“Psychiatric sequelae and mental health aftercare experiences in women who had a life-threatening complication in pregnancy and those with uncomplicated pregnancies: An explorative-descriptive study.”

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A thesis submitted to the Faculty of Health Sciences, University of Pretoria.

DECLARATION

I, Nadira Khamker, declare that this thesis is my own work. It is submitted to the University of Pretoria for the degree of Philosophy. It has not been submitted before for any degree at this or any other university.

----------Day of ----------2018

"There is in every women's heart a spark of heavenly fire which lies dormant in the broad daylight of prosperity, but which kindles up and beams and blazes in the dark hour of adversity." ***(Washington Irving)***

DEDICATION

Eternal gratitude and servitude to God Almighty for granting me life and the health to embark on this journey and thank you for the strength and wisdom to persevere.

This thesis is dedicated to my loving parents, Sadullah and Farida Khamker. Dad, thank you for watching over me and guiding me from Above and Mom, thank you for your love, constant support, encouragement and for bearing with me during this arduous journey.

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SUMMARY

Introduction

Studies in the literature indicate that women are vulnerable to develop psychiatric conditions during the perinatal period. Mental health is a neglected topic and that of women's mental health to a greater extent, with limited attention paid to these women in the South African public health sector. Furthermore, maternal mortality persists as a major public health problem in developing countries, despite global initiatives and strategies aimed at improving maternal health and decreasing mortality. An improvement in maternal health can ensue if together with a decrease in the number of maternal deaths, a reduction in the complications during pregnancy and the postpartum period occurs. Recognition and treatment of severe complications are important as they can have an adverse effect on women's health not only from a biological but a psychosocial perspective too. The study set out to determine whether women who experience severe life-threatening stressors during pregnancy are more vulnerable to develop psychiatric complications and what are their lived experiences after discharge from hospital?

Methods

A mixed-method study conducted at two hospitals in Pretoria, South Africa consisted of two arms, a qualitative and a quantitative arm executed in a parallel convergent manner. Data collection occurred concurrently and merging of the data occurred at the level of interpretation. Two groups of participants namely women who experienced life-threatening complications and those with uneventful pregnancies were selected and interviewed at four-time intervals namely, shortly after delivery, at six weeks, three months and six months postpartum. The quantitative arm consisted of completion of Level 1, symptom appropriate Level 2 cross-cutting symptoms measures and a WHO Disability Assessment. The qualitative arm consisted of in-depth semi-structured interviews of sixteen participants who were purposefully sampled to obtain maximum variation and richness of information.

Results

A total of eighty-nine women participated in the study. (Forty-six of whom were women with life-threatening complications and forty-three were women with uneventful pregnancies.) Women with life-threatening complications were more vulnerable to develop psychiatric sequelae and presented with a greater variation in their levels of functioning as compared to women with uneventful pregnancies.

Psychiatric sequelae included major depressive disorder, anxiety disorders, somatic symptoms, and cognitive impairments; sleep disturbances, anger, psychotic disorders and substance abuse. Common themes identified from the lived experiences included amongst others, feelings of inadequacy, guilt, loss and disappointment, fear of rejection, abandonment, and infidelity and feelings of anger.

Conclusion

Women in the present study were not only susceptible to risk that predisposed them to develop postpartum psychiatric complications, but also experienced life-threatening complications. These women displayed resilience in that they were able to adapt despite experiencing severe stressors and adversity. The women displayed acceptance, a will to survive and cope as well as strong belief and unwavering faith in God.

Glossary of Terms and Abbreviations

PTSD	Post-Traumatic Stress Disorder
PTS	Post-Traumatic Stress Symptoms
HIV	Human Immune Deficiency Virus
AIDS	Acquired Immune Deficiency syndrome
PMHP	Perinatal Mental Health Project
WHO	World Health Organization
MDG	Millennium Development Goals
DALYS	Disability Adjusted Living Years
NCCEMD	National committee for confidential enquiries into maternal deaths
ICD	International Classification of Disease
PPCM	Peri-partum cardiomyopathy
MDD	Major Depressive Disorder
OCD	Obsessive Compulsive Disorder
DSM	Diagnostic and Statistical Manual
PROMIS	Patient reported outcomes measurement information system
ICU	Intensive Care Unit
HELLP	Haemolysis elevated liver enzymes and low platelet count

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SECTION 1

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1 THE CONTEXT OF THE STUDY

1.1 INTRODUCTION

Psychiatric disorders associated with childbearing are a significant public health problem. These disorders that occur during the perinatal period are associated not only with morbidity and mortality in the affected women as well as with increased morbidity in their children. Exposure to maternal psychiatric illness may represent a stressful life event and may increase the child's vulnerability to future psychopathology. (Stuart, O'Hara and Blehar 1998:333)

An important aspect of safer childbirth in the 21st century is reducing maternal and child mortality. One of the goals established in the Millennium Declaration was a 75% decline in maternal mortality worldwide by 2015. (Hogan, Foreman, Naghavi, Ahn, Wang, Makela et al 2010:1609) However, in South Africa there is still an increased incidence of maternal and perinatal mortality rates in the postnatal period. This increase in perinatal mortality rates persists despite improvements and utilisation in antenatal care. Furthermore, "postnatal care in South Africa has not been adequately prioritized as a maternal health care service. As a result of these increased mortality rates found in the postnatal period, guidelines and systems need to be implemented to ensure that adequate care of women and that of her new-born should continue beyond the delivery." (Bekinska, Kunene, Mullick 2006:297) Furthermore, mental health is a neglected topic and that of women's mental health even more so, with little attention paid to these women in the South African public health sector (Moultrie and Kleintjes 2006:347)

1.2 POSTPARTUM PSYCHIATRIC CONDITIONS AND MATERNAL MENTAL HEALTH

The most common complication of childbirth in developed countries is perinatal psychiatric conditions with epidemiological studies indicating that women are more likely to be admitted to a psychiatric unit after giving birth than at any other time in their lives. Women are vulnerable to develop perinatal psychiatric conditions as a result of hormonal changes that occur during the perinatal period. These hormonal changes have been hypothesized as possible etiological factors in the development of postpartum psychiatric conditions. (Lusskin, Pundiak and Habib 2007)

Furthermore, there is an almost 35-fold increase in relative risk for a woman to develop a psychotic episode during the perinatal period as the first twelve months after childbirth is considered a vulnerable period for women to develop such complications. The incidence of postpartum psychosis varies from 1–3 per 1 000 births and is found to be consistent across cultural divides (Fatoye et al 2002: 508) Despite these increased risks, and although both mother and child are seen by health professionals during the perinatal period, data on the prevalence of postpartum morbidity is scarce.

Maternal depression that occurs during the perinatal period is associated with an increased burden of disease in mother and child alike, as an ill mother can have an effect on child health and development. The sequelae of depression and its effect on both mother and child highlight the need for prompt diagnosis and management of these conditions. Postpartum depression is the most frequently studied postpartum condition and lifetime rates of mood and severe depressive symptoms during the postpartum period range between 10 and 15%. (Mian 2005: 389) A study conducted in Khayelitsha, South Africa found prevalence rates of 34% in maternal depression at two months postpartum. The figure was almost three times higher than that found in studies conducted in developed countries. (Cooper, Tomlinson, Swartz, Woolga, Murray and Molteno 1999) Early detection and treatment of perinatal psychiatric conditions is important as these conditions can affect both the mother and child adversely. (Stuart et al 1998: 334; Oates 2003: 280) As a result of these potential risks, it is imperative to highlight and educate health practitioners – including obstetricians and midwives, as well as paediatricians and primary health care practitioners who have contact with mothers during the perinatal period – about this condition and its sequelae to avert negative or adverse outcomes to both mother and child.

Anxiety disorders are estimated to affect 10% of new mothers. Mothers who experience stressful life events in addition to perinatal medical complications are at risk for experiencing anxiety-related conditions. These conditions cannot only impair maternal functioning but also impact on the mother-infant relationship. (Fatoye 2002: 508; Fottrell 2010: 24; Miller, Pallant and Negri 2006: 2) Furthermore, the experience of trauma severity during the perinatal period is a predictor for the development of post-traumatic symptoms. A study conducted in Nigeria reported a 5.9% prevalence of PTSD in the pregnant population.

The factors independently associated with PTSD included hospital admissions due to pregnancy complications, instrumental deliveries, emergency caesarean sections and poor maternal experience of control during childbirth.

Although there is an increasing number of studies found in the literature pertaining to PTSD related to childbirth, there are a limited number of studies that have documented effective intervention strategies in these conditions. (Zaers et al 2008: 62; Ayers, Joseph, McKenzie-McHarq, Slade and Wijma, 2008: 240)

Another important illness that has a significant impact on mental health of women during the postpartum period is HIV/AIDS-related conditions. According to the Perinatal Mental Health Project (PMHP), almost half (43.7%) of people living with HIV/AIDS in South Africa have an identifiable mental illness that requires an intervention. This number is significantly higher than that found in the general population where the prevalence of mental illness is 16.5%. The presence of HIV infection can predispose women to mental distress. Furthermore, the burden of living with HIV infection makes women vulnerable to developing mental illness during and after pregnancy, which further affects their ability to access and utilize maternal health services. (Perinatal Mental Health Project 2013)

1.3 MATERNAL MORTALITY AND SEVERE ACUTE MATERNAL MORBIDITY

Maternal mortality persists as a major public health issue. The WHO estimated that there were over 500 000 maternal deaths worldwide in 2005. Eighty-six percent of these deaths were found to occur in developing countries of Africa and Asia, and less than 1% in developed countries. Maternal mortality rates in sub-Saharan Africa are as high as 900 deaths per 100 000 new-borns. (Reichenheim, Zylbersztajn, Moreas and Lobato 2009:337)

Severe obstetric complications are common in developing countries. These complications could be due to the lack of accessible good-quality emergency services. Thus, women who do not receive prompt care suffer from acute complications; furthermore, they may become critically ill (near miss) or even die from the complications. It is therefore important to recognize and treat severe obstetric complications, as these might lead to long-term complications for women's health, from both a physical and mental health aspect. (Fottrell et al 2010: 24; Kaaya, Mbwambo, Kilonzo, van den Borne, Leshabari, Fawzi et al 2010; Weeks, Lavender, Nazziwa and Mirembe 2005:1302)

Approximately 1.5 million women worldwide suffer from near miss complications during pregnancy and childbirth ever year. These complications are of such severity that the woman's survival is threatened.

A near-miss event, or severe acute maternal morbidity (SAMM), is defined as a woman experiencing and surviving a severe health condition during pregnancy, childbirth or the postpartum period. According to the literature, (Say, Souza and Pattinson 2009:288) these women are identified according to three approaches, namely, disease-specific criteria, intervention-based criteria and organ system-based criteria (Appendix B).

The study of near miss cases could assist in evaluating the quality of obstetric care, which can lead to an improved understanding of the causes of maternal death. However, there is a lack of research on the experiences of women who survive severe complications in all countries, and studies that describe the diverse experiences over an adequate period of time are rare. (Souza et al 2010:117; Say et al 2009:294)

A master's study (Nkosi 2011) conducted at Steve Biko Academic Hospital and Kalafong Hospital in Pretoria, where the present study was conducted, consisted of interviews with women who experienced near-miss events. The complications experienced by patients in the study included major depressive disorder, self-limiting psychotic symptoms probably as a result of a delirium, memory impairments, adjustment disorders, anger, as well as sleep and sexual dysfunction. Furthermore, from the narratives of the women's experiences, an impending sense of death and fear was a prominent finding. The women also complained of memory impairments, sleep disturbances, impaired levels of functioning, feelings of guilt and repression, and self-blame. Women who had foetal losses also reported isolating themselves from others and a prominent theme identified in majority of the women was feelings of anger, directed either at themselves or towards others, especially health workers whom they believed mismanaged them, resulting in a poor outcome of their pregnancies.

Another study in Burkina Faso also found that women in the near miss perinatal group were more likely to experience mental health problems. The women expressed more suicidal ideation and the babies born to mothers who experienced a near miss were more prone to die post discharge. The study also found an increased rate of mortality among women who experienced a near miss in the postpartum period. It was further reported that women in the near miss group tended to use postnatal services more frequently than women with uncomplicated pregnancies, expressed more negative feelings and lack of self-esteem for up to a year postpartum, and were under pressure to have another pregnancy relatively soon after the near miss event. Furthermore, psychological distress expressed in the form of physical symptoms was also found to be prominent in the group of women who experienced a perinatal death. Studies show that some of the women are more likely to be diagnosed with or to report health problems at 6 and 12 months postpartum.

