancy was planned or unplanned, their knowledge about contraceptives, knowledge about signs of pregnancy, attitudes and practices around family planning

Pregnancy: Knowledge, attitudes and practices around pregnancy, experience at the local clinic

Delivery: Near-miss experience: accessibility of services, social networks and the role of social networks, experience at the tertiary hospital

Post-delivery: Post-delivery experiences, perinatal counselling, postnatal care, perceptions on the reproductive health services, opinions and recommendations.

The following codes emerged from the information that was received from participants:

Warning signs before the near-miss experience: These were used after discovering that the first few participants did not experience or did not recognize the warning signs as serious messages and did not act immediately.

Routes and roads to the local clinics also emerged after one participant mentioned that they were afraid to go to the clinic because the route to the local clinic was not safe.

Availability of postnatal services: This emerged when one participant cried during the interview, stating that she does not even know what caused her to be ill and whether she was going to be ill again.

The researcher then coded the full text. The data were analysed using the MAXqda2 qualitative software package and a MAXqda2 software expert from the University of Witwatersrand was consulted to assist.

8.1 Development of themes

Themes were developed from the codes that were done independently and agreed upon by two people from different backgrounds (the researcher and her supervisor). A step by step analysis from quotes from raw data was followed to demonstrate how the themes were developed to

ensure that interpretation made from this study is from data received from participants, using inductive coding (Fereday and Muir-Cochrane, 2006). Themes were developed from the codes through clustering together preliminary codes which were built into patterns which were further refined into key themes. These are discussed in the results chapter.

9. DISSEMINATION OF FINDINGS

The findings of the study will be available in the University of Witwatersrand and will also be made available in the institution where the study was conducted. A copy of the study will also be submitted to the Eastern Cape DoH. Options to publish the study in a recognized peer-reviewed journal as a journal article will be considered. The findings of the study will also be shared in conferences.

CHAPTER 4: RESULTS (Part 1)

1. CHARACTERISTICS OF PARTICIPANTS

The ages of participants ranged from 18 to 29. All participants had one pregnancy (the current one) except for one who was in her third pregnancy, having lost her second pregnancy. Five participants were from rural areas whilst two were from urban and two from peri-urban areas. Seven women were single and two were married. Educational attainment ranged from grade 7 to grade 12 plus 1 year tertiary education. When defining their socio-economic status most participants reported that they were either managing or had adequate financial support, although three reported that they were struggling, with no one working in one family, one family having to sometimes borrow food from neighbours and another family relying on pensioner‟s grant which was not enough for the entire family. Table 4.1 gives the demographic characteristics of these women.

Table 4.1: Demographic characteristics of participants

Name (pseudonym to protect identity)	Married/ Single	Age	Rural/ Urban/ Peri-urban	Gravidity, Parity	Education	Pregnancy Outcome
Zipho	S	20	Urban	G1P1	Grade 11	Alive
Anda	M	29	Peri-urban	G1P1	Grade 11	Alive
Noluthando	M	24	Peri-urban	G3P2 (1Alive)	Grade 13	Pregnancy 1= Alive Pregnancy 2=Miscarriage Pregnancy 3=Died
Nontombi	S	23	Rural	G1P1	Grade 11	Alive
Nomfezeko	S	18	Rural	G1P1	Grade 11	Alive
Zimbini	S	18	Rural	G1P1	Grade 10	Alive
Thuletu	S	27	Urban	G1P1	Grade 7	Alive
Zodwa	S	21	Rural	G1P2	Grade 11	Alive
Emma	S	22	Rural	G1P1	Grade 11	Alive

Gravidity: Number of pregnancies, Parity: Number of viable babies delivered. The type of household (rural, urban and peri-urban) was as defined by participants. Names have been changed to maintain confidentiality

2. ACCESS AND BARRIERS ACROSS THE REPRODUCTIVE HEALTH CYCLE

2.1 Pre-pregnancy period

A number of factors influence women‟s actions around falling pregnant. A major element explored in this phase was the utilization of contraceptives and family planning services.

2.1.1 Use of contraceptives

The respondents were asked to talk about their use of, and experience with contraceptives. All women reported that they had previously used contraception, mostly the injection, which they got at their local clinic on regular bases. Some also used condoms with their regular partners. Married women and one single older woman (27 years old) reported that their pregnancies were wanted. The other six single women reported that their pregnancies were unwanted however, their use of contraceptives was erratic and some stopped using contraceptives at all. Age, socio-economic stability, educational attainment or location did not seem to influence use or non-use of contraceptives. The reasons why these women failed to use contraception are explored below.

2.1.1.1 Beliefs about susceptibility to pregnancy

Older women reported that their pregnancies were wanted while lack of adequate knowledge on how contraceptives work contributed to unplanned pregnancies of younger women who did not use contraception because they did not think they could fall pregnant.

Zodwa did not think she could be pregnant although she was not on contraceptives. She was not clear as to when the contraceptives were supposed to „wear off‟ from her system after having stopped taking them.

I: Why did you not think that you could fall pregnant?

R: It‟s because I was using contraception before and I did not know that it would take such a short time for the injection to lose its effect. (Zodwa, 21, Single, G1P2)

Noluthando was asked questions around her non-use of contraceptives and why she thought she could not be pregnant regardless.

R: I think it is because even when I was having a boyfriend previously I was sexually active but I did not fall pregnant although I was not using contraceptives. (Noluthando, 24, Married, G3P2)

Some women thought that the contraceptives (that they were no longer taking) were still effective as they were not having their menses; and therefore did not think they could fall pregnant.

Deliberate non-use of contraceptives was sometimes attributed to fear of the "side effects of using contraceptives for a long time". Nontombi thought she was still protected and thought she might end up being infertile if she used contraceptives for a long time.

R: I was thinking that because I was not having my menses I was still having a lot of an injection in my body. I was worried because the injection blocks one sometimes.

(Nontombi, 23, Single, G1P1)

One participant mentioned the fact that she did not think she was at risk of falling pregnant because her partner told her that he would not make her pregnant.

R: My partner told me that he would not make me pregnant and he said even if we do not use a condom, I will not be pregnant.

I: and you believed him?

R: Yes I thought that was true. I thought that there was something that he was told that made him think that he would not make me pregnant. (Nomfezeko, 18, Single, G1P1)

2.1.1.2 Unavailability of family planning services

The distance to health facilities was a challenge for most participants irrespective of whether they lived in rural, peri-urban or urban areas. In many cases, women had to travel long distances to their local clinics. The safety of routes to the local clinics and times when the clinics were open affected a number of participants. Only one participant staying in a rural area reported that the clinic was close-by and one in a peri-urban area explained that "it was not too far" (although she did not say that the clinic was close). All other participants used phrases like "far", "very far", "too far" and "there is no clinic where I stay" to define the proximity of the clinics to where they lived.

R: It is very far, it‟s in another area

I: How much time do you take to travel to the clinic?

R: You see, if I leave here at 08h00, I arrive at the clinic at 09h30 (Nomfezeko, 18, Single, G1P1)

Distance (with related transport costs) to the local clinic was one of the things that Emma found unsatisfying about her local clinic.

R: It is too far. We walk or we have to pay. It is R6

I: Is it R6 to go and R6 to come back

R: Yes (Emma, 22, Single, G1P1)

When Zimbini was asked why she stopped going to the local clinic for contraception, in addition

to stating the distance as a problem, commented about the **safety of routes to their clinic**:

I: Do you get them (taxis) close to where you are?

R: Yes. But when they go; moss the clinic is that direction. When they come back they sometimes take a different route and they drop you far. And there is this thing about body parts. The thing about people whose body parts get amputated.

I: Oh! What do they do with the body parts?

R: They amputate them and they exchange them for quantums (Minibus taxis)

I: So they drop you far away. Even when you come back during the day? Do the body parts get taken even during the day?

R: Anytime (Zimbini, 18, Single, G1P1)

Moving to a new location also contributed to access barriers. Nontombi who moved to Johannesburg could not go to the clinic for contraceptives because she could not speak the language used in the clinic.

R: The ones in Johannesburg are close but there are no Xhosa speaking people. I would not know where to queue if I went there

I: Have you ever been there and realised that they do not understand your language?

R: We took one of my siblings to that clinic and when we were asking questions they did not understand what we meant.

I: And you did not have anyone to accompany you who could speak the language?

R: No (Zimbini, 18, Single, G1P1)

Being new in an area, not knowing where the clinic was, being told that the clinic was far, and not knowing people in the neighbourhood who could accompany her were reasons Zodwa did not go for contraception. She was asked if she would go to the clinic if she knew where it was even if it was far.

R: No, I would go if I knew where it was. If only I could find someone who could take me to the clinic, I would go but the problem is that there are no contraceptive services during the weekend (the only time that her partner was available to accompany her). They are only during the week days (Zodwa, 21, Single, G1P2).

In a number of cases there were multiple factors which contributed to participants not using contraceptives. In Nontombi‟s situation, the contributing factors were the **distance to the clinic** and **the influence from friends**, as even when she came back from Johannesburg, she did not go to the clinic for contraceptives.

R: No, the reason I did not use contraception was because… the clinic is far and you travel a long distance to go there. I used to ask people to accompany me to the clinic and people would say they do not want. They used to ask if there are still people who use contraception and I would say "yes it‟s me". They would just dismiss me. (Nontombi, 23, Single, G1P1)

2.1.1.3 Side-effects of contraceptives

Cessation of menses, as one of **unwanted side-effects of some contraceptives**, discouraged some women from using them irrespective of whether they wanted to fall pregnant or not. They found the cessation of menses confusing. Some thought that the absence of menstruation meant that it was still the effect of contraceptives and they therefore thought it was safe to be sexually active without contraception. Others stopped because of the side-effects more generally.

R: I was using an injection but it stopped my menses

I: You did not like it when your menses were stopped?

R: Yes. It was making me feel dizzy and I stopped.

I: You thought it was the injection that made you dizzy?

R: Yes

I: Did you go to the clinic to report?

R: No I didn‟t (Emma, 22, Single, G1P1)

2.1.1.4 Perceived side-effects of contraception

In addition to known side-effects of contraception, perceived side-effects were also a reason for some participants not using contraception. For example, there was **a perception that contraceptives cause people to be infertile if used for a long time**.

R: …. and at the time I was also not having menses and people used to say that the injection has a way of sterilizing you if you have used it for a long time. (Zimbini, 18, Single, G1P1)

2.1.1.5 Succumbing to partner's wishes to have a baby

Pressure from partners seems to have contributed to some of the women falling pregnant regardless of their age, marital status and socio-economic status. Although these women may have refused a number of times, their partners seem to have put some kind of pressure on them. Emma reports that her partner wanted a baby. From the discussion below, it seems as if his numerous requests contributed:

I: Did you want to have a baby?

R: No, it‟s him who wanted a baby…he was pushing me…saying we must make a baby and I was telling him that I was not ready. (Emma, 22, Single, G1P1)

Zodwa also had pressure from her partner who was asking for a baby:

R: It was a long time that he has been asking for the baby. But I did not agree because I was studying. So I took that it (making her pregnant) was deliberate. I think he was happy

I: Why do you think he was happy?

R: Because he has been asking for this for a long time. (Zodwa, 21, Single, G1P2)

Although these women report that they did not want the pregnancies, their partners seem to have appreciated the pregnancies from what these women reported as their partners‟ responses to the news about their pregnancies:

R: He said Thank you. (Emma, 22, Single, G1P1)

R: I think he was happy. (Zodwa, 21, Single, G1P2)

R: He was boastful. (Zimbini, 18, Single, G1P1)

The interviews and information gathered during the field observation showed that teenagers were not comfortable talking about circumstances resulting in their pregnancies. This was noticed through moments of silence when they were asked why they fell pregnant or whether they planned to have babies. There were no such silences during other parts of the interview. Similarly, older women did not seem to find it uncomfortable to talk about the circumstances surrounding their pregnancies.

2.2 Pregnancy period

This phase covered a period from when women started experiencing the symptoms of pregnancy, suspected that she might be pregnant or heard rumours that she might be pregnant (whether at that time they knew that they were pregnant or not), to a period just before delivery or the near-

miss event. This section explores the use of antenatal services, barriers experienced by the participants and other contributing factors. It covers mostly antenatal services as this is the main site of interaction between the patient and the health system and explores challenges that women go through to access this service are also explored.

2.2.1 Delay or failure in attending antenatal clinic

2.2.1.1 Failure to recognize the signs of pregnancy

Most of the women interviewed presented only during or after the second trimester at the antenatal clinic. The reason commonly given was that they did not know that they were pregnant as did not recognize cessation of menstruation as a symptom of pregnancy. They reported that when they were on contraceptives and immediately after, they were not menstruating although they were not pregnant. This delayed them from going to the antenatal clinic. In the case of one woman, she only found out that she was pregnant when she went to hospital during her near-miss experience. When asked what made them eventually suspect that they might be pregnant, the majority reported symptoms such as feeling tired, feeling dizzy, having a big abdomen or feeling something moving in the stomach.

Emma reported that it was only when she had dizziness and her tummy started showing that she thought she might be pregnant. In her case, the confusion seems to have been caused by the fact that she had amenorrhoea (absence of menstruation) due to contraception and she could not differentiate that from amenorrhoea caused by pregnancy. The conversation below occurred after Emma reported dizziness and a tummy being big as her first hint that she might be pregnant.

I: If someone could not have dizziness and vomiting and the tummy not showing, is there anything that would make her think that she is pregnant?

R: Cessation of menses

I: Did that not happen to you?

R: No because when I was using an injection the menses just stopped.

I: So that is the reason that cessation of menstruation could not be a hint that you were pregnant.

R: Yes (Emma, 22, Single, G1P1)

Similarly, not everyone knew about the relationship between pregnancy and the cessation of menses. Nomfezeko did not know that someone who is pregnant does not have menstruation. It was only when her mother suspected that she might be pregnant and asked when last she had her menses that she became aware that there was an association between menstruation and pregnancy.

R: I did not know anything about cessation of menses (as a symptom of pregnancy). I only noticed that I was not having my menses.

I: When did you know that the person who does not have menses may be pregnant?

R: I heard from my mom. She asked me if I was having my menses. I said "No I am not". She said I should go to the clinic. I went to the clinic and I was told that I was pregnant (Nomfezeko, 18, Single, G1P1)

Anda also did not think that she might be pregnant. It was only when she had stomach-ache and had to go to the doctor that she was told that she was pregnant.

R: I only became aware of the pregnancy on the third or fourth month because I was having abdominal pains and it started on the third month and I used to have epigastric pain. I went to see a doctor who told me that I was pregnant. (Anda, 29, Married, G1P1)

2.2.1.2 Perceptions that antenatal services were unnecessary

Failure to understand the importance of antenatal service was another reason why some women did not attend the antenatal clinic.

One participant did not report any physical or financial barriers that hindered her from attending the antenatal clinic. Rather, she said that she was "lazy" to go to the clinic.

I: What happened?

R: I was lazy to go to the clinic

I: Nothing happened to discourage you from going back to the clinic in the first visit?

R: No. The clinic was far, but not very far.

I: It was far? But it was a walkable distance?

R: Yes (Zipho, 20, Single, G1P1)

When the discussion continued, Zipho reported that she did not think attending antenatal clinic was important.

I: From the discussion that we have heard, you did not give me a reason for not attending a clinic. What did you think?

R: I thought it was a waste of time. (Zipho, 20, Single, G1P1)

2.2.1.3 Lack of health service integration

One of the barriers to use of reproductive health services was lack of health service integration; where patients are seen on different days according to their „different" needs. This means that pregnant women who come to the clinic for the first time are seen on a particular day and will be turned away if they come on a different day. According to participants in this study, in a number

of clinics patients are seen on different days based on the condition or the reasons they are visiting the clinic.

Lack of service integration affected Zipho who ended up being a near-miss before she went for antenatal care service. Zipho first came to the clinic for fever and the nurses suspecting that she might be pregnant, told her to come another day to be tested for pregnancy. When she returned, she was tested and told that she was pregnant but that she should come the following week for her first antenatal visit.

R: The first time I went for fever and the following week I went to check myself for pregnancy and when I was about to go the third time for antenatal care I became sick before the date that I was given.

I: And what happened then?

R: It‟s then that I had a fit before the day I was supposed to return to the clinic. (Zipho, 20, Single, G1P1)

2.2.1.4 Unavailability of resources

Services that women need at the clinics are not always readily available because of inadequate resources. Some women, although they became aware of the fact that they might be pregnant and went to the clinic, were not offered pregnancy testing or antenatal care, despite these services forming part of a basic primary health care package.

In Nontombi‟s case, a positive pregnancy test confirmation was needed and she had to go and buy it herself because they did not have stock at the clinic. This added another burden and inconvenience for a woman, coming from a family which already had limited financial resources.

R: The nurse said I should buy the pregnancy test kit and check if I am not pregnant. In our clinics our problem… Sometimes you go there and you are told that they do not have some medication for some condition you must come again and when you come again you do not get it. That is the situation with our rural clinics

I: So what do you do if you don‟t get it the second time?

R: If I do not get it (medicine) the second time I do not go there again because I know it is going to be the same story even if I go there for the third time. (Nontombi, 23, Single, G1P1)

2.2.2 Experience at the local clinic

2.2.2.1 Negative experiences at the local clinic

Some women‟s experiences were below their expectations. Anda reports how she attended the clinic but received no satisfaction until she left the local clinic for another clinic far from where she was staying. Anda thinks that nurses in her clinic were either less knowledgeable or not concerned about people‟s health.

R: I had a problem with the swelling and they told me that they did not know what to do and the swelling was becoming worse and worse and I decided to go to another clinic and they said that I may be having high blood pressure. I went to hospital on Tuesday and it was there that they saw that I had high blood pressure and that it was very high and they called an ambulance to fetch me to have the operation done. (Anda, 29, Married, G1P1)

Experiences at the local clinic differed from one patient to the next, also depending on that particular clinic. Women participating in this study experienced a number of barriers during pregnancy and childbirth but not all experiences were bad. Some had good experiences at their local clinics,

2.2.2.2 Positive experiences at the local clinic

Positive treatment that women experienced from their local clinics was described by some as "nice" and "good". Nomfezeko reports how the clinic staff were good to her:

R: "because I was told the truth". (Nomfezeko, 18, Single, G1P1)

Zimbini thought clinic staff were humane and considerate.

R: If you have forgotten the card by mistake, they write on paper and when you come back they would transcribe on your card. (Zimbini, 18, Single, G1P1)

Information on what participants were taught at the local clinic about pregnancy did not come spontaneously. One participant answered after a lot of probing and only after keeping quiet for a long time.

2.3 Delivery period

2.3.1 Delayed response to the near-miss event

All, except for one woman, attended antenatal care, although most went during or after their second trimester. Despite the others having received antenatal care, the near-miss event occurred when least expected by most women. Although the DoH suggests that all pregnant women should be informed of danger signs of serious morbidity (National Department of Health, 2007b), respondents - including those who were attending the antenatal clinic regularly –did not respond to the warning signs of serious morbidity until they experienced a near-miss event.

2.3.1.1 Failure to recognize the signs of serious morbidity

Most participants failed to recognize or did not respond to the warning signs of serious morbidity. Although during the first interview, most participants who experienced eclamptic fit

did not remember the near-miss event itself, because they were unconscious at the time, in their subsequent interview, many reported that help was sought (usually by a family member) only when the respondent collapsed or had a fit, not when they were still experiencing warning signs.

I: When is the last time you remember?

R: I was home

I: What is the last thing you remember? The thing that happened probably before you fell sick.

R: I only remember that it was during the day and we were sitting. (Zipho, 20, Single, G1P1)

Noluthando did not respond immediately to the warning signs.

R: I was given a date for the 22nd but I am told that I had a fit and I regained my consciousness when I was already here (in hospital).

I: What happened?

R: It was at night and I am told that I had a fit. They say I complained before going to bed that I had headache. (Noluthando, 24, Married, G3P2)

2.3.1.2 Transport to the health facility

Women experienced a number of transport challenges even during the near-miss event when they desperately needed immediate medical attention. Of the nine participants, four called an ambulance. In the case of three participants the ambulance came immediately. However, in one instance the ambulance took long and they ended up using alternative transport. Four participants did not call an ambulance because of the perception that ambulances do not come when called or that ambulances do not go to their areas. One participant had her near-miss experience whilst in hospital and did not need to get transport.

Nontombi explains why her mother had to borrow money to hire a car to take her to hospital.

R: They (the clinic staff) say that the ambulances do not go there because they get robbed. They say sometimes people (from the community) phone and say someone is in labour and when the ambulance comes they tie the ambulance driver and take the ambulance. The ambulance only goes to the clinic and does not come to those rural areas. (Nontombi, 23, Single, G1P1)

Anda reported that she was told (by clinic staff) not to go to their clinic when in labour because the clinic closes in the afternoon and that the ambulance does not go to her area. Instead, she was told to take a taxi or organize her own transport:

R: When you go for antenatal care they write under transport section in your card that if you are in labour do not go to them, get a taxi to hospital. Taxis do not take people who are in labour, they say it‟s a big risk to take someone who is in labour.

I: So where does a person go if she goes into labour after the clinic is closed?

R: She has to phone an ambulance, if the ambulance does not come she has to hire a car to take her to clinic 2.

I: What happens to people who do not have cars?

R: They hire them or they deliver at home. (Anda, 29, Married, G1P1)

In one instance, an ambulance was called but it did not come and the patient had to use her father‟s car to go to the clinic. Even when the ambulance was called at the clinic, it did not come and she was taken to the next hospital in her father‟s car.

R: The ambulances are not usually available at Clinic 10. Even that day, they (clinic staff) asked for an ambulance and they could not find it

I: From Hospital C to Hospital B; how did you go there?

R: I went to Hospital C in my father‟s car and in Hospital C we managed to find an ambulance to take me to Hospital B (Nomfezeko, 18, Single, G1P1)

The experience and perception that ambulances do not come, seems to have compounded the problem as some families did not even bother to call an ambulance because they thought it would delay. However, although some of the women in this study experienced such delays, for others, an ambulance came immediately when it was called:

I: Did it take time?