There also appears to be limited recognition of the difficulties experienced by women who have suffered severe obstetric complications or perinatal death. Filippi et al highlighted in their study that it is important to reach out to women who have lost their babies because these women may not have access to services in the postpartum period, as most of the services available during this period focus on child health.

Studies have indicated that the focus of postnatal services in developing countries are directed primarily towards the child and reducing child mortality, paying limited attention to the need to improve maternal health and survival. There is only one published intervention trial in a developing country that tested the provision of postnatal care to women, but women with complications were excluded. Filippi et al further recommended that women with near-miss complications might benefit from active screening of emotional and physical complications during postnatal visits or other periods of contact with health professionals in the postpartum period. (Fottrell et al. 2010:23 Fillippi, Goufodji, Sisimanisis, Kanhonou, Fottrell, Ronsmans et al 2010: 740)

A study conducted in Benin found women who experienced near miss complications and had a perinatal loss appeared to suffer more than those who had a live baby. The women described the postpartum period as an emotionally challenging time, and expressed feelings of sadness, worry and discouragement after the near-miss event. These symptoms were prominent when women were interviewed soon after birth. For a considerable period after the event, the women with near miss experienced financial difficulties (particularly debt incurred for the birth), emotional and physical complications, marital difficulties, and strained relations with family and in-laws. Some women described feeling pressured to have another pregnancy soon after the distressing events. These women felt desperate and described the traumatic birth and subsequent social, personal and economic instability as contributing to the feelings of desperation. Furthermore, the study showed that near miss was not associated with an increase in psychological complications at 6 and 12 months postpartum among women who had a live infant (as compared to women who had uncomplicated deliveries). However, women who experienced perinatal loss were predisposed to psychological complications, as was evident when the near miss group was compared to the other groups. (Fottrell et al. 2010: 23) It was further found that women's postpartum health was adversely affected by the negative life circumstances, which occurred subsequent to the near miss and perinatal loss. The women who experienced perinatal loss reported that spousal abuse began in the six months following delivery, and the rates were similar to lifetime prevalence rates of intimate partner violence reported in other studies.

A study of narratives of women who almost died during pregnancy and childbirth, conducted in Brazil by Souza, Ceccatti, Parpinelli, Krupa and Osis (2009) reported that most women who survive severe complications of pregnancy present with significant emotional reactions to severe maternal morbidity. These women presented not only with physical experiences, but also with feelings of impending death. The experiences resulted in women reviewing their life histories as well as their expectations for the future.

The authors also reported that women who had lost their babies, or had very sick babies, were particularly at risk for experiencing negative psychological sequelae. Furthermore, the authors described an acute stress disorder, which may occur as a result of severe maternal complications. Souza et al (2009) reported that describing the traumatic experiences aids knowledge and understanding of causes and effects of adverse life events in the context of maternal and perinatal health. They further indicated that the value of describing such a syndrome is that it raises awareness among health care providers of the non-physical aspects of complications related to pregnancy and childbirth.

As previously described, there is a paucity of studies on maternal mental health and complications during the postpartum period in developing countries. (Shen and Williamson 1999) An intensive search on the subject literature has revealed that few studies of this nature have been conducted in South Africa and a limited number have been conducted in sub-Saharan Africa. The Perinatal Mental Health Project (PMHP), which commenced in Cape Town more than ten years ago, recognised the need for maternal mental health services and aimed to act as an incubator for the development of maternal mental health interventions in low resource settings. The PMHP argued that the high prevalence of maternal depression in South Africa required that maternal mental health screening should be performed routinely on-site, and that screening should be sensitive to the local risk factors such as high rates of interpersonal and community violence, which may influence mental distress. (Perinatal Mental Health Project 2013)

An improvement in maternal conditions can only be achieved when a reduction in the number of deaths is accompanied by a reduction in the frequency of severe complications of pregnancy and the postpartum period. (Souza et al 2010:149) Although significant attention is given to determining the cause of medical complications in women during childbirth, the psychiatric complications that these women experience require further attention.

Furthermore, the stress diathesis model has been described as an etiological factor in a number of psychiatric conditions. This model posits that stressful situations can predispose vulnerable individuals to develop psychiatric complications. (Shen and Williamson 1999: 201)

1.4 RESEARCH QUESTIONS

Bearing the above in mind, the following research questions evolved.

- What happens to women who experience life-threatening stressors during pregnancy?
- Are they more vulnerable to developing psychiatric complications than women who have uneventful pregnancies?
- Furthermore, is there a difference in intensity and duration of psychiatric symptoms between women who experience life-threatening stressors and those with uneventful pregnancies?
- What are the lived experiences of these women who have experienced life-threatening stressors after discharge from hospital?

1.5 AIMS AND OBJECTIVES

1.5.1 Research aims

The formulation of the research questions led to the construction of the following aims of this mixed method study:

- To determine whether women who experience life-threatening events during pregnancy and the postpartum period are more vulnerable to developing psychiatric complications than women with uneventful pregnancies.
- To determine the extent to which the presence of psychiatric complications affects the functioning of these women and what resources are available to them in the health service during this vulnerable period in their lives.

- To examine the lived experiences of women who have had a life-threatening complication compared to those of women who have had uneventful pregnancies.

1.5.2 Research objectives

The objectives of the study are as follows:

- To explore and describe the experiences of women who have experienced life-threatening events in their pregnancies compared to those of women who have had uncomplicated pregnancies.
- To determine the risk of developing psychiatric complications among women who experience life-threatening events compared to those who have normal deliveries.
- To identify the impact of severe obstetric complications on postpartum mental health in mothers.
- To explore if there is an association between the life-threatening stressor and the psychiatric presentation in terms of:

  Type of symptoms

  Severity of symptoms

- To identify critical sites of health care intervention to meet the mental health care needs of women who have experienced near miss events.

1.6 RATIONALE FOR CONDUCTING THE STUDY

- The motivation for conducting this study relates to a keen interest in women's health, especially women's mental health. The study of women's reproductive health and mental health is an area of evolving research. As is evident from the studies cited, women are vulnerable to developing psychiatric complications in the postpartum period and there is growing recognition that severe obstetric complications can lead to long-term adverse consequences, not only for women's health, but for that of their children as well.
- Women's mental health is a relatively neglected area in the public health sector. Little attention is paid to psychiatric comorbidity in the postpartum period. With regard to developing countries, there is limited research on the mental health and the degree of disability of recently delivered women, particularly survivors of complications.

(Moultry and Kleintjes 2006) It is with this in mind that a study of this nature was embarked upon.

1.7 ANTICIPATED CONTRIBUTIONS OF THE STUDY

1.7.1 Theoretical and clinical contributions

Embarking on this study would provide:

- an understanding of the psychiatric complications that women who have a severe life-threatening complication in pregnancy experience;
- insight into the degrees of impairment that these women experience and how it affects their functionality;
- a platform for further research and targeted interventions for psychiatric conditions in the perinatal period (It is anticipated that it may lead to a better understanding of not only their difficulties but also their experiences when returning to their environments and what hurdles they experience during this vulnerable period in their lives.); and
- valuable information to obstetricians, paediatricians and primary health care workers (who have the most contact with mothers following delivery), through insights gained from these women's experiences.

1.7.2 Methodological contributions

- Research in psychiatry has predominantly been of a quantitative nature, with a recent introduction of qualitative studies. Therefore, a mixed methods study, employing the strengths of both methodologies, will be invaluable.

1.8 STRUCTURE OF THE DISSERTATION

The dissertation consists of four sections.

Section 1 "The study, existing knowledge and methodology"

This section incudes Chapters 1, 2 and 3

In Chapter 1, an introduction to the study is presented, and a brief overview of the literature pertaining to perinatal mental health and acute maternal morbidity is given.

This is followed by the formulation of the research question, a rationale for conducting the study, and the aims, objectives and anticipated contributions of the study.

The literature review is presented in Chapter 2. The chapter focuses on the various factors that influence maternal morbidity and mortality, with special attention to the woman who forms the nucleus around which interventions are targeted.

Furthermore, the Millennium Development Goals, which highlight the plight of maternal mortality, are addressed, as are the health systems, with particular attention being paid to the South African health system and the various policies aimed at promoting maternal wellbeing. Women's health is reviewed, with specific reference to psychiatric complications in women who have experienced a life-threatening stressor in pregnancy. As mentioned previously, there are at present a limited number of studies in the literature that focus on the psychiatric complications in women who experience life-threatening stressors.

In Chapter 3, the research methodology is discussed. The methodological approach in this study is that of a mixed method study, consisting of two arms – one qualitative and the other quantitative. The study was executed in a convergent parallel design. The literature on mixed methods is introduced and the paradigm debates are addressed. The quantitative arm entailed the completion of a Level 1 cross-cutting questionnaire by the research participants that served as a screening tool for psychiatric symptoms. In the presence of mild to severe symptoms, the researcher completed Level 2 questionnaires. As the Level 1 questionnaire served as a screening tool, other scales, which were validated in pregnant women, were used for diagnoses. Furthermore, the WHO Disability Assessment scale was completed to identify impairments in personal, social and occupational functioning.

The qualitative arm of the study entailed conducting in-depth, semi-structured interviews with research participants, as well as case studies of participants that were purposefully sampled. The sample included women who experienced life-threatening complications as well as women who had uneventful pregnancies.

Section 2: ***"The findings of the study***"

This section includes Chapters 4 and 5.

In Chapter 4, the results of the quantitative arm of the study are presented. These include the socio-demographic results, and results of functional impairments as elicited by the WHO Disability Assessment. The psychiatric sequelae identified from the Level 1 and Level 2 questionnaires are presented. The results of the individual psychiatric scales, such as the Becks Depression Inventory, are also presented. The common psychiatric sequelae experienced by study participants are presented.

Chapter 5 presents the results of the qualitative component of the study. These include the narratives of participants that were purposefully sampled for the case studies, namely women who experienced life-threatening complications as well as those who had uneventful pregnancies.

Common themes were identified using the grounded theory method and included both positive and negative aspects pertaining to the following categories: birth experiences, psychological and socio-cultural experiences, and health system related experiences. Positive and negative experiences regarding interactions with the interviewer are also described.

Section 3: ***"Psychiatric sequelae, narratives and integration"***

The section includes Chapters 6, 7and 8.

Chapter 6 presents a discussion of the quantitative results. Psychiatric sequelae occurred in women who experienced life-threatening stressors as well as those who had uneventful pregnancies. The psychiatric conditions that were identified in these participants included major depressive disorder, anxiety disorders, memory and sleep disturbances, psychotic disturbances, as well as manic and somatic symptoms. The symptoms were not enduring and decreased during the subsequent appointments. Furthermore, the participants experienced impairment in social and occupational functioning as depicted by the results of the WHO Disability Assessment Scale.

In Chapter 7, a discussion of the qualitative arm is presented. The participants from both groups, namely those with life-threatening complications and those with uneventful pregnancies, had either positive or negative views of the following: birth, psychological and socio-cultural experiences, religious experiences, experiences of the interview process, and

the health system. Later in the chapter, a literature review of the identified experiences described by the participants is presented.

In Chapter 8, a discussion of the combination of the two arms of the study, namely the qualitative and quantitative arms, is presented. The participants in the present study were not only susceptible to risk that predisposed them to developing postpartum psychiatric complications, but also to life-threatening complications that further increased the propensity to developing complications. A discussion of coping mechanisms that these participants employed is explored and the concept of resilience as well as the various factors that could have contributed to this resilience, including individual traits, the role of the community, and culture is discussed. A resounding factor in this study however was the religious practice and belief expressed by the study participants that contributed to this resilience.

Section 4: "***Concluding notes"***

Chapter 9 presents a summary of the dissertation and discusses the research validity, ethical considerations, and the strengths and limitations of the study. A summary of the findings of the study, as well as its implications and contributions, is also presented.

Chapter 10 includes personal reflections on the doctoral journey.

2 LITERATURE REVIEW

2.1 INTRODUCTION

Poor maternal mental health and maternal mortality are multifaceted conditions, with a number of factors influencing the outcome. The presence of psychiatric pathology cannot only be viewed from a biological perspective, as the psychosocial elements form an integral part of the disease process. The complex interaction of biological and psychosocial elements not only influences the disease process but also complications of the disease, as well as its prognosis. The link between women's reproductive health and mental health is an evolving area of research, and therefore, an understanding of psychobiological factors unique to women is imperative, as the stress of specific life events, such as the postpartum period, can affect female mental health from both a biological and a psychosocial perspective. (Chandra and Ranjan 2007:168)

Most of the literature on maternal mortality focuses on the medical, social and cultural causes, which vary according to country and geographical region. (Shen and Williamson 1999:201) The causes of maternal mortality are multifactorial, which would require that the social, economic and health status of women be addressed, if maternal mortality rates are to be reduced. Despite the important role that women play in the family and society, their needs are often unaddressed and neglected. Furthermore, despite over two decades of awareness, campaigning and commitment by the WHO Safe Motherhood movement, global health continues to be in a predicament as a result of the apparent resistance of decreasing maternal mortality. The United Nations 2009 report card on Millennium Development Goal 5 between 1990 and 2015 concluded that little progress had been made, especially in sub-Saharan Africa, where half of all maternal deaths take place. (United Nations 2009)

Approaching this literature review was a complex task, as this dissertation sets out to explore the psychiatric sequelae in a very specific group of women, namely those who have experienced a severe life-threatening stressor in their pregnancies. Extensive literature searches on studies conducted on this specific population have yielded limited results. In order to discuss this complex interplay of factors, this literature review is divided into three sections.

The first of these reviews the focus on important aspects of maternal mortality, morbidity and the Millennium Development Goals, as well as the absence of mental conditions from these goals.

In the second section, the health systems will be discussed, with special attention paid to the South African health system, as this is the context of the conditions to which the subjects in this research project have been exposed. The final section explores maternal mental health, with specific attention paid to psychiatric conditions in the perinatal period, as well as the psychiatric conditions of women who have experienced severe life-threatening events.

During the literature searches, a number of studies conducted in pregnancy and the postpartum period with respect to psychiatric conditions and treatment modalities came to the fore; they were, however, beyond the focus of this review.

2.2 MILLENNIUM DEVELOPMENT GOALS

The United Nations Millennium Summit was held in September 2000, where 189 heads of states and various international organizations signed the Millennium Declaration and made a commitment to achieve eight Millennium Development Goals (MDG) by the year 2015. The goals represented global consensus about measures that were required to reduce poverty and focus on improving the health, education and wellbeing of people in impoverished countries of the world. The eight goals address targets to:

- increase incomes;
- reduce hunger;
- achieve universal primary education;
- eliminate gender inequality;
- reduce maternal and child mortality;
- combat the spread of HIV/AIDS, tuberculosis and malaria;
- reverse the loss of natural resources and biodiversity;
- improve access to water, sanitation and good housing; and
- establish effective global partnerships.

This global awareness of the need to address and reduce maternal and child mortality was preceded by events, which highlighted the risks that pregnancy poses to women, especially those in developing countries. The first event was the announcement by the World Health Organization at the end of the UN Decade for Women, that half a million women were dying each year from obstetric complications, and the second was an article by Rosenfeld and Maine (Rosenfield and Maine 1985) which highlighted the fact that maternal and child

programmes focused on the child, with limited attention paid to factors that were causing women to die. The Safe Motherhood campaign was subsequently launched which heralded the awareness of safe motherhood as a core component of reproductive health. (Starrs 2006)

2.2.1 Mental health and the Millennium Development Goals

Although the Millennium Development Goals were established to address key issues in developing countries, mental health issues were not included in global health targets or agendas, (Miranda and Patel 2005: 0963) even though mental health is being prioritized as a major health problem in a number of developing countries. (Patel 2007:82)

It is important to note that mental disorders are amongst the most important causes of sickness, disability and premature mortality in certain groups, especially in developing countries, and that these disorders are not only associated with social determinants, such as poverty, gender inequality, poor physical health (including having HIV/AIDS), and poor maternal and child health. (Miranda and Patel 2005: 0964) Although mental health is considered a low global health priority, it is important to address mental health problems, as they form an integral part of health system interventions and are thus necessary to achieve some of the Millennium Development Goals. This was indicated by a large number of population-based studies of mental disorders, which have consistently shown that poor and marginalized people are at an increased risk of suffering from psychiatric conditions. (Miranda and Patel 2005:0963) Psychiatric illness has been shown to play an important role when matters of global health concern, such as violence, displacement and women's health, were addressed. Neuropsychiatric disorders account for 9.8% of the total burden of disease in low- and middle-income countries. Unipolar depressive disorders account for 3.1% of the total burden of disease attributable to non-communicable conditions. (Patel 2007:83)

Women's health especially with attention focused on sexual and reproductive health is now being recognised as a global health priority. (Ribeiro, Jacobson, Mathers and Garcia-Moreno 2008: 82) According to the World Health Organization Global Burden of Diseases study of 2005, neuropsychiatric disorders were estimated to be responsible for 2.5% of all deaths in women aged 15 years and older worldwide. The study revealed that women are more likely than men to develop neuropsychiatric disorders as observed in low- and high-income countries.

Women experience more migraines, post-traumatic stress disorder, panic disorder, Alzheimer's and other dementias, unipolar depressive disorder, insomnia and obsessive-compulsive disorder. (WHO 2008)

Depression is also the leading cause of burden of disease, as well as the single leading cause of 'years lived with disability', along with schizophrenia and alcohol-use disorders. Self-inflicted injuries accounted for 1.5% of deaths in low-income countries and for more than 2% of total deaths in Europe and Central Asia.

Although these disorders may only account for a fraction of all deaths in women, they are responsible for 27.6% of disability-adjusted living years (DALYs) worldwide for women over 15 years. Furthermore, mortality statistics do not highlight the true burden of mental health disorders, which account for about 19.1% of all DALYs. (WHO 2008)

One of the most common health problems affecting mothers during pregnancy and after childbirth is depression. (Miranda and Patel 2005) A large number of studies from the developing countries inform that between 10 and 30% of mothers suffer from depression. (Miranda and Patel 2005; Cooper, Tomlinson, Swartz, Woolgar, Murray and Molteno 1999; Murray, Cooper and Hipwell 2003) This condition may be missed, as many of the core features, such as fatigue and poor sleep, are also symptoms associated with new motherhood. Maternal depression does not only have an effect on the mother but can also affect the child's ability to thrive. Depression may impair the mother's ability to not only care for herself, but for her child. Known risk factors of stressful life experiences, such as exposure to violence and poor physical health, can predispose women to developing psychiatric conditions. (Miranda and Patel 2005:0962; Patel 2007:87)

Suicide is a leading cause of maternal deaths in developed countries and is now also a leading cause of death in young women of reproductive age in India and China. (Oates 2003:279; Aaron, Joseph, Abraham, Muliyil, George, Prasad et al 2004:117; Philips, Li and Zhang 2002:835)

Furthermore, women who become pregnant in developing countries face a risk of death due to pregnancy that is more than 300 times higher than that faced by women in developed countries. (Shah and Say 2007:18) The average maternal mortality rate in developed countries in 1990, was 27 per 100 000 live births, whilst in countries such as Angola, Bhutan, Chad, Guinea, Nepal, Sierra Leone and Somalia, the rates were approximately 1 500 per 100 000 live births. (WHO 1996)

Between a quarter and a third of deaths of women in their reproductive years in most developing countries have pregnancy-related causes. (Hill, Thomas, AbouZahr, Walker, Say and Suzuki 2007: 1317; Royston and Armstrong 1989:31)

2.3 MATERNAL MORTALITY

4.7 million mothers, new-borns and children die each year in sub-Saharan Africa. Of these, 265 000 mothers die due to complications of pregnancy and childbirth. (United Nations Children's Fund 2009:3) This amounts to approximately 13 000 deaths daily, which accounts for half of the world's maternal deaths. (Stanton, Lawn, Rahman, Wilczynska-Ketende and Hill 2006:1487) Worldwide, more than 500 000 women die from pregnancy and childbirth every year, (WHO 2004a: 1) and ninety-nine percent of these deaths occur in developing countries. These alarming numbers indicate that the risk of a woman dying in childbirth is 250 times higher in sub-Saharan Africa than in developed countries. (WHO 2004a: 1)

Most women in sub-Saharan Africa deliver alone, with a large number of the deaths occurring in rural settings where skilled birth attendants may not be available, or there may be a delay in reaching appropriate facilities for emergency obstetric care. (Fortney, Susanti, Gadalla, Saleh, Feldblum and Potts 1988:21)

Although certain pregnancies are classified as high-risk, most of the cases deliver normally; however, life-threatening complications can occur in pregnancies, which were identified as low-risk. (Greenwood, Greenwood, Bradley, Williams, Shenton, Tulloch et al 1987:635) Maternal mortality is used as an indicator of the status of women, their access to health care and the ability of the health care system to respond to their needs. This is difficult to measure in areas where civil registration of causes of death occurs. A number of approaches have been developed for measuring maternal mortality under these circumstances, but they may be of limited use for regular, short -term monitoring. (WHO 2004b) Furthermore, statistics on levels of maternal mortality may be insufficient, as information pertaining to preventative factors is also required. Maternal deaths were made a notifiable condition in 1997 and the National Committee for Confidential Enquiries into Maternal Deaths (NCCEMD) secretariat is responsible for coordinating the process of notification, reporting and making recommendations. (Ronsmans and Graham 2006:1189)

The data collected during the enquiries provide an understanding of the primary factors contributing to death, which are either direct or indirect, avoidable factors, missed opportunities, and standard of care.

Gathering this information is important as it highlights not only potential areas of clinical intervention but also avoidable or remediable factors in the health sector, community or public health-related areas. (WHO 2004b: 4)

2.3.1 Definition of maternal deaths

A maternal death, as defined by ICD-10, is" the death of a woman while pregnant or within 42 days of the end of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes. "(WHO 2004b: 4)

Maternal deaths can then either be:

- **direct**, resulting from conditions or complications or their management, unique to pregnancy that can occur during the antenatal, intra-partum or postpartum period; or
- **indirect**, resulting from an existing disease or a disease developing during pregnancy, which was not due to direct obstetric causes, but was aggravated by the physiological effects of pregnancy. An example of indirect deaths would be HIV-associated deaths, which may be one of the leading causes of death among pregnant or recently delivered women in many countries. (WHO 2004b: 24)

ICD-10 introduced the following two additional terms that relate to maternal deaths:

- Pregnancy-related death is defined as the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the cause of the death. Pregnancy-related deaths include deaths from any cause, including accidental and incidental causes. Incidental deaths would have occurred even if the woman had not been pregnant.
- Late maternal death is the death of a woman from direct or indirect obstetric causes more than 42 days, but less than one year, after the termination of pregnancy.

There is a need to accurately define and monitor maternal mortality in order to improve maternal health. Three distinct measures of maternal mortality are used, namely:

- maternal mortality ratio,
- maternal mortality rate, and
- lifetime risk of maternal death.

Maternal mortality ratio is a measure of the risk of death once a woman has become pregnant, this is the number of maternal deaths per 100 000 live births during a given time period.