R: No, my mother says it came early. It did not take time. (Zimbini, 18, Single, G1P1)

Similarly, in Zipho‟s case, they were not disappointed when they called an ambulance.

I: How did they take you from home to Hospital E?

R: …they called an ambulance….It was around seven

I: In the evening?

R: Yes… it did not take time it came immediately. (Zipho, 20, Single, G1P1)

Nontombi also gives the same report,

R: I am told that the ambulance did not take long. Unlike what most people usually say, I am told that the ambulance came immediately. (Nontombi, 23, Single, G1P1)

2.3.1.3 Referral processes

While transport, in some cases, posed a barrier to getting to a facility, a lengthy referral process also contributed to delays in getting care during a near-miss event as women were not referred

directly to the destination hospital which would be in a position to attend to the near-miss.

Nomfezeko was moved to a number of facilities before being attended to.

R: I don‟t know. I only woke up in hospital but I am told that I started by snoring and had blood coming from my mouth and my mother then knew that it was time and took me to Clinic 10 and they said I was too bad and I was sent to Hospital I. At Hospital I they also sent me to Hospital C and Hospital C also sent me to Hospital B. I was not delivered on the day of arrival. I was delivered the next day (Nomfezeko, 18, Single, G1P1)

2.3.2 Experience in tertiary hospital

Due to the seriousness of their condition, all of the women were eventually referred to tertiary hospitals, where they were admitted, often for a number of days or weeks. During their stay, most reported that they were treated well:

R: Things were very good at Hospital A…They have a way with people. They know how to take care of people…When they come to give you something they ask you how you are feeling…They talk to you so that you end up forgetting about everything that happened.

I: How was your relationship with the staff in Hospital A?

R: It was very good (Zipho, 20, Single, G1P1)

In Zimbini‟s case, she reports that her basic needs were met - they were given food and water - and this constituted good treatment for her:

R: At Hospital B, the treatment was very good…When you are thirsty they just give you some water and you do not have to ask especially if they see that you cannot walk slowly and get yourself some water, they just offer you some water…When they give you food, they ask you

whether you have had enough and they give you some more if you still want some more food.

When you go there they take you back home by an ambulance. (Zimbini, 18, Single, G1P1)

Zodwa, however, was not as fortunate as the others. Although she reports good treatment in the medical ward of Hospital B, she also mentioned that she was treated badly in the ICU of the same hospital. This bad treatment was only mentioned in a second interview that was held at her home and, perhaps unsurprisingly, it was not mentioned in the first interview that was held in hospital. The second interviews proved to be helpful as some information could have been lost if only one set of interviews were conducted. A different emotion emerged as when in hospital Zodwa reported that the treatment at the tertiary hospital was good. During the second interview she started crying when the name of the hospital was mentioned, reporting that she was ill-treated; information or the emotion which was withheld during the first interview.

R: The nurses there do not treat people well. Some are fine. I could not do anything. You remember when you came I had hair extensions. When they were going to give me a bath the nurse would pull me with my hair in a painful way.

I: Mh.

R: (*Crying).* It was painful there in ICU. Even when I mess on the bed they would shout at me. They asked why I didn‟t call someone, but I called and was told that I was making noise and disturbing other patients and that I was not the only patient there (*Crying).* It was only in ICU. I was worried about the ward (medical ward) but the nurses were fine and the patients were also fine. (Zodwa, 21, Single, G1P2)

2.4 Postnatal period

Although the respondents were generally satisfied with their stay in hospital, most did not get an adequate explanation of what happened during the near-miss event. They also did not get the relevant perinatal counselling after the near-miss event or a physical examination after the

postnatal period. At the time of her second interview, one woman was still crying when talking about her illness, reporting that she did not know whether she was going to be sick again. Women were not given dates for postnatal check-up to ensure that everything was fine.

Two women were still particularly affected by their painful experiences three months after the event (at the time of their follow-up interviews). The researcher made appointments for them to see the obstetricians who would explain the circumstances around their illnesses and how their future pregnancies might be affected, however they did not honour those appointments and it was not clear why. Although women were not offered postnatal check-ups, they were all given dates for contraception and for their babies‟ immunization.

R: I am told that the day I became sick, I was just sitting and everything was fine. I am told that what happened…… (*Starts crying).* I am told that I started jumping up and down on the bed and I was calling and saying Mom and Dad, let us leave (Crying).

3. PARTICIPANTS' RECOMMENDATIONS

Most participants took time to answer the question requesting information on how the Department of Health could change the way things were done. Although participants had stated the barriers that they encountered during their pre-pregnancy, pregnancy, delivery and postnatal period, there were a lot of quiet moments and the researcher had to spend time probing to get information on what the Department was not doing well and needed to improve on.

A number of participants came with recommendations although one thought there was nothing to recommend. Recommendations centred on accessibility and acceptability of reproductive health services. Women recommended that medical resources, reproductive health services and ambulances should be available in all areas at all times for women who need those services. They also recommended that nurses should demonstrate a positive attitude when talking to and

dealing with patients and that staff should be rotated as the same staff working in the same area for a long time get used to the community and stop respecting them. The other recommendation was that clinics should be built closer to the communities and they should be more accessible to those communities.

RESULTS (Part 2)

Presenting access difficulties separately can cloud the complex ways in which these barriers overlap and intersect within someone‟s overall life. This section focuses on presenting the findings in a more holistic way. The complex intersections described below and presented in verbatim in appendix 1 and 2 take the reader through the difficulties and the feelings of the women when sharing their experiences.

1. COMPLEX INTERSECTIONS OF ACCESS BARRIERS

Some women experienced a number of challenges and made a number of sacrifices before they even reached the health facilities or got the services they needed. Some were returned from clinics a number of times before they were eventually attended to. For these women, health services – themselves free - were very expensive in terms of time and money, Noluthando experienced the complexity of access and barriers, which often play out in different ways for the same patient. In her previous pregnancy she had a miscarriage but received no explanation for what caused it. In this, her current pregnancy, she attended the antenatal clinic only after she was turned away three times at the local clinic. During her near-miss experience, she struggled with transport and her relatives had to hire a car because they were convinced that an ambulance would take longer. Her story shows how patients distrust the public sector transport system and are willing to use the private sector even within their constrained resources (see appendix 1).

In Anda‟s case accessing the clinic was not a problem but she had a problem with management

at the local clinic which she subsequently had to leave because nurses did not give her enough information and did not seem to be knowledgeable (See appendix 2). These cases show that the health facilities may be physically available but may still be inaccessible to the communities they are supposed to serve. They also illustrate the challenges that women who want to use reproductive health services go through in their effort to access them. She also had to sleep over in hospital on a chair because she could not make it for her next appointment which was the following day as she had transport problems and was staying far from hospital.

2. CONTEXT OF THE INTERVIEWS

The physical context/setting of the study during the first interviews- East London Hospital Complex and the referral area provided an immediate „context" for the study and participants" homes were chosen by most participants as the settings for the second interviews. These interviews allowed an opportunity to explore the wider circumstances around which the participants live, influences on their decision-making and, in this case, their health service utilization, their socio-economic situations, their positions in their families and relationships, whether they were from rural or urban communities, their past experiences, as well as their direct contact with the health system as key contextual issues (and some of these were noted in the second interview through my observations).

During the first interviews which were conducted in hospital participants seemed to be less relaxed when compared to the second interviews which mostly took place in their homes. This occurred in spite of having interviews conducted in private rooms and being assured of confidentiality. This was only picked up during the second interviews when participants expressed emotions they did not express in hospital. This was probably due to the fact that the second interviews were conducted in the venues deemed convenient by participants and rapport was developed. Two participants cried during the second interviews when one of them cried

during the first interview.

3. SUMMARY OF KEY FINDINGS

The following patterns were formulated based on a number of participants who had those experiences and the intensity of those experiences.

1. Most participants did not use contraceptives although they did not have any intentions of falling pregnant.

2. Most partners of young and unemployed participants were influential in getting women pregnant.

3. Most participants did not recognize the cessation of menstruation or continued absence of menstruation in the event of no contraceptive use as a sign of pregnancy.

4. Lack of resources at the local clinics was seen as a major barrier in accessing reproductive health services.

5. Bureaucracy in accessing local clinics contributed to barriers in accessing reproductive health services.

6. Participants did not experience or notice any warning signs before the near-miss events.

7. Transportation was seen as a barrier although most women did not experience this barrier themselves.

8. Lengthy referral processes delayed access to the destination hospital.

9. Some staff members took advantage of a vulnerable patient.

10. Women neither had perinatal counselling to explain their near-miss experiences nor postnatal care.

The following themes emerged:

1. Contraceptive use is not only influenced by the desire to or not to fall pregnant

2. Power relations affected the decisions of most women who were in lower positions of power

3. Cessation of menstruation as a side effect of contraception resulted in failure to recognize absence of menstruation as a signs of pregnancy

4. Lack of resources delayed and discouraged women from seeking reproductive health services

5. Bureaucracy due to requirements before attending the local clinic and lack of service integration affected women irrespective of their demographic characteristics

6. Warning signs that women were at risk of acute serious morbidity could not be relied upon to prevent the near-miss events as women did not experience or did not recognize any

7. Transport is seen as one of the major barriers whether it is available or not

8. Lengthy referral processes delays treatment of near-misses and can contribute negatively to prevention of maternal deaths

9. Patients are at risk of abuse in health facilities

10. Tertiary hospitals concentrate more on the antenatal and perinatal care and less on the postnatal care of women of reproductive health.

4. THE AAAQ FRAMEWORK WITHIN THE REPRODUCTIVEHEALTH CYCLE

The framework was used to assess whether the health system satisfied or complied with the elements of the AAAQ framework. The areas where the health system did not comply with or partially satisfied the AAAQ framework are incorporated in the recommendations.

4.1 Pre-pregnancy period

Availability: During the pre-pregnancy period the availability condition was ***not realized*** because most participants reported that the resources were not adequate. These include medicines, adequate and adequately trained health workers. Judging from women‟s lack of knowledge the family planning services were not adequate because women did not know how contraceptives work and they ended up missing the signs of pregnancy.

Accessibility: The condition of accessibility was ***not realised*** because although family planning services were free, they were not accessible after working hours and some women ended up falling pregnant. The routes to the clinic also made it difficult to access the clinics. Failure to accommodate people speaking different language was also making things difficult, therefore discouraging women from seeking the service.

Acceptability: Although some studies like Wood & Jewkes (2006) reported that nurses were rude and stigmatized young women who were sexually active, in this study none of the women reported their family planning nurses as being rude and impolite. One actually reported that they were taken good care of and they were attended to even if they forgot their clinic cards at home. Acceptability during the pre-pregnancy stage was ***realized***.

Quality: Quality was ***partially realized*** because although women‟s understanding of how contraceptives work showed that they had inadequate knowledge about contraceptives, none of them of the women reported having stopped contraceptive use because of bad treatment at the clinic.

4.2 Pregnancy period

Availability: The availability condition was ***not realized***. Services during pregnancy were not adequately available because the clinics were far; one participant had to go to a far away clinic because nurses in her clinic were not knowledgeable. Medication was also not available at all times.

Accessibility: Accessibility condition during pregnancy was ***not realized*** because the clinics were far; although services were free, women had to pay taxi fares to go to the clinic; routes to some clinics were scary making it difficult for women to go to the clinic. Another woman found it difficult to access the clinic for antenatal care because she was told that she would not be accepted if she did not bring proof of residence and had to come to the clinic very early to be accepted.

Acceptability: This condition was ***not realized*** because during the pregnancy period one woman reported that she had to leave her clinic because she found the services unacceptably inadequate when other women did not complain the nurses. Also the fact that one woman had to be sent home a number of times because she did not have proof of residence does not adhere to medical ethics.

Quality: The quality condition of the AAAQ framework was ***not realized*** because women were turned away from the clinics and told to come back on certain days, one woman reported that she had to leave her clinic and use another far away clinic which offered a better service, and one woman was turned away many times because she did not have proof of residence. This affected the quality of ante-natal services as one woman had a near-miss experience before the date she was told to return by came and the one who ended up going to another clinic reported that she was not given adequate information about her medical condition.

4.3 Delivery period (including near-miss period)

The near-miss period was included in the delivery period because women had to be sent for delivery when they experienced the near-misses.

Availability: The lengthy referral process when women needed immediate medical attention contributed to the availability condition ***not being realized***. The fact that women had to organize their transport also contributed although those who called an ambulance reported that there were no delays.

Accessibility: Women had to organize transport to be able to access the hospitals for delivery because the emergency medical services were not considered accessible. This cost them a lot of money as it was an emergency and took place mostly after hours. Access problem resulted in one woman sleeping over in hospital on a chair because she was staying far and would not be able to come to hospital for her appointment the next day. Accessibility condition during delivery period was ***not realized***.

Acceptability: The nurses were rude to one patient who went to hospital during her near-miss experience. They ill-treated and ridiculed her when she wet her bed and when she requested a bedpan to pass urine in bed. Although some women reported that they were treated well in hospital when they went for delivery, the trauma experienced by the woman who was ill-treated resulted in the acceptability condition ***not being realized.***

Quality: Except for the fact that one woman was ill-treated in one of the facilities when she came for delivery, women reported that they were treated well when they were referred to the tertiary hospital for delivery and that all except for one baby were saved resulted in the condition of quality during delivery being ***realized***.

5.4 Post-delivery period

Availability: Like in all other availability conditions in the reproductive health cycle, the availability condition during the postnatal period was ***not realized***. Most women reported that the clinics were far and postnatal care was not offered.

Accessibility: Again, postnatal care was free and women were not expected to pay for anything but they had to pay taxi fares to and from the clinic. As postnatal care was not offered at all, this condition was ***not realized***.

Acceptability: The acceptability during the postnatal period is difficult to measure as the service was not offered to women. The acceptability condition was therefore ***not realized.***

Quality: The quality condition was ***not realized*** because women were not offered any postnatal counselling to inform them about their near-miss experience and to equip them for their future pregnancies. Women reported that they were only given dates for baby clinic and for their follow up contraception and not for postnatal care and that when they went to the clinic no examinations were done on them; only the babies were taken care of.

Table 4.2: Realization of reproductive health services according to the AAAQ Framework

	Pre-pregnancy	**Pregnancy**	**Delivery**	**Post-delivery**
Availability	NR	NR	NR	NR
Accessibility	NR	NR	NR	NR
Acceptability	R	NR	NR	NR
Quality	PR	NR	R	NR

R: Realised, PR: Partially realised, NR: Not realised

CHAPTER 5: DISCUSSION

1. SUMMARY OF FINDINGS

This chapter discusses the study findings and uses a framework dividing contributory factors into "patient factors", "health system factors" and "other factors" (factors that could neither be solely categorized as patient nor health system factors). An access framework is also used to form a discussion around issues of access as they emerged in the study.

A number of issues came up in the interviews held with women who experienced near-misses across all participating age groups, women from different settings and women of different marital status from pre-pregnancy to postnatal period. This study allowed for an examination of health seeking behaviour of women from pre-pregnancy (family planning), antenatal, near-miss period to postnatal period. There did not seem to be a pattern in the way these women sought health services as the services are different and the reasons for not using them are also differed from woman to woman. The most common reason for erratic or non-use of contraception was side effects of contraception and myths around contraception; which is different from the reasons mainly given for delayed or non-use of antenatal care services- failure to recognize signs of pregnancy. These reasons are also different from reasons given for seeking help late during the near-miss event instead of when there were still warning signs.

Knowledge (especially partial or lack of knowledge) seems to be a major barrier cutting across all phases of the reproductive health cycle instead of a certain pattern of either seeking or not seeking health services for some participants as opposed to others. All women were not working; some were depending on their parents for financial support when in some cases the only income was from pension. A majority of women experienced barriers to utilize reproductive health services but continued to seek those services. Lack of knowledge was a limitation cutting across

all age groups as women did not have adequate information on contraceptives, their side effects, symptoms of pregnancy and warning signs of severe acute morbidity.

2. BARRIERS TO USE OF REPRODUCTIVE HEALTH SERVICES

2.1 Quality of reproductive health services

What came strongly from this study was that the overall quality of reproductive health services was not very good. There were bureaucratic barriers limiting access to the local clinics, clinics were running out of stock on medicines and equipment such as pregnancy test kits. Overall, the treatment in health facilities was not very good with cases of women not given adequate health education, being turned away without having received the service and one extreme case of a woman who was shouted at and physically abused. Although a single incident in this study, Jewkes, et al. (1998) show a more systemic pattern of how patients were abused in some health facilities in Cape Town with some being shouted at and others not given support and attention they needed during delivery.

Participants in this study were very modest and had low expectations around what constitutes good care. Reports that nurses were kind were supported by statements such as “they told me the truth”, they gave me water”, “they teach us” and “they gave me pain tablets when I asked for them” when these are in fact patients‟ rights that they are entitled to. Considering that participants had low expectations, their report on bad treatment at the facilities may actually be worse than portrayed.

Whilst the DoH recommends that women book for antenatal care as early as pregnancy is detected (National Department of Health , 2007b), the absence of basic resources such as pregnancy test kits, defeats the purpose of attending antenatal clinic early, especially to people who are not financially independent. This delays antenatal clinic attendance, thus increasing the

chances of a woman being a near-miss as danger signs may be picked up very late if she attends the antenatal clinic after the first trimester of pregnancy. Absence of medical resources puts women at a higher risk of being near-misses because they may not have money to buy medicines that they were supposed to get from the clinic.

2.2 Women's knowledge about reproductive health issues

This study showed that women have inadequate knowledge about menstrual cycle, contraception and other reproductive health issues. As described in chapter 4, women did not seem to clearly link the cessation of menstruation with pregnancy. This is a gap which the health system needs to close by educating women on reproductive health issues as it may be one of the reasons women go to the antenatal clinic after the first trimester of pregnancy, putting them at risk of being near-misses. As shown in Ekwempu (1988) where booked uneducated women had reduced mortality, health education on reproductive health issues would equally empower women with knowledge.

2.3 Unplanned and unwanted pregnancies

Most women reported that their pregnancies were unplanned and unwanted, for reasons ranging from their unfavourable socio-economic situations, to being unmarried, being unemployed, or being young and still at school. These same factors may have contributed to them failing to utilize or inadequately utilizing reproductive health services and possibly also being near-misses. Women who did not want to be pregnant are supposedly less likely to be as excited about their pregnancies compared to women who had planned their pregnancies and therefore attend the antenatal clinic less (Erol, et al., 2010). They may miss, ignore or deny the signs of pregnancy. They may not go to the clinic for antenatal care or may go later in pregnancy if they go.

The same reasons they did not want to be pregnant may also have put them at risk of being near-misses. An example is the fact that if the family does not have money to buy food (a potential

reason not wanting a baby), the same family may not be able to buy healthy food for a pregnant woman or buy her supplements and treatment in cases where there are no medicines at the clinic as poor health is associated with social, economic and environmental conditions (Freedman, Waldman & de Pinho, 2005).

2.4 Power relations between partners

There seemed to be an element of subtle power relations between partners in this study; with men in a higher position of power. In this study, most women were either studying or unemployed while most of their partners were working. Participants reported that their partners repeatedly requested them to give them babies. The subtle pressure placed on some of the participants resulted in them having babies irrespective of their socio-economic situation or personal desire to have a child. South Africa is a patriarchal society with a very low ranking on gender development index and social norms. This gives men a higher position in relationships especially when they are employed and thus in a better socio-economic situation compared to their partners (Centre for Gender and Development, 2006). This may put women in a position where they have to put their partners‟ feelings and opinions first in their decisions.

2.5 Unavailability of transport

Appropriately staffed and equipped ambulances should be available 24 hours a day to move women from their homes to the health facilities or from one health facility to another (National Department of Health, 2007b). The perception of poor, or no service from Emergency Medical Services (EMS) Division predisposes women to a risk of being near-misses as they have to seek other transport alternative based on hearsay and perceptions that ambulances do not come when called. The findings of this study suggest that there may have been improvements on EMS as the ambulances responded immediately in 75% of cases. The assumption about ambulances may

remain a barrier for most people until such time that women are made aware of an improvement in EMS.

2.6 Lack of service integration

Reproductive health services seemed to be unintergrated as women had to visit the health facility more than once to access different services. This affects patients as they have to spend more money on transport when their financial resources are already depleted. Based on the fact that most women were unemployed, they might not have been in a position to raise more money to go to the health facility again. This may affect the health system as some patients may end up not coming back on the days they were asked to return to the health facilities. As stated in Greene (2004), patients may end up abandoning the service because of the inconveniences they experience.

2.7 Lengthy referral process

In cases of emergencies, patients need immediate medical attention as soon as they experience a near-miss or a warning sign of serious morbidity. A lengthy referral process also posed a threat to the health of the already-sick women especially during the near-miss event. Fig 5.1 shows how one woman was moved from one clinic to two other hospitals before eventually reaching her final destination hospital; a time-consuming process that put her at even greater risk. One of the functions of a clinic is to refer patients with problems to a hospital, and for a level 1 hospital to refer problem patients to level 2 or 3 hospital (National Department of Health, 2007b). Level 1 hospitals are therefore expected to be able to assess and refer to an appropriate referral facility instead of each hospital making its own assessment and referring to a higher level hospital.