Maternal mortality rate reflects the frequency with which women are exposed to risk through fertility and refers to the number of maternal deaths per 100 000 women of reproductive age during a given period. **Lifetime risk of maternal death** takes into account both the probability of becoming pregnant and the probability of dying as a result of that pregnancy, cumulated across a woman's reproductive years. These measures require reliable registration or notification of vital statistics. (Ronsmans and Graham 2006:1189)

2.3.2 Causes of maternal deaths

Pregnancy-related complications are the leading cause of death and disability globally among women aged 15–44 years. This figure accounts for 18% of the burden of disease in developed countries. (Geller, Cox, Callghan and Berg 2006:176) Furthermore, approximately 8 million women suffer pregnancy-related complications per year, where one in 16 women may die due to these complications in developing countries compared to one in 2 800 women in developed countries. (WHO 2004b: 1)

The risk of pregnancy-related deaths increases as women age. Women older than 35 years have a higher pregnancy-related mortality ratio than younger women. Compared to women in their twenties, women aged 35–39 years are 2.5 times more likely to experience a pregnancy related death, and that figure increases to 5.3 times for women older than 40 years. (Chang, Elam-Evans, Berg, Hendon, Flowers, Seed, et al. 1999:3) Approximately 90% of pregnancy-related deaths occur during pregnancy or within six weeks of the end of pregnancy. The remaining 10% occur between six weeks and one year after the pregnancy ends. (WHO 2005:4)

More than 66% of pregnancy-related deaths follow delivery of a live birth, 14% occur before delivery, 12% occur after a loss of early pregnancy from ectopic pregnancy, or spontaneous or induced abortion, and 8% occur after a stillbirth. (Berg, Chang, Callaghan and Whitehead 2003: 292) A third of pregnancy-related deaths occur within 24 hours of delivery, whilst 18% occur during the 2–7-day period after delivery. (Penney and Brace 2007:145)

The highest levels of maternal mortality in 2011 were seen in Eritrea, Liberia, Burundi and Afghanistan, whilst the lowest were in Iceland and Austria. Although more than half of the countries in the world – including India and China, as well as some countries in sub-Saharan Africa such as Kenya, Swaziland, Zimbabwe and Botswana – have had a decline in maternal deaths in the past ten years; other countries, including South Africa, Brazil and Mexico, have shown a limited rate of decline in maternal deaths. Furthermore, South Africa is one of 12 countries in which the mortality rate for children is higher than that at baseline in 1990, with data on maternal mortality showing no improvement and the maternal mortality ratio being observed to have risen. (Lozano, Wang, Foreman, Rajaratnam, Naghavi, Marcus et al 2011:1152)

Haemorrhage, sepsis, eclampsia, unsafe abortion and obstructed labour are considered as direct causes of death. A report by the WHO on global cause distribution attributed 25% of maternal deaths to haemorrhage, 20% to indirect causes, 15% to infection, 13% to abortions, 12% to eclampsia, 8% to obstructed labour and 8% to other direct causes. (WHO, AbouZahr and Royston 1991) A systematic review conducted by Khan et al. estimated haemorrhage, which accounted for more than 30% of deaths, to be the main cause of maternal mortality in developing countries of Asia and Africa. (Khan, Wojdyla, Say, Gulmezoglu and van Look 2006)

Deaths that occurred as a result of eclampsia, unsafe abortion and obstructed labour combined, accounted for 17.7% of maternal deaths in Africa and 26.7% in Asia. Hypertensive disorders were found to be the leading causes of death in Latin America and the Caribbean, whereas other direct causes, such as complications of anaesthesia and caesarean sections were found in developed countries. The contributions of sepsis and HIV in Africa, anaemia in Asia, abortion in Latin America and the Caribbean, and other direct causes related to caesarean section, anaesthesia and embolism in developed countries, seem to be more region-specific and heterogeneity was found within and across regions. (WHO, AbouZahr and Royston 1991)

The systematic analysis by Khan et al. showed modest coverage of deaths within regions, especially in Africa. Although regional estimates may be useful as indicators of causes of deaths, national and subnational data are also required to identify emerging causes and other local characteristics such as access to services. (Khan et al 2006) Underreporting of deaths and misclassification were encountered when causes of maternal deaths were assessed. (United Nations 2009) Figures related to abortion were also probably much higher, but these deaths may be underreported due to social stigma and legal restrictions associated with abortion in many countries. (Singh 2006)

The challenge in estimating the maternal mortality ratio in South Africa is that reporting of deaths is the responsibility of individual health institutions, and deaths that occur in the community may be underreported. The Saving Mothers report, 1999–2001, indicated that the maternal mortality ratio of 150/1 000 000 reported in the South African demographic health survey may have been an underestimate, and a figure of between 175 and 200/100 000 was more likely. There has also been an increase in the maternal mortality ratio due to an increase in non-pregnancy-related infections such as HIV. Reported maternal deaths in South Africa increased from 676 in 1998 to 1 173 in 2004. Whether this was due to improved reporting or to increased deaths is unknown, and the five main causes of deaths in South Africa remain the same: these include non-pregnancy-related infections (including HIV), complications of hypertension, obstetric haemorrhage, pregnancy-related sepsis and pre-existing maternal disease. (South Africa. Department of Health 2007)

Death or long-term complications represent an individual tragedy for the woman and her family. More than 80% of deaths, even in poorer countries of the world, can be prevented or avoided if effective and affordable actions are implemented. (WHO 2004; Hill, AbouZahr and Wardlaw 2001:190) Surveys conducted in Egypt and other countries have shown that the quality of care provided to women is an important determinant in maternal outcome. Furthermore, many lives could be saved and most deaths averted if simple changes are implemented and the right kind of information is available to indicate appropriate action. (Kassas, Hefni, Hanafi and Campbell 1995) Studies in the United States and in Western Europe found that approximately two thirds of pregnancy-related deaths may have been averted if there were improvements in a variety of areas, which include:

- the fact that that the clinical care does not meet the expected standards, as indicated by provider factors;
- system factors (problems with the functioning of the health care system); and

- patient factors (social factors that influence accessibility of health care systems, which include actions or delays by the patient that contribute to death). (Geller et al 2006)

In every study, provider-related factors or substandard care were the most commonly found factors that contributed to preventable maternal deaths.

The Confidential Enquiry into Maternal Deaths in the UK from 1997–1999 found that substandard care contributed to approximately 40% of all maternal deaths, including 60% of direct maternal deaths or maternal deaths caused by conditions that occur during pregnancy. Studies of this nature assist in understanding the clinical, as well as non-clinical factors that lead to maternal deaths. These studies also aid in developing appropriate interventions to reduce the occurrence of these deaths. (Geller et al 2006)

Death is the culmination of a series of adverse events. Maternal morbidity presents a huge burden on not only the women, but their families too. Maternal mortality and morbidity were previously studied as separate entities. However, as rates of maternal deaths have decreased over time in developed countries and are now rare, these rates may not serve as sensitive indicators of the quality of services. (WHO 2004) Therefore, it is thought that by identifying a larger number of women with serious, life-threatening complications, and including these in clinical case reviews, opportunities arise to examine the quality of obstetric care related to the preventability of both near miss conditions and maternal death. (WHO 2004; Ronsmans and Graham 2006; Pattinson, Buchmann, Mantel, Schoon and Rees 2003) Furthermore, in developing countries, the review of severe maternal morbidities is considered to be of value as an outcome measure for the evaluation of safe motherhood programmes. (WHO 2004; Geller et al 2006:177)

The extent of maternal morbidity is huge, with some studies reporting that approximately 43% of women experience some form of morbidity, which may have been preventable. There is, however, limited attention paid to precisely identifying severe categories of morbidity, such as near-miss severe morbidity. The use of the near miss concept to review clinical care was previously limited due to the lack of a standard definition and uniform case-identification criteria. (Say et al 2009)

As a result, limited research has been conducted on preventing morbidity. A study of women who experienced severe morbidity and death in Chicago found that experiencing a preventable event placed women at a higher risk of a more severe outcome. (Berg 2003)

An event was considered preventable if it could have been avoided by any action or inaction on the part of the health care provider that may have caused or contributed to the progression of more severe morbidity or death. Factors that could contribute to such events include mismanagement of patients, failure or delay in diagnosis, the system (e.g. failure in communication) or the patient (e.g. non-compliance). (Pattinson et al 2003; Say et al 2009; Danel, Berg Johnson and Ash 2003)

Every death that occurs during pregnancy is devastating and every effort should be made to decrease the number of these events. Studies should not focus solely on identifying and treating medical conditions, but should also consider the role of the individual, society, and system factors that can affect maternal health. Differences among different racial, ethnic and socio-economic groups need to be considered.

The inclusion of near miss and severe morbidity cases in the study of maternal morbidity provides information on ways to improve women's health during pregnancy. Research suggests that decreasing preventable events will decrease maternal mortality and morbidity. This information may also help answer the question of why some women with life-threatening complications die and others do not. Interventions required improving healthcare delivery systems and decreasing the risk for mortality and morbidity can be developed through an understanding of preventable events. (Geller et al 2006; Chang et al 2003; Berg et al 2003)

2.4 LIFE-THREATENING COMPLICATIONS

2.4.1. Definitions of life-threatening complications

Maternal morbidity can be defined to include both physical and mental health, and it is especially high among socio-economically disadvantaged groups, adolescent mothers and unmarried women. (Geller et al 2006)

A number of terms are used to describe incidents of severe maternal ill health, including life-threatening complications, severe maternal morbidity and near misses. The terms are often used interchangeably, which can create confusion. Ill health during pregnancy represents part of a continuum that ranges from normal health to death.

On this continuum a pregnancy may be thought of as being uncomplicated, complicated (morbidity) severely complicated (severe morbidity) or life threatening. The woman may recover from the life-threatening condition, she may be temporarily or permanently disabled, or she may die.

Therefore, a near miss represents one of two possibilities of a life-threatening complication: the woman either survives, representing a near miss, or she dies, representing a maternal death. (WHO 2004) A near miss is defined as "a severe life threatening obstetric complication that requires urgent medical intervention to prevent the death of the mother". (WHO 2004:106)

The level above which an adverse obstetric event becomes life threatening depends not only on the women's general state of health and her capacity to cope with the complications, but also on the facilities available to her as well as the access to and quality of care she receives. A study conducted by Mantel et al. defined a near miss as a case where a woman is very ill and would have died were it not for the fact that luck and good care were on her side.

Near miss case reviews in conjunction with, or in addition to, facility-based case reviews are already incorporated in the confidential enquiries into maternal death methodologies used in South Africa and Scotland. (Mantel, Buchmann, Rees and Pattinson 1998)

The value of studying near miss morbidities is reflected in an increase in the number of systematic reviews on the prevalence of near miss. The reported prevalence has ranged from less than 1 per 1 000 live births to 82 per 1 000 live births. Rates of near miss morbidities in resource-poor settings range from four to eight percent of hospital-based deliveries. (Say et al 2009; Minauskien, Nadisuaskiene, Pradaiga and Makari 2004) Souza et al. reported a mean for near-miss cases of 8 per 1 000 live births. The variation in these rates is due not only to differences in the populations studied, but also to the definitions used. Near miss conditions are difficult to define. Previous definitions have used a number of approaches, which included criteria of organ dysfunction, criteria of clinical management such as admission to intensive care, signs and symptoms, or clinical entities such as eclampsia or uterine rupture. (Souza et al 2010:117; Say et al 2009:288; Adisamita, Deviany, Nandiaty, Stanton and Ronsmans 2008:2)

The WHO has defined a uniform set of identification criteria for maternal near-miss cases that enable uniform reviews of these cases for monitoring and improving quality of obstetric care. (Appendix B)

An investigation into the pattern and timing of near miss can assist in developing preventative programmes and health care resources at the level of the health facility. (Murray et al 2009) Hospital data on near miss provide information on events that may have occurred in the community, especially if the near-miss condition was at the extreme end of the severity spectrum where the woman may not have survived without effective intervention in the hospital. (Mantel et al 2009:989; Minauskien et al 2004:307)

Avoidable factors include patient-related factors, such as whether the patient attended antenatal care (including the number and frequency of visits), and if there was any delay in seeking medical help. Information on administrative factors, where access to health services – such as transport availability, barriers to facility entry, availability of facilities, appropriately trained staff and communication – is analysed. Health care provider factors include which level of provider conducted the initial assessment, whether there were problems in the recognition or diagnosis of symptoms (including the level at which it was done), whether the patient was managed appropriately at different levels of care, and whether a minimum standard of care was given at each level. (South Africa. Department of Health 2004; Danel et al 2003)

Soma-Pillay and Pattinson indicated in their study that patients encounter high rates of barriers during pregnancy, with 66% of near-miss patients in their sample encountering more than one delay in accessing care. (Soma-Pillay and Pattinson 2016) Inadequate antenatal care (37%) and lack of patient knowledge were identified as barriers. Also, delays in seeking services were 2.5 times more frequent in patients with maternal near misses and increased six-fold in women who died compared with those who had uncomplicated pregnancies. (Pacagnella, Cecatti, Parpinelli, Sousa, Haddad, Costa et al 2014) The researchers also found that despite having underlying risk factors, 25% of their sample was late in making bookings at the antenatal clinic or had inadequate antenatal care due to non-compliance with prescribed antenatal care.

In hospitals in Benin and South Africa, near misses were between five and ten times more frequent than deaths. Depending on the definition used, the ratio may be as high as 117 near miss cases per maternal death in developed countries. (Filippi et al 2010: 733) The majority of cases of severe complications may have arisen while the women were hospitalized, thus providing opportunities to observe and review the care that was given in the hospital. Some maternal deaths cannot be prevented in the hospital because women arrive at the health facility too late or because they die during the early stages of their admission.