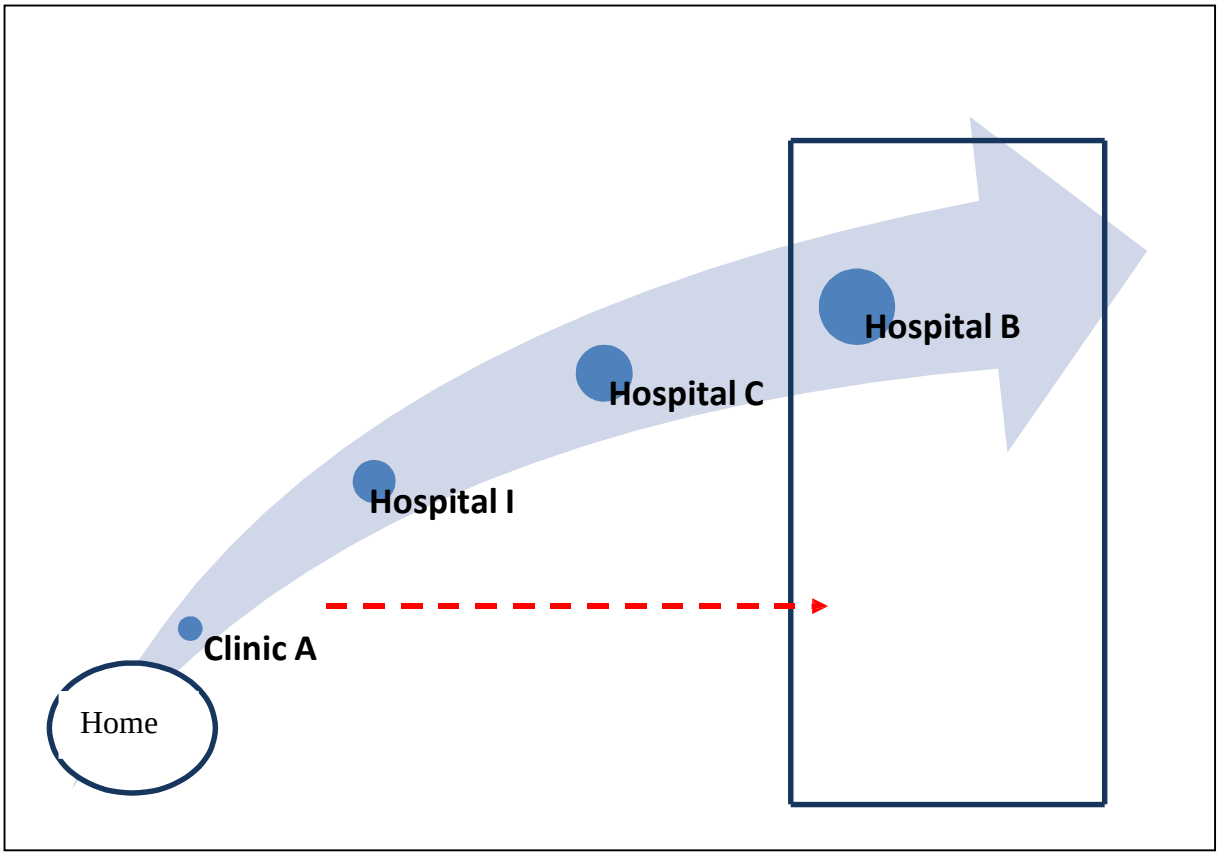

Fig 5.1: A lengthy referral process from clinic to destination hospital (The red line indicates the short route that the participant should have followed to the destination health facility, instead of taking the long route indicated by the curved blue arrow).

3. DISABLING FACTORS AROUND USE OF FAMILY PLANNING SERVICES

All participants reported that they at some stage used family planning services. This study shows that there were missed opportunities as family planning clinics are, most of the time the first point of contact where a healthy woman interacts with the health system and should therefore be used as a source of information on family planning options, pregnancy and other reproductive health services. Although demand-side factors may encourage women to make use of family planning services, for example if a woman is young and still at school, is unemployed, not married and not financially stable, their courage to use contraception may be played down by the disabling factors such as barriers to accessing reproductive health services. Family planning may also determine a pattern of accessing health services. Women who have developed a pattern of

regularly attending the clinic for family planning may continue with the same pattern even during antenatal care when those who were not regular with the family planning may be irregular in attending the antenatal care. These barriers may be the fact that the local clinics are far; that the clinics do not open throughout the day but only between 08h00 and 16h00 and only during the working week; that the resources at the local clinic, including medical resources are sometimes not available and the fact that some of women‟s partners have been requesting babies may have carried a lot of weight when compared with other reasons why these women should use contraception and not fall pregnant. As indicated in figure 5.2 the barriers and the disabling factors may carry more weight as they happen where women are; in their families or their communities and may result in women being discouraged on their use of contraceptive measures.

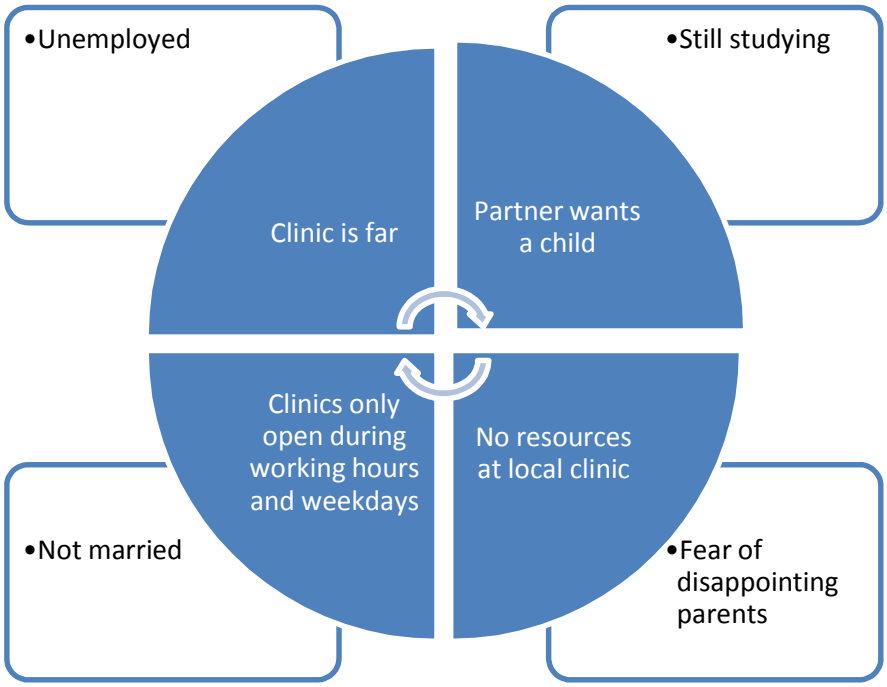

Fig 5.2: Enabling and disabling factors around the use of family planning services. The blue circle shows the disabling factors that affect women more when the squares represent the enabling factors.

4. MULTIPLE CHALLENGES EXPERIENCED BY CONSUMERS OF REPRODUCTIVE HEALTH SERVICES

The findings of the study show that most women did not only experience isolated problems but experienced a number of challenges throughout their reproductive health cycle. That may be discouraging and some women may end up giving up on their efforts to access reproductive health services. The challenges most women experienced started from pre-pregnancy phase through the full reproductive health cycle.

Noluthando‟s story (fig. 5.3) reveals multiple challenges, which may drive some women to stay at home or resort to other alternatives such as the traditional healers and traditional birth attendants. This may result in home deliveries which are prone to more complications. Women who go through such challenges may also feel the pinch of inequity as some are not even in a position to go seek health services somewhere else because they are not well-resourced financially.

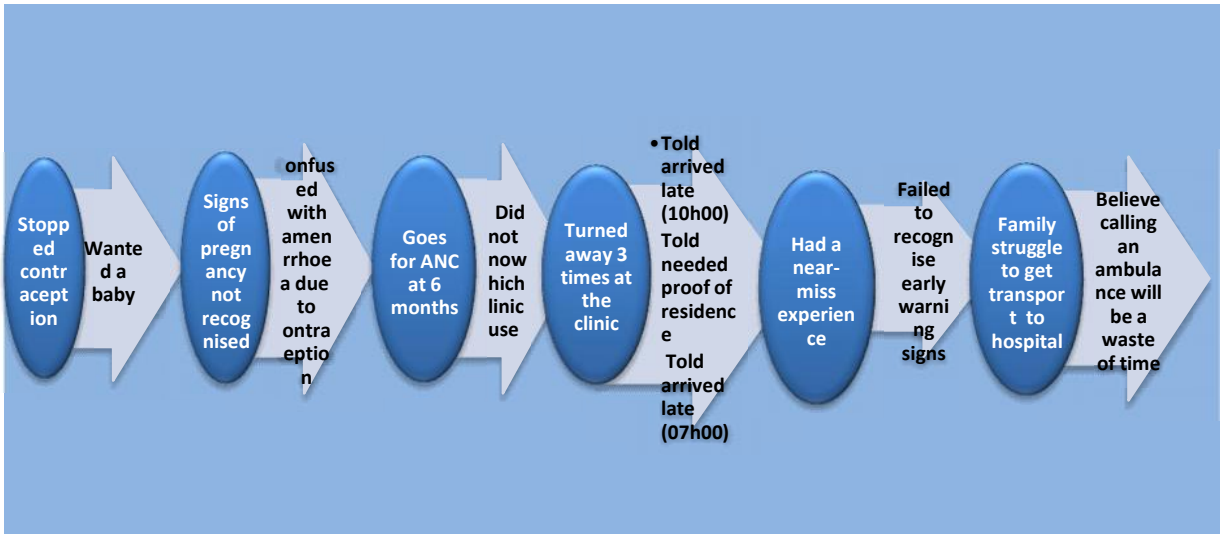

Fig 5.3: Multiple challenges experienced by one participant who struggled to access reproductive health services

5. POSTNATAL SERVICES

As part of postnatal care, post-delivery, women who experienced serious morbidities should receive perinatal counselling where they get full explanation on what went wrong and how their illnesses are expected to affect their health and their future pregnancies (Personal communication, Registrar in Obstetrics and Gynaecology Department, East London Hospital Complex, 4th October 2010). They are also supposed to be given an appointment for postnatal check-up, including contraception (National Department of Health, 2007b). Patient check-up during postnatal period is important as they allows an opportunity to identify and correct whatever went wrong in the antenatal and perinatal period. Helping women understand their near-miss experience and what they need to do to minimize the risk of recurrence of the problem in the future pregnancies would give them more confidence in facing their future pregnancies or an understanding of how important it is that they should avoid future pregnancies, if they have to.

As stated in the access framework by Thiede, et al. (2007), this study shows that the dimensions of access are interrelated. Limited availability of transport in this study impact on affordability as poor families had to hire cars to take patients to their local clinics. There was no degree of fit between the health system and users of reproductive health services as women needed services (such as ambulances, family planning services and delivery) when the clinics were only open during working hours.

6. FACTORS CONTRIBUTING TO USE OR FAILURE TO USE REPRODUCTIVE HEALTH SERVICES

The CEMD uses the language of “Health System factors”, “Administrative” and “Patient factors”, focusing on patient records and information received from clinicians. In this study,

factors that have been identified in the chapter 4 as having contributed in use or failure to use services are summarized below according to the responsible or relevant stakeholder. “Health System factors” and “Patient factors” were used to summarise main points in this study because they speak the language of Confidential Enquiries into Maternal Deaths (National Department of Health, 2009). In allocating the barriers according to relevant stakeholders, the decision was based on which stakeholder would best be in a position to address the situation. These allocations show that there is a very thin line between health systems and patient factors as it has emerged in this study.

Patients have not been found to be solely responsible for any of the factors that contributed in them being near-misses. Health system factors account for most of the barriers, for an example the patients‟ lack of knowledge may also be associated with failure of health system in that it is the responsibility of the health system to ensure that the consumers of reproductive health services are knowledgeable and put that knowledge to good use. In addition to patient and health system factors, “other” factors describe other stakeholders who have a responsibility for or have the authority to address the situations discussed. These are the factors that are not solely health system and/or patient factors although the health system and the patients or communities may have the power to influence.