Reviewing the outcome of severe obstetric morbidity has other advantages: for example, discussing the case of a woman who survived a life-threatening complication may be less threatening to providers than discussing maternal deaths. In this way, the enquiry would be less likely to assign blame, and as the woman survived, positive elements in the care may be identified. Secondly, the woman, rather than her family members, can be interviewed about the quality of care she received. Important aspects of the quality of care that may have been overlooked can be identified and the interview may also complement the information from records. Lastly, by involving health professionals in identifying case studies, responsibility for the accuracy and completeness of the data on severe morbidity is given, which in turn may be a step towards improving the quality of obstetric care. (WHO 2004)

The disadvantage of near miss reviews is that the events can only be identified in health facilities, and community data may not be available. The majority of the cases require hospital care to save the woman's life; hospital records may thus be the likely sources of information on the complications. Although some authors have argued that cases can also be identified in the community because women can remember distressing events such as near misses, evidence suggests that this does not represent a reliable source.

Studies, which assessed women's recall of obstetric morbidity, showed that there was disagreement between the woman's recall of her childbirth experience and the medically diagnosed complications or near misses. (WHO 2004:109)

Investigators of a study conducted in Benin hypothesized that, as women might be able to recall events, an interview-based survey assessing the incidence of near miss might be a way of evaluating programmes at the population level. (Fillippi et al 2010) While the study showed that women's recall of their childbirth experience was inaccurate, surveying them may serve as a starting point for audits and case reviews in developing countries. (Soma-Pillay and Pattinson 2014) Although these cases are relatively easily identified within health facilities, it is much more difficult to identify avoidable factors in community-based settings. (WHO 2004: 110)

The aforementioned sections focused on the women and the causes of maternal death problems with the woman as the core component. However, in order for women to reach their full potential, attention needs to be given not only to maternal factors, but also to ways in which the health care provider, as well as health systems, can be reinforced to provide basic care. (ten Hoope-Bender, Liljestrand and MacDonagh 2006)

Although there is good evidence available on the clinical interventions that are required for preventing maternal death and disability, there is a lack of understanding as to how to deliver the interventions, especially in countries with high maternal mortality ratios and dysfunctional or weak health systems. (Razzuto and Rashid 2002) Evidence pertaining to maternal and new-born health policy and programmes has been obtained from reviews in countries where interventions have been successful in reducing maternal deaths. These interventions have been summarized as follows:

- Requiring political commitment to improve maternal health and save women's lives.
- Investing in social and economic development, with an emphasis on achieving gender equity as well as to ensuring access to basic services for the poor.

- Strengthening health systems, with an emphasis on ensuring access to facilities and providing a comprehensive package of evidence-based care, which should include family planning and abortion, as well as post-abortion care and emergency obstetric care.
- Investing in developing and supporting health care providers with midwifery skills, which will enable them to attend to women before, during and after childbirth.

A combined approach to the abovementioned interventions is required to facilitate a reduction in maternal mortality, as improved health and poverty reduction go hand in hand. Factors that affect basic health status are gender equity, access to clean water and sanitation, education, and communication. The packages of interventions that provide a continuum of care for mothers, new-borns and children from a health-system perspective have been identified, but strategies for implementation of these interventions at the district and community levels are lacking, and reasons for the lack of progress include both historic factors and global policy concerns. (Mathai 2008)

2.5. THE HEALTH SYSTEMS

The World Health Organization defines health as a "state of physical, mental and spiritual wellbeing and not merely an absence of disease or infirmity."

A health system includes all the activities with the primary purpose of promoting, restoring or maintaining health, and includes communities and organizations, as well as people who

work in or are part of the health system with the objective of improving the health of the population they serve, responding to the people's expectations and providing financial protection against the costs of ill health. (WHO 2006) The health systems should be strengthened to ensure access to good-quality, effective health interventions that are safe and appropriate for the needs of the population. The system should also provide health services that are efficient at delivering safe and effective health interventions to those who need them, at the time of need. (Mathai 2008)

Strategies to ensure efficient implementation would require:

- an efficient health workforce;
- adequate supply of cost effective essential medicines, technologies and supporting infrastructure;
- adequate financing to ensure people can use services when needed without the fear of impoverishment;
- health information systems that work efficiently to ensure availability and use of reliable and timely information on the various issues concerning health; and
- good governance and leadership.

Improvement in maternal survival will require a joint approach by communities, academic organizations and governments, and should include the seven components detailed below.

2.5.1 Provision of health services

The concept of continuum of care encompasses care that spans the home, community, health centre and the hospital where care is provided, as a continuum throughout the life cycle, including adolescence, pregnancy, childbirth and childhood.

Comprehensive care should ideally start before conception to ensure that women become pregnant at the optimal time; thus, education and information are important. Health services should work towards improving access to family planning and improving maternal health by prevention of unwanted pregnancies. Improved outcomes in maternal and child health will depend on the integration of packages delivered at the community level, at primary care facilities (health centres, outpatient departments) and district hospitals (first referral level), so that women and children benefit from a continuum of care.

The package of maternal, new-born, and child services should address the population health needs and ensure provision of care close to the woman and the family, as travelling a great distance to seek care in an unfamiliar setting can limit the use of services during pregnancy, childbirth and the postpartum period.

Antenatal care is important for the mother and baby, and is one of the most utilized services, even in developing countries. (WHO 2006; WHO UN Children's Fund 2003) Contact with the health care services during this period provides an opportunity to promote healthy lifestyles and family planning, as well as to address programmes such as malnutrition, vaccine-preventable diseases, HIV/AIDS or other sexually transmitted infections, malaria and TB. (WHO UN Children's Fund 2003)

Addressing the availability and accessibility of services as well as being sensitive to the cultural needs is as important as improving the quality of care. It has also further been shown that women in urban settings are twice as likely as women in rural settings to report at least four antenatal clinic visits. (WHO UN Children's Fund 2003)

An integrated approach to maternal, new-born and child health across sector – including education, women's empowerment, legal advice, social protection, water and sanitation, transport and communication – is also required to improve outcomes, because inequalities in health tend to reflect differences in education, housing and other sectors. (Freedman, Graham, Brazier, Smith, Ensor, Fauveau et al 2007)

Most maternal deaths occur during and immediately after childbirth, and research has shown that utilization of services during this high-risk period is low in countries with high maternal mortality. Complications that occur during and following childbirth cannot be predicted beforehand, and services should therefore be easily available, with adequate referral systems that are accessible should complications arise. Integration and co-ordination remain a challenge within health systems, with limited evidence of what works.

If quality is low or there is a lack of competent providers, drugs or life-saving interventions at the first-level services, users will either utilize district-level centres or other facilities and may in some cases not seek services at all. (Ekman, Pathmanathan and Liljestrand 2008)

A number of studies have shown that evidence-based, cost-effective interventions can improve health outcomes for mothers, newborn babies and children in low- and middle-income countries. The reports of several countries confirm that the health of women and children can be improved through carefully designed and incrementally implemented strategies.

Barriers and constraints in many sectors, including health, education, infrastructure, water and sanitation, and social protection, need to be addressed. An important step towards progress in this regard is gradual strengthening of health care systems to enable delivery of effective primary health care with maternal, new-born and child health at its core. (Ekman et al 2008)

Improvement of primary health care services to achieve the Millennium Development Goals, have evolved from under-investment and single-disease focus, to increased funding and multiple new initiatives. For primary healthcare the debate focused on selective or vertical approaches versus comprehensive or horizontal delivery. There is a shift towards combining the strengths of both approaches in health systems, with debates around community versus facility-based health care shifting towards building integrated health systems. However, factors that limit the capacity for implementation of packages for maternal and child health include:

- inadequacy of human resources, with insufficient numbers, and inadequate distribution of skilled birth attendants and medical teams for emergency obstetric care;
- irregular and inadequate supplies of drugs and materials because of weak logistical systems;
- delayed release of funds; and
- poor planning and management capacity. (Ekman et al 2008)

2.5.2 The health workforce

A critical shortage of healthcare workers and restrictions placed on salaries in the public sector have discouraged and demotivated workers. The low density of health care workers in rural areas is one of the main factors responsible for the lack of provision of care and high maternal mortality rates. In an effort to ensure a workforce that performs well, it is necessary to not only improve the distribution and performance of existing health workers, but also address these workers' entry into and exit from the health system.

2.5.3 Information

A functioning health information system is imperative to provide good-quality services. In maternal and perinatal health, information should be available on determinants of health, health status of mothers and babies, and the performance of the health system. A good system should ensure production analysis, dissemination and utilization of reliable information at all levels. Maternal health is not only the responsibility of the government, as individuals, families and communities are integral stakeholders in this area. Organizations have important roles to fulfil because they are necessary to develop health systems that respond to the needs of all mothers and babies in a just and equitable way. It is important to identify barriers to universal access to care, and steps to overcome these barriers should hold the government and health providers accountable. (Mathai 2008; WHO 2006; WHO UN Children's Fund 2003)

2.5.4 The role of communities in reducing maternal mortality and morbidity

Although strengthening of the health systems to reduce maternal mortality has been highlighted for a considerable period, it has been challenged as being too rigid and beyond the abilities of many low-income countries, where the burden of maternal deaths is the greatest. (Bhutta, Alli and Cousens 2008; Costello, Azad and Barnett 2008)

Pagel and colleagues showed that through augmenting health facility strengthening with improved drug treatment of postpartum haemorrhage and sepsis via antenatal care and the participation of community health workers and female village volunteers, a third of the maternal deaths could be averted annually. (Pagel, Lewycka, Colburn, Mwansambo, Mequid, Chiudzu, et al 2009)

Community-level interventions primarily focused on child health have been emphasized for several decades. However, in maternal and newborn health, emergency care and skilled birth attendance have taken precedence over community-level interventions. (Rosato, Mwansambo, Kazembe, Phiri, Soko, Lewycka, et al 2006) Community-based interventions have been shown to contribute to an improvement in maternal and newborn health.

This was shown in Malaysia and Sri Lanka, where maternal and newborn mortality have been reduced since the 1950s, facilitated by an approach that targeted underprivileged groups. In both countries, multi-sectoral strategies combined improvements in maternal health care with efforts to improve water and sanitation, communication and schooling, especially for girls. (Pathmananthan, Liljestrand, Martins, Rajapaksa, Lissner, de Silva, et al. 2003).

In China, both maternal and child health improved in the 1970s and 1980s due to an area-based primary health care approach that addressed barriers to emergency care. This was achieved through the use of basic health workers, the "so-called barefoot doctors". The advances in Sri Lanka, Malaysia and China over the past few decades have shown that mortality and morbidity in mothers and children can be reduced by sustained, incremental and integrated efforts within gradually expanded and strengthened health systems. (Koblinsky 2003) Local communities in these countries have been involved in the development of these improvements, which enabled increased local accountability. (Ekman et al 2008:996)

In societies where women's status is low, pregnancy and deliveries are often considered a woman's priority, and neither transportation to a hospital or clinic, nor the money to pay for such services may be accessible. In some countries, even if hospitals and clinics provide specialist care and emergency obstetric care, they cannot ensure the delivery of such services to all women. (Ekman et al 2008: 993)

Progress to reduce maternal mortality can be made if stakeholders recognize the importance of maternal health, not only to the family, but also to the future health of the nation, by addressing women's needs.

Research in Nepal has shown that women's participation is an important aspect in reducing mortality. However, findings of randomized controlled trials, to see if maternal mortality rates at population level will be reduced by the mobilization of communities through women's groups, have yet to be revealed.

Maternal health in Africa has been a low priority, not only because of poor epidemiological data, but also because of poor community involvement in decision-making about health priorities. (United Nations Population Fund 2003) Improvements in preventative care and care seeking behaviours to reduce maternal mortality in rural Africa depend on the knowledge and attitudes of women and communities. A study conducted in Malawi showed that behaviour at the village level can contribute to maternal mortality.

Most births and deaths of pregnant women happen at home, whilst some behaviour within the community could hinder prompt and appropriate seeking of care. (Rosato, Mwansambo, Kazembe, Phiri and Soko 2006; United Nations Population Fund 2003) In certain cultures, issues surrounding pregnancy and childbirth are viewed as the domain of women, and furthermore, it is often the case that rural women are not given opportunities to speak about their issues or are not listened to by policymakers or people in local positions of power. Women's concerns remain invisible to both policymakers and members of their communities, with the responsibility for these issues resting on the individual women. (Rosato et al 2006: 1180)

Previous studies that have asked women about their perceptions about maternal health issues focused at an individual level on the gaps and misconceptions in the women's knowledge. (Freda, Damur and Merkatz 1991; Hasan and Nisar 2002; Tadese and Muula 2004) Studies conducted in rural Malawi showed that groups of women, through sharing their experience, could identify most maternal health problems, realize their importance and were willing to address them. These groups, however, appeared to underestimate the complications of HIV/AIDS and sepsis despite them being among the top five direct and indirect causes for maternal deaths in Malawi. (Rosato et al 2006; Tadese and Muula 2004) Another study conducted in Blantyre showed that, among a population accessing a tertiary hospital, nearly three quarters of the maternal deaths had an infection-related component. Reservations about discussing issues around HIV/AIDS in rural Malawi still existed and this was highlighted by the fact that only 15% of women in this group had voluntary counselling and testing. There was also limited availability of antiretroviral treatment, and only a few facilities offered services for prevention of mother-to-child transmission.

Furthermore, voluntary testing and counselling were inaccessible to much of the population. This could explain why HIV/AIDS was judged as untreatable and why women's groups felt there was no point in addressing it. The women were, however, able to identify and prioritize problems and to realize the severity of the consequences.

The findings of these studies have indicated that, apart from raising awareness, women in groups have developed certain attitudes that reinforce the intention to change behaviour. The studies have also highlighted the motivation of women to not only move from identifying and prioritizing illness, but also exert effort to address the problems. To facilitate an improvement in care-seeking behaviours, there is a need for an increase in knowledge and a change in attitudes.

Previous studies suggested that individual women did not have a comprehensive awareness of the problems that affect them but that the awareness could be accessed by women who meet and discuss important issues, as indicated in the aforementioned studies (Rosato et al 2006)

In the preceding sections of the review, the global overview of maternal mortality and morbidity, as well as the health systems and community participation were discussed. It is also important to discuss the South African perspective at this point to provide an understanding of the current health systems.

2.5.5 The South African health systems

South African society has evolved from the era of apartheid, which was characterized by racial segregation and discrimination, where black racial groups were denied political, social, economic and health rights. Geographical and racial inequalities (Van Rensburg and Harrison 1995; Klugman, Stevens, van den Heever and Federal 1996) were present in the health system, where the greatest proportion of health resources was allocated to ensure delivery of health care for the white minority in urban areas. Reproductive health policies consisted of maternal and child health services which emphasized the use of contraceptive services to limit population growth. Primary health services were poorly developed and inaccessible to the majority of the population, especially those in rural areas. (Van Rensburg and Harrison 1995; Klugman et al 1996)

The dawn of democracy saw transformation of the health system into a single system with equal distribution of services and resources. Health was emphasized as a basic human right and health reforms were provided for in the Constitution and the Bill of Rights, which prohibited discrimination on the basis of sex, gender and sexual orientation. (Klugman et al 1996) The Department of Health adopted the Primary Health Care approach as the orientation of the health care system. Health services were decentralized, and the district health system evolved in an attempt to address not only local health needs, but also involvement of the community. (Health Systems Trust 2000) Equity in resource distribution, expanded access, and preventative and health care promotion were adopted. This was an attempt to address the neglect of the health needs of poor black women. (Klugman et al 1996)

2.5.6 Maternal health services and policies

The Mother, Child and Women's Health directorate was established with the objective of increasing women's access to appropriate health services, empowering women, increasing gender equality and providing services to males and females. Its ultimate aim was to achieve optimal reproductive and sexual health. (South Africa. Department of Health. 1997: Ch. 8) This was a step towards acknowledging that women bear a disproportionate burden of reproductive health problems.

The South African Gender-based Violence and Health Initiative was formed in the year 2000 to encourage recognition of violence against women. Furthermore, the initiative sought to train health care providers and conduct research to help develop policy on gender-based violence. Despite the gains made, high levels of violence against women persist. In an attempt to decrease these levels, preventive interventions are needed to address the societal values, attitudes and beliefs that can predispose and perpetuate violent and abusive behaviour. Research continues to show that women are not given adequate information about contraceptive methods, and the information available frequently represents the opinions of primary care nurses. Health service providers do not take women's concerns regarding particular methods seriously, and there has been a tendency to pay limited attention to women's health problems that don't fall under reproductive health. (De Pinho and Hoffman; South Africa. Department of Health 2002; South Africa. Department of Health 2001; Magwaza and Cooper; Cooper, Morroni, Orner, Moodley, Harries, Cullingworth, et al 2004.)

The Choice on Termination of Pregnancy Act 92 of 1996 allows for termination on request for pregnancies of a maximum of 12 weeks' gestation, facilitated by a certified midwife or doctor. Pregnancies of 13–20 weeks may be terminated when continuation of the pregnancy poses a risk to the women's social, economic or psychological wellbeing. Prior to the passing of the law, it was estimated that 34% of incomplete abortions admitted to public hospitals annually resulted from unsafe abortions. Subsequent to the passing of the new act, the number of women with serious abortion-related morbidity had almost halved (9.5% in 1999 compared to 16.5% in 1994). Maternal mortality from unsafe abortions has also decreased. De Pinho and Hoffman 1998; Magwaza and Cooper, 1999; Cooper et al 2004.)

Subsequent to 1994, a set of prevention and clinical packages were established, which include evidence-based interventions that are in line with WHO recommendations, consisting of four levels of care within the health system. (Chopra, Daviaud, Pattinson, Fonn and Lawn 2009) Although community-level services, which focus on promotion and healthy behaviours as well as appropriate care seeking, are important, they have not been resourced in a systematic or large-scale manner.

Primary-level services – such as reproductive health services and antenatal care (HIV testing and interventions for prevention of mother-to-child transmissions), limited postnatal care, and preventative and basic child health services (including early identification and supportive treatment for HIV/AIDS) – are provided in clinics that are predominantly staffed by nurses. Some of the clinics also supervise deliveries and provide treatment for HIV infection, although in many areas these functions are provided by district hospitals. (Chopra et al. 2009) Primary health care facilities generally have high rates of use, with 94% of women attending at least one antenatal visit and 83% of children fully immunized at one year. (South Africa. Department of Health 2008)

The third level consists of district hospitals, which provide in-patient care for mothers, neonates and children, and has the capacity to undertake caesarean section deliveries. The highest tier is regional hospitals, which have specialist and tertiary hospitals with sub-specialists who provide comprehensive obstetric and paediatric services. Access to basic packages of care is good: 84% of women give birth in a health facility, 17% of these births are at clinics, 42% at district hospitals, 30% at regional hospitals and 11% at tertiary hospitals. In all levels of facilities there is an acute shortage of beds. As a result of suboptimal referral systems in the primary and secondary facilities, many patients bypass lower levels and access higher levels of care. Thus, regional and tertiary services have an increased burden of providing care that could have been provided by district hospitals. (Chopra et al 2009)

In spite of the aforementioned packages of care, the challenge in the South African context is to understand the paradox of a supportive policy and funding environment with high rates of maternal and child health service utilization, yet poor and worsening health outcomes.

Since 1994, life expectancy in South Africa has reduced by 20 years, mainly due to the rise in HIV-related mortality. (Abdool Karim, Churchyard, Abdool Karim and Lawn 2009; Mayosi, Lawn, van Niekerk, Bradshaw, Abdool Karim and Coovadia 2012)

The proportion of the global burden of disease borne by South Africa, which has a population of approximately 48 million people, is disproportionately high. The total disability-adjusted life years for high-burden diseases in South Africa is almost equivalent to that of Bangladesh, which has a population three times that of South Africa and where poverty levels are much worse. A census of health in South Africa has shown that the country faces a number of health challenges, including the HIV and TB epidemics, (Mayosi et al 2012) a high burden of morbidity and mortality (which results from violence and injury), chronic diseases, mental health disorders, and maternal, neonatal and child mortality. The combination of acute and chronic diseases places a huge burden on the public health system – a system that is already struggling to overcome poor administrative management, low staff morale, lack of funding and brain drain. (Mayosi et al 2012)

The continuation of poverty and poor environmental conditions – especially in rural areas – and the spread of peri-urban townships may partially explain the slow progress in reducing mortality rates. Another factor contributing to the increase in maternal and infant mortality is the rapid spread of HIV and AIDS. The maternal mortality rate for HIV-negative women is 34/100 000 live births, which is similar to middle-income countries such as Brazil, Argentina and Thailand. The maternal mortality rate for HIV-infected women, however, is almost ten times higher. South Africa bears the greatest burden of mother-to-child transmission than any other country. (Patrick and Stephen 2007; UNAIDS 2008) About 300 000 HIV-infected mothers give birth to infants each year. Despite a national programme launched in the year 2000 to provide single-dose antiretrovirals to HIV-infected women in labour and to their infants postnatally, a study found that 7.2% of all six-week-olds attending their first immunization were already HIV-infected. (Rollins, Little, Mzolo, Horwood and Newell 2007)

This may be due to the lack of comprehensive policies, which include prevention of mother-to-child transmission, as well as delays in extending the programme to all clinics and hospitals. (Jackson, Chopra, Doherty, Colvin, Levin, Willumsen et al 2007; Doherty, McCoy and Donohue 2005) Education and information promoting primary prevention and services that support pregnant women in remaining negative are non-existent.

Furthermore, family planning services remain inadequate and separate from other maternal, child and women's health services. The processes to identify women and infants in need of lifelong antiretroviral therapy and start treatment are fraught with difficulties and represent missed opportunities for decreasing maternal and infant deaths. The spread of HIV was predicted many years before its arrival in South Africa. (Abdool Carim et al 2009)

However, the spread can be largely attributed to weak political leadership, underlying social displacement, inequality, and a fragmented health system. These are the same underlying reasons for the persistently high proportion of neonatal maternal and child deaths with avoidable causes.

The WHO estimates that reproductive ill health accounts for a third of the total disease burden for women. Maternal morbidity and mortality is responsible for a large proportion of this figure. South Africa has continued to develop strategies to meet the global call for a 75% decrease in maternal and child mortality by the year 2015 (United Nations 2000). The Department of Health has developed the Health Goals, Objective and Indicators (HGOI) long-term strategy for 2006–2010, which includes improving access to antiretrovirals for pregnant women, improving women's health and reducing maternal and child mortality and morbidity. Between 1998 and 2003, deliveries conducted by skilled health workers have increased from 84% to 92%. Despite these improvements, maternal mortality is on the increase, with the Saving Mothers Report showing an increase in maternal mortality in the 2002–2004 triennium from the previous three years. (Bekinska, Kunene and Mullick 2006; Bradshaw, Copra, Kerber, Lawn, Moodley, Pattinson et al 2008)

The provision of an integrated and comprehensive antenatal and postnatal package faces a number of challenges in a fragmented and vertical health care system. (Bekinska et al 2006) National maternity guidelines are provided on how maternity services should be rendered, but many of the practices around the care of pregnant women undertaken by nurses at the primary health care level are traditional rather than evidence-based. Antenatal and postnatal care is task-orientated rather than patient-orientated, and this leads to impersonal and incomplete care. Twenty-two percent of women, who died during pregnancy, labour or postnatally had not attended antenatal care. (Bekinska et al 2006) Many women attend antenatal care late during their pregnancies, delaying access to testing for HIV and anti-retroviral treatment, the prevention of complications of previously diagnosed or undiagnosed medical conditions such as cardiac disease, and complete treatment of sexually transmitted infections. Screening for domestic violence is not included in routine antenatal or postnatal care.

Antenatal services in the South African Public Sector do not encourage good provider-patient communication. Patients often see a different provider for each procedure, making it difficult to establish a relationship with any particular provider. Services are often provided with a lack of privacy, making it difficult for a patient to discuss any personal problems or concerns without being overheard.

Women are usually grouped together, which makes it difficult for partners to attend the consultations. Although many studies report that patients are generally satisfied with antenatal clinic services, the quality of services was found to be a problem. Regarding quality of care in contraceptive services, 20% of women reported that the provider shouted at or scolded the patient in a family planning setting. The poor quality of care extends beyond the antenatal settings to the delivery, where women often deliver without the support of a partner or family member, and environments for delivery often afford the woman no privacy.