6.1 Health system factors

Lengthy referral processes, treatment of consumes of reproductive health services, quota system where women are seen on certain days based on their health needs, distance to the local clinic and unavailability of resources including medication and emergency medical services are factors that are solely health system factors.

6.2 Health system and patient factors

Factors like ignorance about contraceptives, failure of patients to identify the signs of pregnancy, delays in attending antenatal clinic and failure to identify the warning signs of acute serious morbidity are both patient and health system factors because these are due to lack of knowledge that the health system is supposed to provide.

6.3 Other factors

Some factors could not only be attributed to health system and/or patient factors. These factors include unsafe routes to the clinic, problems with ambulances not going to some areas because of crime and power relations between males and females as they also made it difficult for women to independently make decisions of use of reproductive health services.

7. LIMITATIONS

Near-misses are a rare event and are few and far between. This made it difficult to sample a representative sample in terms of demographic characteristics of women of reproductive age.

The researcher works for the DoH and this may have made it difficult for the participants to disclose bad experiences that they had about the Department. Women were, however given information on the purpose of the study and how the information gathered would be used. The researcher however was aware of the possibility of this limitation and continued to remind them about the purpose of the study and that information they give would be kept confidential and not used against them even in the middle of the interview to allay their concerns.

Most of the participants had eclampsia and did not remember what happened during the near-miss event but what happened before at the time of the interviews. During the second interview women could give the requested information which they got from their families.

The study only focused on patients and does not get the side of the providers who might have given a different story if they were also interviewed. The study was interested in the experiences of the near-misses and their opinions and wanted to find out from the near-missed how they interpret the treatment they receive.

Planned triangulation between interviews and medical records was not feasible. This was due to the fact that medical records seem to detach the patient and patient experience from history taking and only consider medical information. Medical records could therefore only be used to confirm the diagnoses as the only information they give is the symptoms and the time the symptoms commenced. This shows that the near-miss studies use a completely different language from the one used by the CEMD, hence the importance of near-miss studies to complement CEMD because they bring an understanding that is not captured in the CEMD report.

The study did not assess the quality of health care in terms of how the patients were managed and did not measure the preventability of the near-misses. The purpose of the study was to find out from the near-misses their experiences and opinions as there are some research studies that have explored the area of quality of health care.

There were contradictions on information given by two participants between the first and the second interviews. This contradiction may be an indication that there is no way one can assume that all the information he/she is receiving is accurate. The researcher tried to be neutral and uninvolved in her way of handling the discussions so that participants would relax and not think they would be judged from the answers they were giving.

8. IMPLICATIONS

Literature on near-misses shows that there is no standard definition of a near-miss. This study showed that knowledge on reproductive health issues was limited irrespective of demographic characteristics of participants, that warning signs for acute serious maternal morbidity were not clearly understood by both the participants and their families and that health system had an important role to play to improve reproductive health services. The implications for research are that future examination of near-misses needs to be conducted to complement information received on maternal deaths. A standard definition of near-misses should be developed and used on all near-miss studies. Implications for practice are that DoH needs to improve on counselling for reproductive health services, availability and strengthening of emergency medical services, strengthening of the referral system and ensuring that all reproductive health programmes are closely linked and monitored. Information on reproductive health issues should be made available to the entire society, not only women using reproductive health services. This will also help family members to identify early signs of pregnancy and warning signs for acute serious morbidity.

9. RECOMMENDATIONS

Information in patients' records should include qualitative information e.g. why patients delay in seeking help as is usually the case with near-misses. This information could assist CEMD to understand the problem that contributes in women being near-misses as studies on near-misses are not ongoing and this information cannot wait for the near-miss studies to be conducted.

Train nurses to offer extensive counselling to women who come for contraceptive services: Family planning may be the first encounter for women who come to the clinic for reproductive

health services and have a potential of being used as a vehicle to empower women on all important reproductive health issues. Nurses should be trained to counsel women on one on one basis when they come for contraceptive services for the first time; including information on how contraceptives work, their side effect and reasons why women should come to the clinic for repeat injection and when they experience side effects and provide information on emergency contraception.

Empower women to exercise their right to request alternative contraceptive methods if they are not happy with one method: Some women stopped using the contraception when they experienced unwanted side effects. Women should be given information on different types and their side effects, and their option to request another method when they experience unwanted side effects.

Educate women about early signs of pregnancy: The fact that some women of reproductive age who have at some stage gone to the clinic for contraception do not know about the cessation of menses during pregnancy reflects negatively on the quality of reproductive health services. Women should be educated about the signs of pregnancy at the family planning clinic so that they go to the clinic early when they notice those signs.

Educate women about importance of early antenatal care: One of the participants mentioned how she thought attending the antenatal clinic was a waste of time. Women should be made aware of the dangers of going to the antenatal clinic only after the first trimester of pregnancy. This information should be made available to the general community and should cover information on how early antenatal clinic attendance can prevent illness and also allow for early treatment of diseases so that the mother and the baby can be saved.

Women should be taught about early warning signs for acute serious morbidity: Most women did not take notice of warning signs or did not take them seriously. As Kesterton & Cabral de Mello (2010) suggested, nurses should ensure that pregnant women are aware of all the warning signs and respond to them with the urgency they deserve.

Ambulances should be more available and more accessible: The fact that EMS are seen to be poor undermines the purpose of Removal of User Fees Policy that was implemented with the aim of allowing access to services at no cost as these women, mostly from under-resourced communities end up hiring cars to visit their clinics. Ambulances should be readily available for 24 hours for use by all women irrespective of where they stayed.

Promote awareness about available health services: Oftentimes what goes around about health services is negative publicity, for example perceptions about unavailable ambulances. This may mean that whatever improvement that was made has not been well communicated to the consumers of the service - women use services only if they think they are of good quality and they can access them. There is little known about health services and improvements on health services. It is important that the DoH should improve their promotion strategies so that whatever services they improve get known by people who are utilizing those services. Robust promotional strategies need to be implemented especially around the issue of ambulances to undo the damage already done by the perception that the services are poor.

Integrate health services: Health services are expensive and this should not be only calculated in terms of money paid to access them. To access health services, women have to go to the clinic and leave their day to day chores or jobs. These women may also have to organize people to take care of their families before they can be able to access health services. The disappointment they experience when they are told to come some other day may be difficult to comprehend. The services rendered at the clinic should be integrated so that women are not sent back home and be

told to come back on another day and this should be monitored.

Collaborate with other relevant stakeholders to address issues that affect health: The issues of unsafe routes to the local clinic affect health services in a negative way. The DoH may have to engage and convince the relevant stakeholders to address the issue of safety. The issue of ambulances that do not go to some areas because of crime also falls under this area of concern.

Health care workers should treat patients with respect: According to the patients‟ rights charter, everyone has a right to a healthy and safe environment. The safety of the environment does not only refer to an environment that is free from infection and environmental danger, it means that the environment must be safe in a holistic way. A hospital is a place which should bring a sense of relief and hope to those who seek its services. Patients also have a right to access health care and their rights should be respected. This also covers the fact that the health worker should display a positive attitude, treat the patients with dignity, courtesy, patience and demonstrate empathy. In this way the service would be more acceptable, making it easier for the same patient to seek help from the same facility again. Managers should supervise the services received by patients and should find out from patients themselves how they are treated and offer them an opportunity to complain about bad service. Patient should also be encouraged to participate in the patient satisfaction survey where their concerns can be addressed.

Monitor and evaluate the services rendered at the clinics: Bad practices that happen at the clinics and hospitals may go unnoticed if the clinics are not properly monitored. Part of this evaluation should cover patients‟ concerns about their health services. In one clinic patients are asked to provide proof of residence and are turned away after a certain number has been taken. Clinics should be supervised and problems should be dealt with before they destroy the image of the Department.

Offer women postnatal services: Women report that no one took time to explain to them what really happened and counselled them. Some report that they do not want to be pregnant again because they do not how the near-miss event will affect their future pregnancies. Women who went through these experiences should be counselled and be prepared for future pregnancies or be discouraged from falling pregnant again if needs be.

Involve families and communities in reproductive health matters: Reproductive Health service should stop being an individual matter but a family matter. Families should be made aware of what constitutes an emergency in reproductive health care. This will empower them to act immediately when the need arises and prevent or reduce the occurrence of near-misses.

10. CONCLUSION

The concerns that women are voicing out emanate from their experiences or the experiences of people they know. Health systems‟ issue which according to the AAAQ framework were not satisfactory for an example bureaucracy in accessing reproductive health services, lengthy referral process, inadequate information given in health facilities which resulted in women failing to understand early signs of pregnancy and warning signs of acute serious morbidities contributed in women being near-misses. It is important that the providers of reproductive health services take good care of all consumers as their experiences and the experiences of those around them determine their health seeking behaviour. The issue of inadequate knowledge also needs immediate attention as knowledge can assist in making informed decisions. Women also suggest that the Department should improve the issues of staffing, availability of equipment and ambulances as these form major barriers that affect the outcomes of pregnancy in a very negative way.

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Appendix 1

Bureaucracy in accessing public health services

Case study 1 below shows the challenges that Noluthando went through in her third pregnancy. Noluthando was a 24 year old married Grav 3, Para 2 (1 alive) and she describes her experience as follows:

R: This one was planned. I went to the clinic.

I: When?

R: When I was six months pregnant.

I: When you were six months pregnant.

R: Yes, when I was six months. These clinics give us a lot of problems. I was already giving up and I was telling myself that my husband will have to struggle with the little money that he was earning and take me to the doctor.

I: The clinics give you problems? Which problems?

R: You have to get a paper from where you are staying to state where you stay. To get the paper you also struggle.

I: You cannot just go to the clinic and tell them where you stay.

R: No, you have to bring proof.

I: Which proof?

R: A paper from your counselor.

I: If you have to go to the clinic you have to start at the counselors?

R: If you want to go to the clinic. I went there the first time and I was told that I have to bring a paper.

I: and you didn't have proof of where you were staying.

R: No I didn't have proof. I used to ask who the counselor was and where she was staying. I thought she was staying in Location A but I was told she was staying in Location B. I was also told that she was very fussy with those papers. The lady who told me said her sister could not get proof of residence from the counselor when she needed it. I ended up going to city hall and the lady who was there told me that she did not have papers. She wanted to know what I needed papers for and I told her. She asked me where I stayed and I told her. She then gave me the paper.

I: Did you go to the clinic before you went around looking for that paper? Did you go there or did you hear from the others that you would be turned away if you did not have that paper?

R: I did go there and I asked how one can attend a clinic and I was told that I had to bring proof of residence

I: Did you ask from other people of from the nurses?

R: No, I asked from other people outside.

I: Were these people who were working there?

R: The receptionist when I went there the first time told me that it was already late.

I: What time was it?

R: It was around 10. They told me that they take a certain number. I asked what I should bring next time I come. He said I should bring proof of residence but I went there the following week because I thought that the nurses will understand when I tell them that there is no clinic where I stay. When I went there for the second time I had an ID and they told us that they take people for the first time but the next time they come they should bring proof of residence or they are not going to be attended to.