Poor quality of care may partly be related to low staff morale, with 27% of nurses reporting that they did not care for the patients like they used to and 60% saying they no longer felt motivated to work as hard as they could. Poor motivation was blamed on a number of factors including poor promotion prospects, poor management and staff shortages. (Bradshaw et al 2008)

2.5.7 Postnatal care

Postnatal care is an integral component of maternal care which focuses on assisting the woman to return to optimal health as soon as possible after delivery and ensuring that the woman has all the information required to manage everyday situations with her new-born baby and family. Information from the Saving Mothers report shows that 43.7% of emergency cases involving non-pregnancy-related infections that lead to a maternal death were found to be in the postpartum period. (Bradshaw et al 2008)

A key recommendation from the report was that special attention be paid to postnatal care, as most women are prone to ill health during this period, especially for HIV and non-pregnancy-related infections. (South Africa. Department of Health 2006) Access to postnatal care is not routinely measured but is estimated to be less than 10%. (South Africa. Department of Health 2002). This gap must be addressed, especially during the first few days postpartum, as this period is the time of highest mortality for mothers and babies.

Studies have shown that maternal and neonatal mortality commonly occurs within three to seven days after delivery. (Beksinska et al. 2006) Women are discharged from the place where they give birth and are subsequently down referred to their local clinics.

The clinics to which this responsibility is given do not have staff to do home visits, nor is there an effective communication system to inform them that a woman from their clinic has given birth. Limited health education and planning take place at the antenatal visits and there is an absence of community, family and partner participation in the care of pregnant women and new mothers. Although postnatal care is an important aspect of comprehensive care, the main focus has been on the antenatal period. Postpartum care for women focuses primarily on the infant and little attention is paid to maternal health and risk behaviour in the postpartum period. Coordinating family planning and other health services during and after pregnancy can help improve reproductive health. Extending the stay of women after delivery is an option but will need to be evaluated in terms of these constraints. Another option would be to make use of community health workers to visit the women and their babies postnatally, provided an effective communication method could be found between the delivery site and the clinics. (South Africa. Department of Health 2002) Furthermore, a strategy to re-energize and motivate health workers is a priority as their role is crucial in delivering adequate services. Until recently, most of the interventions within maternal and child health and nutrition services were not introduced in an integrated way. This resulted in neither primary care nurses nor supervisors having an understanding of how to deliver comprehensive services. Society also has a crucial role in increasing demand for quality services. The adoption of similar strategies, such as mobilizing communities to identify and demand appropriate services, increases the capacity of health care users to monitor services and highlight shortcomings. (Pattinson et al 2008)

2.6 WOMEN'S MENTAL HEALTH

The interface between female health and mental health has been the subject of much research in the past three decades. While most gynaecological problems have been found to be associated with psychosocial stress, certain conditions have been studied more than others due to the extent and nature of the condition. (Chandra and Ranjan 2007: 168)

About 90% of women become pregnant at least once in their life, with pregnancy being an event that changes many aspects of a woman's life and has important implications not only for her health, but also her wellbeing and ability to fulfil social roles. (Striegel-Moore, Goldman, Garvin and Rodin 1996:395; Yali and Lobel 2006).

Hormonal and environmental factors have been hypothesized as etiological factors in postpartum psychiatric conditions. (Chroussos, Torpy and Gold 1998:235) Apart from postpartum depression, which has been studied extensively in the past decades with improvements in screening and measurement across cultures, other areas such as anxiety and pregnancy-related psychological problems were neglected until recently.

2.6.1 Women's mental health in South Africa

Neuropsychiatric disease accounts for an estimated 21% of the non-fatal disease burden experienced by South African women. The estimated non-fatal burden of depressive disorders, panic disorder and post-traumatic disorder is higher for women. In spite of these facts, mental health is a neglected topic in the South African public health sector, and women's mental health even more so. There are also limited South African-based studies of prevalence rates for psychiatric disorders published to date. (Moultrie and Kleintjes 2006:348) According to the South African revised burden of disease estimates for the year 2000, depressive disorder was the second leading cause of years of life lost to disabilities, after HIV, for South African women. (Norman et al 2006) Evidence-based reviews have reported significant correlations between HIV sero-positivity and a range of psychiatric conditions. Associated conditions include delirium, dementia, personality disorders, mood disorders, PTSD, suicide and suicidal ideation. South African studies with clinical samples found higher rates of depression and PTSD in HIV-positive women. (Freeman 2004; Ciesla and Roberts 2001; Botha 1996; Kelly, Murphy, Bahr Brasfield, Davis, Hauth et al 1992; Martines, Israelski, Walker and Koopman 2002; Olley, Zeier, Seedat and Stein 2005; Stein, Seedat, Emsley and Olley 2005)

As mentioned previously, there is an encouraging legislative and policy framework directed at providing integrated maternal and child health services; however, it has not been implemented sufficiently to impact practice on the physical and mental health and wellbeing of the majority of South African women. Women remain among the poorest people of the nation and have limited access to resources in every sphere of society, be it political, economic or social. Gender disadvantage, higher levels of poverty and HIV continue to play a role in the incidence of mental health problems experienced by South African women. (Ciesla and Roberts 2001)

2.7 PERINATAL MENTAL HEALTH

Mental disorders associated with childbearing are a significant public health problem. As mentioned previously, the presence of psychiatric pathology during the perinatal period is associated not only with increased morbidity and mortality in affected women, but with their children having an increased vulnerability to developing psychopathology. A number of studies have indicated that maternal stress is associated with premature delivery and lower birth weight adjusted for gestational age. (Dunkel Schetter 1998; Copper, Goldenberg, Das, Elder, Swain, Norman et al 1996) The babies also have a smaller head circumference, which may reflect suboptimal brain development and may be a predictor of impaired cognitive development. (Lou, Hansen, Nordentoft, Pryds, Jensen, Nim et al 1994) Despite their prevalence, these conditions are often not recognized by primary care providers and are thus untreated. (Stuart et al 1998) Furthermore, health professionals responsible for the care of women during the perinatal period are cautious to treat women with medication during this period for fear of adverse effects on the foetus and the newborn. Also, psychosocial interventions for mental disorders associated with the perinatal period, although on the increase, have not been widely investigated, thus limiting options for treatment. (Stuart et al 1998)

2.7.1 Postpartum psychosis

Puerperal insanity was first described in the psychiatric literature by Esquirol and later by Marcé in 1857. (Oates 2003:220)

The risk of a woman developing a psychotic episode in the year following delivery is said to be increased 14-fold in relative risk and 35-fold in the 30 days following the first childbirth. (Kendell, Chalmers and Platz 1987:663) Approximately 1–2 women in every 1 000 develop a postnatal mental illness of significant severity to require in-patient psychiatric care. (Murray, Cooper and Hipwell 2003:772; Shoeb and Hassan 1990:427)

The majority of episodes occur within the first four weeks following delivery. The condition presents acutely and is characterized by a rapid onset of symptoms. Postpartum psychoses are psychiatric emergencies, which have a variable course.

The condition can present similarly to the affective psychoses that occur at other times during a woman's life, for example, depression and bipolar disorder. (Ranzini, Vinekar, Houlihan, Scully, Cho and Vintzeleos 1996; Brockington, Cernik, Scholfield, Downey, Francis and Keelan 1981).

The psychotic disorders arising during the perinatal period are a complex, heterogeneous group, and formal diagnostic classifications do not adequately address these conditions. (Brockington et al 1991:830)

There may be transient and alternating episodes during which the women may express delusions of guilt, persecution, grandiosity or worthlessness, ideas of reference, other hallucinations, delirium-like symptoms and confusion, as well as symptoms of motor retardation or over-activity. They may also present with lability of mood, disorganized behaviour, poor judgement and impaired functioning. (Murray et al 2003) Some women express delusions that relate to their infants. (Kumar 1994)

The onset of postpartum psychoses is difficult to predict due to the infrequency of these conditions. The risk of postpartum psychotic episodes increased from 1 to 2 per 1 000, to 1 in 5 or 7 in the presence of a personal or family history of bipolar disorder. (Marks et al 1992) Longitudinal studies suggest that most cases of postpartum psychoses are related to bipolar disorder and not schizophrenia. (Davis, Mc Ivor and Kumar 1995)

A study conducted in Nigeria Fatoye et al (2002) found that 58.2% of women in their sample developed symptoms within the first six weeks after delivery, with two out of five patients having onset of symptoms beyond six weeks. Over half of the patients in their study had received alternative treatments before presentation and more than three quarters of them had associated complications or experienced significant life stress within a year preceding the onset of illness. Fifteen of the patients in their study had associated obstetric complications. Previous studies conducted by Videbach and Cooper et al. reported an association between marital stress and peripartum complications, as well as postpartum mental disorders. (Videbach and Gouliaev 1995; Cooper et al 1999) It was postulated that the mental disorder may be the primary cause of the disharmony, or that the presence of psychological distress in the woman during the postpartum period was as a result of desertion by the spouse. Similar findings concerning marital disharmony were found in studies conducted by Marks et al (1992) and Cooper et al. (2004)

2.7.2 Pregnancy and stressful life events

Pregnancy and childbirth are often considered happy events and are normally associated with positive emotions. These emotions may, however, not be experienced by all women. Stressful circumstances may precede or occur during the pregnancy. Pregnancy in itself may be a stressful event, particularly if it was unplanned or unwanted, or if it ends with a foetal or infant death. (Gazmarian et al 1995) A study by Cooper et al (2004) indicated a positive relationship between postpartum depression and unwanted/unplanned pregnancy, with a common reason for the pregnancy being unwanted being denial of paternity by the partner. Women with unplanned pregnancies are four times more likely to experience violence by their partners than those with planned pregnancies.

Of unintended pregnancies occurring in the United States in 1994, 54% ended in abortion, as did approximately 40% of all adolescent pregnancies. (Henshaw 1998) Adler and colleagues highlighted in their review that although post-abortion responses may involve feelings of sadness, anxiety, guilt, or regret, most women are not at risk for developing adverse psychological sequelae. The lack of social support and ambivalence regarding the pregnancy or the implications of abortion may, however, contribute to the negative reactions. The rejection or desertion by the spouse, as well as the lack of emotional and financial support for the mother, can impact on the prognosis of the illness. (Adler, David, Major, Roth, Russo and Wyatt 1990; Cooper et al 2009)

2.7.3 Medical conditions

Medical complications during pregnancy can present as risk factors for developing severe health problems and can predispose a woman to experiencing a stressful pregnancy. A common condition that can present with both adverse physical and psychosocial sequelae is chronic hypertension in pregnancy, which is often diagnosed before 20 weeks' gestation. This occurs in 1–5% of all pregnancies, and if it occurs in conjunction with super-imposed preeclampsia, presents an increased risk for many adverse maternal and neonatal health outcomes such as foetal growth retardation, placental abruption, premature delivery and stillbirth. (Agency for Healthcare Research and Quality 2015)

Another condition that can contribute to a stressful pregnancy is the development of gestational diabetes mellitus, found in 1–12% of pregnancies. (Jovanovic 2000a) Risk varies by ethnicity and race, as well as factors such as overweight or obesity, poor physical fitness, maternal age above 25 years, and family history of diabetes. (Jovanovic 2000b) About 1–2% of women who develop gestational diabetes may not have any of the identified risk factors. Gestational diabetes can present a risk to both mother and child, with a meta-analysis revealing a relative risk of 6.0 for developing diabetes subsequent to gestational diabetes. This increased number of complications can result in an increased rate of surgical deliveries, as well as other perinatal and neonatal complications, including stillbirth. (Venture, Peters, Martin and Mauer 1996)

A medical condition that can occur during pregnancy, albeit rarely, is peripartum cardiomyopathy (PPCM). This condition can present with life-threatening congestive heart failure during the last trimester of pregnancy or within the first six months postpartum. Estimates suggest that the condition occurs in 1 out of every 3 000–4 000 pregnancies. Among the risk factors identified for developing PPCM are: advanced maternal age, multi-parity, multi-foetal pregnancy, preeclampsia, and gestational hypertension. (Pearson, Veille, Rahimtoola, Hsia, Oakley, Hosenpud et al 2000)

The aetiology of PPCM remains unknown and proposed causes include abnormal immune responses to pregnancy, maladaptive responses to the haemodynamic stress of pregnancy, stress-activated cytokines and prolonged tocolysis. Although PPCM can resolve completely, there is a high rate of mortality of between 25 and 50% for women who do not experience a resolution of symptoms within six months following delivery. (Lampert and Lang 1995; Brown and Bertolet 1998)