I: This second time that you came with the ID, did you arrive early.

R: Yes but I was told that it was already full.

I: What time did you arrive?

R: I arrived at 7 o‟clock

I: At seven the clinic was already full.

R: Yes I was told I had to wake up early. The other lady who was there said she arrived around 4a.m. because one has to register.

Appendix 2

Challenges with availability of reproductive health services at the local clinic

Anda, a 29 year old married grav 1, para1 had to leave her local clinic because although the reproductive health services were available physically- in terms of availability of the clinic and the health personnel, she found the services not adequately available because according to her the nurses were not knowledgeable. Her story appears below:

I: When you realized that you were pregnant what did you do?

R: I became excited because I wanted a baby.

I: And then what did you do?

R: There was nothing. I did not have anything but I felt shortness of breath and I needed to have my pillows up because I was running short of breath and I ignored that because I thought it was because of pregnancy and then in November I could not walk, I felt as if my body was tired and I felt like kneeling. I was admitted here in Hospital A. I slept for 1 day. I slept on a chair because I was told that there were no beds. I slept on Thursday and on Friday I was discharged, I was seen by a doctor and he said there was nothing wrong with the baby and he said it may be blood pressure but it is starting so I had to come the following week.

I: How many months pregnant were you then?

R: I was four months pregnant.

I: When you say you slept on a chair what do you mean?

R: I slept on a chair because there were no beds. I arrived at night and I was told that there was nothing wrong with the baby I could go home and be seen by the doctor the next morning. It was too late for me to go home and I realized that I would not be able to come back tomorrow because the place where I stay is too far and when I started having a problem I phoned an ambulance and I was told that the ambulance cannot fetch us because there was no ambulance where I stayed and we had to hire a car and I arrived here around 10pm and the transport left me. I therefore decide to sleep on the chair because I knew I would not be able to come back.

I: Did the Doctors examine you?

R: Yes, they checked me and said I was fine and gave me an injection.

I: You said your body was swollen when you were attending the clinic there?

R: Yes. And they were saying they do not see anything. If you look at my card you will see that I was visiting the clinic today and I would also go there the next day because I was becoming worse.

I: They said they did not see anything?

R: They did not see anything. They did not see any high blood pressure, and they did not see anything. My feet were also swollen and I could not walk because I felt pain when walking.

I: And then which is the second clinic that you went to.

R: I went to Clinic 2.

I: Where is Clinic 2? Is it close to where you stay?

R: No it is not close because I spend R30 on transport when I go there.

I: But you had to go to Clinic 2 even if it was far?

R: Yes I had to go because I was not happy because I was not getting any explanation and not getting any help. But when I went to Clinic 2 they checked me and they told me that pregnant people get swollen sometimes. They did not see any blood pressure and they said it was not too high. I then had to go home because my months were already close. Then I went home.

I: They also did not see any high blood pressure. Why do you think Clinic 2 is better than Clinic 1?

R: They gave me a better treatment because they took time to explain and they told me that they did not have vitamin B. Complex in their stock and that they will give me the white pills. They told me that they will give me the white tablets and that I must stop attending the clinic in my area and attend the clinic in their clinic so that they can check whether my swelling was becoming better or not.

ANNEXURE 1: REQUEST FOR PERMISSION TO CONDUCT A STUDY

P.O. Box 12915

Amalinda

East London

5219

20 June 2008

The Chief Executive Officer

East London Hospital Complex

Private Bag X13003

Cambridge

5207

Dear Sir

Request for permission to conduct a study at the East London Hospital Complex

I am a second year Master of Public Health Student at the University of Witwatersrand. For partial fulfilment of my studies I am required to conduct a research project in my field of study. I am interested in conducting a study in Maternal Health services.

The population will be women from East London Hospital Complex and the referral area who have recovered or are recovering from serious morbidity during pregnancy and pueperium. Participants will be given full information in their preferred language about the study and they will be requested to sign the consent form. They will be given a chance to ask questions. Personal interviews and record reviews will be conducted. Interviews will be tape-recorded and the tapes will be erased on completion of the study. Participants who are still in severe pain or those who have not recovered to the extent of understanding that they are participating in the research study will be excluded from the study.

Please find enclosed a copy of my research proposal, an interview guide that will be used during the interviews, data collection sheet that will be used during document reviews and the consent form and the information sheets in English and Xhosa.

I hope this request will receive your favourable consideration.

Yours respectfully,

Lindeka Mangesi

TEL: Home: 043 731 2742

Work : 040 609 2483

ANNEXURE 2: THE CONSENT

The consent (i)

Information sheet: (Please read before filling in the consent form)

RESEARCHER: …Lindeka Mangesi…….. TEL. (home): 043 731 2742…….

TEL. (work): 040 609 2483……..

COURSE : MASTER OF PUBLIC HEALTH

INSTITUTION : UNIVERSITY OF WITWATERSRAND

RESEARCH TITLE : NEAR-MISSES IN MATERNAL HEALTH SERVICE IN EAST LONDON HOSPITAL COMPLEX AND REFRRAL AREA: PATIENT-ORIENTED PERSPECTIVES

Dear Madam,

My name is Lindeka and I am doing my second year Masters Degree with the University of Witwatersrand. It is the requirement of this university that students at this level of study conduct a research study. I am inviting you to participate in the study as explained below. My full details appear above.

Background: A high rate of death of women during pregnancy, delivery and shortly after delivery has caused the Ministry of Health to focus their attention in finding the cause of death of these women. A team of health experts have been assigned a task of identifying the problems and suggesting a plan of action that could prevent these deaths. Taking a closer look at the patient‟s records and coming up with recommendations did not solve the problem. Studying women who had serious illnesses during pregnancy, delivery and shortly after delivery would complement the study on maternal deaths and therefore improve the suggested preventive measures.

Purpose: The purpose of this study is to find out from women who have recovered from serious illnesses during pregnancy, delivery and shortly after delivery the possible reasons that led to them coming close to death and the possible ways of preventing these incidents. The information will be used to suggest corrective measures so that these serious illnesses and deaths could be prevented.

Benefits and risks: There are no expected physical risks from participating in the study as the participants will only be interviewed however; there may be emotional risks as some questions may bring about sad memories to some participants. There will not be any financial benefits from participating in the study. Your participation will help improve the health services and it will therefore benefit women who will fall pregnant in the future.

Participation in the study: Your participation in the study will be through personal interviews

and having your hospital records reviewed. Your participation is completely voluntary. You have a right to refuse to participate or to withdraw from participating in the study without any penalty. You have a right to refuse answering some of the questions asked.

Anonymity and confidentiality: The information that you will be providing will be kept anonymous and confidential. Only the research team will have access to this information. The study may be published but the names of participants will not appear.

Questions and concerns: You are allowed to ask questions and voice out your concerns about the study. The researcher will try and answers your questions to your satisfaction.

Approval: Permission to conduct the study has been granted by the East London Hospital Complex managers and by the Eastern Cape Department of Health. The study has also been approved by the Ethics committee of the University of Witwatersrand and nothing has been found unethical about the study. The written approvals will be given to you for your viewing.

NB: Should you find anything unethical about the way the study is conducted, please feel free to contact the chairperson on the Ethics Committee of the University of Witwatersrand, Dr R.D. Fihla at 011 717 5219.

Thank you for your time.

The consent (ii)

(Kindly complete if you wish to participate in the study)

This is to certify that I, …….(Print name) agree to participate as a subject in the above-mentioned study. I understand that there will be no physical risks resulting from my participation in this study.

I give permission to engage in personal interviews and to have my hospital records reviewed. I am aware that the interviews will be tape-recorded and that on completion of research the tapes will be erased. The interviews may be published but my name will not appear and therefore will not be associated with the research.

I understand that I am free to deny any answer to any specific questions during the interview. I understand that I can withdraw my consent and terminate my participation anytime without penalty.

I have been given the opportunity to ask questions and my questions have been answered to my satisfaction.

PARTICIPANT:……SIGNED AT:……..DATE:……

WITNESS:…….SIGNED AT:……..DATE:……

RESEARCHER…… …SIGNED AT:……..DATE:……

ANNEXURE 3: THE CONSENT IN ISIXHOSA (LOCAL LANGUAGE)

Imvume (i)

Inkcazelo : (Nceda ufunde phambi kokuthatha inxaxheba)

UMPHANDI : Lindeka Mangesi… TEL. (Mobile): 083 378 2218

TEL. (work) : 040 609 3792

IZIFUNDO : MASTER OF PUBLIC HEALTH

ISIKOLO : UNIVERSITY OF WITWATERSRAND

ISIHLOKO : NEAR-MISSES IN MATERNAL HEALTH SERVICE IN EAST LONDON HOSPITAL COMPLEX AND REFRRAL AREA: PATIENT-ORIENTED PERSPECTIVES

Igama lam nguLindeka yaye ndenza izifundo zebanga eliphakamileyo kwi University i Witwatersrand. Kungumgaqo wale University ukuba umfundi okwelibanga enze uphando olungqamene nezifundo ezo azenzayo. Ndiyakucela ukuba uthabathe inxaxheba kolu phando njengoko luchaziwe ngezantsi. Inkcukacha zam ziyafumaneka ngasentla.

Intsusa: Izinga eliphakamileyo lokufa komama ngexesha bekhulelwe, ixesha lokubeleka okanye ithutyana nje elincinane bebelekile lwenza inxalabo kuMzantsi Africa. Inzamezo kufumana unobangela woku neendlela zokukhusela oku kufa ngokufumana ulwazi kwincadi zabaguli abathe basweleka azibanga nampumelelo. Ukufunda nzulu ngamakhosikazi/ amakhosazana abe egula kakhulu ngexesha lokukhulelwa, lokubeleka kwanasemva kokubeleka aze asinda cebeshu kunokunceda ukongeza ulwazi kwizifundo eziqhubekayo ezingoomama abasweleke ngexesha bekhulelwe, ngexesha bebeleka nasemva kokubeleka kwaye kunokunceda ukwenza ngcono indlela zokhuselo.

Injongo: Injongo yezizifundo kukufumana onobangela okanye izinto ezibenegalelo ekuguleni kakhulu ngexesha lokukhulelwa, ngexesha lokubeleka nasemva kokubeleka kumakhosikazi aye asinda cebeshu, neendlela ekunokuthintelwa ngazo eziziganeko zinokukhokelela ekufeni. Le nkcazelo izakusetyenziswa ukuza neziphakamiso kwiindlela zokuthintela ezizigulo zinobungozi nokufa.

Inzuzo nomngcipheko: Akukho mngcipheko ulindelekileyo ngoba abathathi-nxaxheba bayakuba nodliwano-ndlebe kuphela kodwa kunokubakho umngcipheko ngokwasemphefumlweni xa oluthethwa-thethwano lunokubuyisela iinkumbulo ezibuhlungu kubanye abathathi-nxaxheba. Akuzokubakho nzuzo yamali ngokuthatha inxaxheba kwesisifundo. Inxaxheba yakho izakunceda ukwenza ngcono inkonzo yezempilo yaye ingaba nenzuzo kumakhosikazi aya kuthi akhulelwe kwixa elizayo.

Ukuthatha inxaxheba: Inxaxheba yakho izakuba ngohlobo lodliwano-ndlebe oluya kuthatha malunga nemizuzu engamashumi amane anesihlanu ukuya kwiyure nokuphenya iincwadi zakho zokugula. Oluthethwa-thethwano luza kushicilelwa ngqo. Inxaxheba yakho ingokuzithandela kwakho. Unelungelo lokwala ukuthatha inxaxheba okanye ukurhoxa ngaphandle kwesohlwayo. Unelungelo lokwala ukuphendula nawuphina kwimibuzo ebuzwayo.

Ukungaziwa-bani: Le nkcazeloiyakufumanekakwesisifundoizakugcinwaiyimfihlofuthiingaziwa-bani. Le nkcazelo iyakwaziwa kuphela yintlanganisela yabaphandi abathatha inxaxheba kwesi sifundo. Iziphumo zesisifundo zisenokupapashwa kodwa amagama abathathi-nxaxheba awayikukhankanywa.

Imibuzo nokuyinxalabo: Uvumelekile ukubuza imibuzo nokuphalaza okuyinxalabo kuwe ngesi sifundo. Umphandi uyakuzama ukuyiphendula imibuzo yakho kwizinga elikwanelisayo.

Imvume: Imvume yokuqhuba esisifundo ifunyenwe kubaphathi besibhedlela iEast London

Hospital Complex ezizibhedlela iCecilia Makiwane neFrere, nakwisebe lezempilo. Esi sifundo sivunywe nayikomiti ephonononga ubume baso kwiYuniversity iWitwatersrand. Uzakunikwa amaphepha-mvume asuka kulemizi ikhankanyiweyo ukuze uwabone.

Iinxalabo ezinxulumene nesimilo/impatho: Ukuba unesikhalazo malunga nesimilo/impatho enxulumene nendlela esiqhutywa ngayo esisifundo nceda uqhagamshelane noNksk. Bronwyn Harris ku 011 242 9905 okanye uNksk. Anissa Keshav ku 011 717 1234.

Enkosi ngexesha lakho

Imvume (ii)

Udliwano-ndlebe nophenyo lweencwadi

(Nceda ugcwalise ukuba unomnqweno wokuthatha inxaxheba)

Oku kukuqinisekisa ukuba mna, …….(Bhala igama) ndiyavuma ukuthatha inxaxheba kwesi sifundo sikhankanywe ngasentla. Ndiyayiqonda ukuba akuyikubakho mngcipheko ngokwasemzimbeni ongumphumela wokuthatha inxaxheba kwam kwesisifundo.

Ndinika imvume yokuthatha inxaxheba kudliwano-ndlebe nokuphenywa kwencwadi zokugula zam zasesibhedlela. Ndiyayiqonda into yokuba le nkcazelo inokupapashwa kodwa igama lam aliyi kuvela ngako oko aliyi kunxulunyaniswa noluphando.

Ndiyayiqonda into yokuba ndinelungelo lokwala ukuphendula nawuphina kwimibuzo ebuzwayo ngexesha lodliwano-ndlebe. Ndiyayiqonda into yokuba ndingarhoxa okanye ndiyeke ukuthatha inxaxheba nangawuphi umzuzu ngaphandle kwesohlwayo.

Ndilinikiwe ithuba lokubuza imibuzo yaye imibuzo yam iphendulwe ngokundanelisayo.

Kutyikitya:

OTHATHA INXAXHEBA:……INDAWO……USUKU:…….....

INGQINA:……..INDAWO:……USUKU:……...

UMPHANDI:…….INDAWO:…….USUKU:…….....

Imvume (iii)

Ukushicilelwa kodliwano-ndlebe: (Nceda ugcwalise ukuba unomnqweno wokuthatha inxaxheba)

Oku kukuqinisekisa ukuba mna, ……. (Bhala igama) ndiyavuma ukuthatha inxaxheba kwesi sifundo sikhankanywe ngasentla. Ndiyayiqonda ukuba akuyi kubakho mngcipheko ngokwasemzimbeni ongumphumela wokuthatha inxaxheba kwam kwesi sifundo.

Ndinika imvume yokushicilelwa kodliwano-ndlebe. Ndiyazi ukuba ukugqitywa kolu phando olu lwazi lushicilelweyo lunonkugcinwa ithuba elingangeminyaka emithandathu luze lucinywe emva koko. Ndiyayiqonda into yokuba le nkcazelo inokupapashwa kodwa igama lam aliyi kuvela ngako oko aliyi kunxulunyaniswa nolu phando.

Ndiyayiqonda into yokuba ndinelungelo lokwala ukuphendula nawuphina kwimibuzo ebuzwayo ngexesha lodliwano-ndlebe. Ndiyayiqonda into yokuba ndingarhoxa okanye ndiyeke ukuthatha inxaxheba nangawuphi umzuzu ngaphandle kwesohlwayo.

Ndilinikiwe ithuba lokubuza imibuzo yaye imibuzo yam iphendulwe ngokundanelisayo.

Kutyikitya:

OTHATHA INXAXHEBA:……INDAWO……USUKU:…….....

INGQINA:……..INDAWO:……USUKU:……...

UMPHANDI:…….INDAWO:…….USUKU……

ANNEXURE 4: ETHICS APPROVAL (UNIVERSITY OF WITWATERSRAND)

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Mangesi

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M081147**
PROJECT	Near-Misses in Maternal health Services in South Africa: Patients' Perspectives from East london Hospital Complex and Referral Area
INVESTIGATORS	Ms L Mangesi
DEPARTMENT	School of Public Health
DATE CONSIDERED	08.11.28
DECISION OF THE COMMITTEE*	

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE **CHAIRPERSON** .....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : B Harris

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

ANNEXURE 5: PERMISSION (EASTERN CAPE DEPARTMENT OF HEALTH)

Eastern Cape Department of Health

Enquiries: Vuyokazi Poswayo
Tel No: 040 608 3408
Date: 16 February 2009
e-mail address: vuyo.poswayo@yahoo.com
Fax No: 040 609 3784

Dear Ms L Mangesi

Re: Near-misses in maternal health services in South Africa: Patients' perspectives from East London hospital complex and referral area

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants. You will not impose or force individuals or possible research participants to participate in you study. Research participants have a right to withdraw anytime they want to. However, you shall be responsible in dealing with any adverse effects following the research treatment provided in your study.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

V Poswayo

EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT

DATE 16/02/09

ANNEXURE 6: PERMISSION (EAST LONDON HOSPITAL COMPLEX)

Province of the
EASTERN CAPE
HEALTH

Office of the Chief Executive Officer• Room 4.60 • Frere Hospital 4th Floor • Amalinda Main Road • East London • Eastern Cape
Private Bag X 9047 • East London • 5200 • REPUBLIC OF SOUTH AFRICA
Tel.: +27 (0)43 709 2360 • Fax: +27 (0)43 709 2484 • Email: Lerato.kizito@impilo.ecprov.gov.za
Website: www.ecdoh.gov.za

10 February 2009

Ms. Lindeka Mangesi
P.o. Box 14081
Wesbank
5218

Dear Ms. Mangesi

RE: REQUEST FOR PERMISSION TO CONDUCT STUDY RESEARCH AT THE EAST LONDON HOSPITAL COMPLEX

Following your request on the above-mentioned subject, and the subsequent clearance by the Ethics Committee, this serves as a formal permission to allow you to conduct your research at the East London Hospital Complex.

You are requested to liaise directly with the Acting Head of Clinical Governance's office at their telephone number 0437092135 or their fax number 0437092443 for any assistance.

We wish you all the best for your studies.

Yours sincerely

LMosana

LUVUYO MOSANA (MR)
CHIEF EXECUTIVE OFFICER

CC – Acting Head: Clinical Governance

ANNEXURE 7: THE CASE STUDY PROTOCOL

NEAR-MISSES IN MATERNAL HEALTH SERVICE IN EASTLONDON HOSPITAL COMPLEX AND REFRRAL AREA: PATIENT-ORIENTED PERSPECTIVES

CASE STUDY PROTOCOL

This case study protocol gives guidance to areas that will be explored. The flow of these in-depth interviews will determine the order of the areas explored.

1. Objectives

- To assess the obstetric history of women who are classified as near-misses (including current pregnancies for those participants who are still pregnant)
- To explore participants‟ perspectives of factors contributing to near-misses (health systems, socio-economic, geographic factors, etc.)
- To participants‟ opinions of strategies that may prevent near-misses
- To participants‟ perspectives

2. Data collection

Two sets of in depth interviews. Interview 1 at East London Hospital Complex where near-misses were identified, Interview 2 at venues chosen by participants (mostly participants‟ homes). Field notes made from observations made during the interviews.

3. Field procedures

Permission to be sought from the operational manager, showing approval from the Department of Health

Appropriate participants to be identified

Explanation given to the prospective participant about the study, given information sheet to read, information on the right not to participate and withdraw, benefits and risks explained. Written consent sought from participant

4. Questions to be asked

4.1 Demographic information (in this pregnancy):

Age, race, nationality, educational status, employment status, role in household, number in household, household income, age and sex of household head, socio-economic status, type of area (rural, urban, peri-urban)

4.2 Obstetric History:

Number of pregnancies, deliveries, miscarriages, causes of miscarriages if any, partners and their ages, household situation in different pregnancies, whether pregnancies were planned or not, factors resulting in unplanned pregnancies if any of the pregnancies were not planned, feelings about pregnancy, reaction of the baby‟s/babies‟ father (s) to the pregnancy/ pregnancies (starting from first pregnancy if more than one pregnancy) or reaction of the parents in cases of young and unmarried women

4.3 Beliefs, knowledge and practices around reproductive health services:

Beliefs, knowledge and practices around family planning services, antenatal services, postnatal services, baby clinic in all pregnancies, positive and negative experiences of seeking and receiving reproductive health services at different stages of their

reproductive health cycle in different pregnancies (starting from the first pregnancy): Availability of the local clinic, distance to the local clinic, treatment at the local clinic, Challenges experienced to access the clinic, routes to the local clinic

4.4 Influence of social networks (friends, partner and family) around use of reproductive health services

4.5 Perceptions of reproductive health services in all pregnancies (starting from pre-pregnancy period until postnatal period).

4.6 Near-miss experience:

Their experiences or warning signs before they had a near-miss experience, response to the warning signs, response to the near-miss experience, experiences of seeking transport, referral system, factors that may have contributed to them being near-misses, feelings about their near-misses experiences

4.7 Future reproductive health practices:

Future practices around family planning, antenatal care and other practices during pregnancy

4.8 Opinions on how the reproductive health services can be improved:

How factors that contribute to women being near-misses can be avoided or minimized.

5. Data analysis

Codes developed by researcher and supervisor, data managed using MAXqda data analysis software. WHO AAAQ Framework used to measure access of reproductive health services following the reproductive health cycle. Categories and themes developed from data.

6. Dissemination of findings

Findings will be made available at the University of Witwatersrand and at the Eastern Cape Department of Health. Findings will also be presented in workshops and seminars and published in journals.