There is a racial discrepancy in pregnancy-related deaths with this condition, with black women's risk of death being six times greater than that of white women. (Whitehead, Berg and Chang 2003) Women with PPCM appear to be at increased risk for pregnancy complications and mortality should they become pregnant again. Due to the limited understanding of the aetiology of PPCM, the majority of the research has focused on the medical aspects. There is, however, limited information pertaining to the psychosocial impact of the condition. Geller and colleagues (1996) examined psychosocial factors in a small sample of women with PPCM and described factors such as stressful life events (history of abuse or unstable relationships, history of miscarriage or caesarean section), health-related behaviours (substance abuse, nutritional/dietary concerns), social support and coping skills as variables associated with PPCM. (Klier, Geller and Neugebauer 2002a)

They further described that the aforementioned psychosocial factors could exacerbate the physical symptoms or contribute to treatment-related issues such as non-compliance, comorbid psychological or substance-abuse disorders, as well as difficulty adjusting to lifestyle changes that can occur as a result of the illness. (Geller et al 1996)

2.7.4 Pregnancy loss

Reproductive loss may be experienced as a stressful situation and can have significant mental health consequences. (Klier et al 2002a: 433; Klier, Geller and Ritsher 2002b: 132) Miscarriage occurs in 10–20% of clinically recognized pregnancies and some pregnancies may end before the mother is aware that she is pregnant. (Kline, Levin, Kinney, Stein, Susser and Warburton 1995:419) Estimates indicate that as many as 45–50% of all pregnancies end in miscarriage. The risk varies substantially by age, at 9% for women 20–24 years of age and up to 75% for women older than 45 years of age. (Nyobo, Anderson, Wohlfahrt, Christens, Olsen and Melbye 2000:1710) Stillbirth presents with a risk of 0.4–1.2/1 000 singleton pregnancies, and can be higher in multiple pregnancies. (Yudkin and Redman 2000:327) Risk factors that have been identified include:

- environmental factors, for example, nicotine and other drug use, toxins;
- stressful life events; or
- biological factors, for example, genetic factors including chromosomal, endocrinological, anatomical, immunological and microbiological abnormalities. (Klier et al 2002b)

Pregnancy loss can be a traumatic experience; it may cause physical pain and discomfort and may even be life threatening. (Saraiya, Green, Berg, Hopkin, Koonin and Atrash 1999:174) Women with pregnancy loss often express emotions such as sadness, distress, anger, guilt and remorse. Women may also experience doubt about their ability to conceive in the future after the loss. (Borg and Lasker 1981) Recent research that included comparison groups has indicated that miscarriage is a risk factor for depressive symptomatology, which can range from depressive symptoms to minor depressive disorder and major depressive disorder. (Thapar and Thapar 1992) In the six months after a pregnancy loss, the risk for an episode of minor depression is 5-fold and that for major depression is 2.5-fold. (Klier et al 2000: 15; Neugebauer, Kline, Shrout, Skodol, O'Connor, Geller et al 1997: 385)

Women who have experienced pregnancy loss may present with other psychiatric symptoms too. They may be anxious about a number of issues, such as continued bleeding, underlying genetic factors, undetected medical illness that may have contributed to the loss, as well as doubt about their ability to carry a subsequent pregnancy to term. Studies that specifically examined the development of anxiety symptoms following a pregnancy loss found mixed results when comparison groups were used, as anxiety levels were found to be substantial immediately after miscarriage and may be sustained for at least four months. (Thapar and Thapar 1992; Henshaw 1998; Lee and Slade 1996) There is some evidence that anxiety symptoms may be even more prevalent than depressive symptoms immediately post loss. Geller and colleagues (2001) reported that miscarriage might also increase the risk of a recurrent episode of obsessive-compulsive disorder, but not of developing panic disorder or specific phobia. The risk of developing post-traumatic stress disorder may also be increased following loss. (Thapar and Thapar 1992)

2.7.5 Pregnancy and other life events

Pregnancy also occurs in relation to life circumstances and this can exacerbate the experience of distress. These circumstances can either be chronic, enduring stressors such as poverty, ethnic/racial discrimination, interpersonal and communal violence, or more acute stressful life events such as the loss of a loved one and changes that occur through life. (Gorsuch and Key 1974; Norbeck and Tilden 1983; Nuckolls, Cassel and Kaplan 1972)

Multiple stressors can be present and exacerbate the experience of distress, for example, the rate of unintended pregnancy is highest among young, unmarried, and women from lower-income groups. (Brown and Harris1978)

Lack of a supportive partner during pregnancy and stressful circumstances related to a spouse or partner can cause significant distress. (Oakley 1998) Regardless of whether the pregnancy is planned or unplanned, if the woman is unmarried or there is a lack of a committed partner, the pregnancy can result in social stigma, the end of the relationship, or strained relationships with the family, community members and others in the social network. This can cause significant distress for the woman. (Nuckolls et al 1972; Brown and Harris 1978; Oakley 1988; Sosa, Kennel, Klaus, Robertson and Urrutia 1980; Pagel and Becker 1987)

Marital problems and poor interpersonal relationships with partners also have significant implications for distress and depression. (Brown and Harris 1978; Pagel and Becker 1987)

If domestic violence is involved, the psychological and physical consequences can be quite severe, irrespective of whether the violence is a longstanding problem or commenced during the pregnancy. Prevalence estimates suggest that approximately 17% of pregnant women are battered. (Newberger, Barkan, Barkan, Mc Cormick, Ylo, Gary et al 1992; Rachana, Suraiaya, Hisham, Abdulaziz and Hai 2002; Johnson, Haider, Ellis, Hay and Lindow 2003) As noted by the American Medical Association, 23% of pregnant women seeking prenatal care are battered, making domestic violence more common than many other complications of pregnancy. (American Congress of Obstetricians and Gynecologists 2017)

Health care providers should be sensitive to the distress and anxiety experienced by many women and their families as a consequence of adverse pregnancy-related and other life circumstances. By recognizing their patients' life circumstances, health care providers can develop a rapport, make appropriate referrals and recommendations, encourage compliance and contribute to the wellbeing of the woman and her family. (Kumar 1994; Videbach and Gouliaev 1995)

2.7.6 Postpartum depression

Depression accounts for the greatest burden of disease among all mental health problems and is expected to become the single leading disease burden amongst all general health problems by the year 2020. (Murray and Lopez 1996) Maternal mental health is of significant importance during the perinatal period.

Postpartum depression (PPD) may be related to sensitivity to hormonal fluctuations that occur during the perinatal period. A study conducted on euthymic women with previous PPD showed that women experienced dysphoria after both addition and withdrawal of supra-physiological doses of oestradiol and progesterone, compared with healthy control subjects. (Bloch, Schmidt, Danaceau, Murphy, Nieman and Rubinow 2002)

In addition to sensitivity to oestrogen and progesterone fluctuations, biological theories have included fluctuations of other gonadal hormone and neuro-active steroid levels after delivery, including altered cytokines, HPA axis hormones, as well as altered fatty acids, oxytocin and arginine vasopressin levels. (Corwin and Pajer 2008; Zonana and Gorman 2005)

The serotonin system has also been identified as an etiological factor for depression as altered platelet serotonin transporter binding and decreased postsynaptic serotonin 1A receptor binding in the anterior cingulate and meso-temporal cortices have been found in studies. (Moses-Kolko, Wisner, Price, Berga, Drevets, Hanusa et al 2008) [A] recent study used a functional magnetic resonance imaging (fMRI) neurophysiological activation paradigm, suggesting altered neural processing in women with postpartum depression. (Silverman, Loudon, Safier, Giacchetti, Macci, Tinelli et al 2007)

Various rates of postpartum depression have been reported previously. Righetti-Veltema et al (1998) found a prevalence of 10.2% three months postpartum in an unselected sample of women. In another study, 5.8% of women became clinically depressed between one and four months postpartum. (Chaudron, Klein, Remmington, Palla, Allen and Essex 2001) White et al (2006) reported a prevalence of 10.2% at six weeks postpartum, whereas Leeds and Hargreaves (2008) found a prevalence of depression of 21.5% among women between 6 and 12 months postpartum. Righetti-Veltema et al. (2008) found multi-parity, deleterious life events and depressive mood during pregnancy to be predictive of postpartum depression. Chaudron et al (2001) found that maternal age, depression during pregnancy, thoughts of death and dying at one month postpartum, and difficulty falling asleep at one month postpartum to be predictive of depression at four months postpartum.

2.7.6.1 Epidemiology of depression during pregnancy

Published reports of the prevalence of depression during the perinatal period have increased over recent years. (Bennett, Einarson, Taddio, Koren and Einarson 2004) Despite increased research into the epidemiology of this disorder, there is still uncertainty about the numbers of women affected, as underreporting of depressive symptoms in the postnatal period and under-identification of cases of depression can occur. (Austin and Priest 2005) Postnatal depression is a serious mental health condition, which is associated with significant detrimental effects to both mother and child. (O'Hara 1986) However, current knowledge of prevalence and incidence of postnatal depression in the first postnatal year is limited, with limited generalizable evidence in the form of high-quality systematic reviews.

Rates determined by structured interviews ranged from 2–21%, and up to 38% for women of low socio-economic status. (O'Hara 1986; Affonso, Lovett, Paul and Sheptak 1990; Kitamura, Shima, Sugawara and Toda 1993) To obtain an explanation for such a wide variation, it is necessary to consider the methods used within the original articles, as a variety of instruments to detect depression and depressive symptoms have been used by researchers, not all of which have been validated for pregnancy.

Although the prevalence of depression has not been shown to be dependent on race, it has been correlated negatively with socio-economic status. Apart from an early study in Uganda, (Cox 1983) there were previously limited studies on the postpartum mood disorders in the developing world. This has, however, changed in recent times and research on depressive disorders is receiving increased attention. Epidemiological evidence suggests a high rate of depression in general (Rahim and Cederblad 1989; Bahar, Henderson and Mackinnon 1992; Abas and Broadhead 1997), especially in women from low socio-economic groups. (Harpham 1994; Stein, Cooper, Campbell, Day and Altham 1989) Evidence from research in developed countries has shown an association between perinatal depression and adverse child cognitive and socio-emotional development. (Cooper and Murray 1998) There is concern regarding the high prevalence of depression in developing countries with the need to develop cost-effective intervention strategies. (Blue and Harpham 1998)

A study conducted by Cooper et al. (1999) in a peri-urban settlement in Khayelitsha, South Africa, confirmed the concern regarding postpartum samples. The rate of postpartum depression found in the study was three times that observed in developed countries. Furthermore, social adversity, a known risk factor for postpartum depression in developed countries (Cooper and Murray1998; Stein et al 1998), was not found in Khayelitsha, as high levels of social adversity were endemic and the variable could not be evaluated effectively. A variable related to maternal depression in Khayelitsha was the absence of a supportive partner to the women. (Murray et al 2003)

Cooper et al (1999) studied 483 mothers from pregnancy to one year postpartum to establish the prevalence and incidence, as well as the onset and course of psychiatric disorder. They found that 8.7, 8.8 and 5.2% of their sample had a non-psychotic psychiatric disorder at 3, 6, and 12 months postpartum respectively. Approximately half of their sample had onset of symptoms within the three months postpartum, with a quarter having symptoms between 6 and 12, whilst two thirds of women experienced symptom duration of three months or less. (Abbas and Broadhead 1997; Harpham 1994)

A systematic review (Gavin, Gaynes, Lohr, Meltzer-Brody, Gartlehner and Swinton 2005) of studies that diagnosed depression by a clinical structured interview reported that the point prevalence of MDD and minor depression ranged from 6.5 to 12.9% through the first six months postpartum, with a peak at two and six months postpartum. Furthermore, a large cohort study conducted in Denmark reported that the first 90 days postpartum was a time when new mothers were at increased vulnerability to developing psychiatric conditions. (Munk-Olsen, Laursen, Pedersen, Mors and Mortensen) The prevalence of postpartum depression in non-Western countries range from 0.5–60%. (Halbreich and Karkun 2006) The wide range can in part be attributed to cultural factors which have been found to influence the development and reporting of PPD. Psychosocial risk factors for postpartum depression described in the literature include: (Beck 2001; Robertson, Grace, Wallington and Stewart 2004; Milgrom, Gemmill, Bislta, Barnett, Marnett, Brooks and Ericksen 2000)

- previous history of depression,
- MDD during pregnancy,
- family history of depression,
- anxiety during pregnancy,
- previous history of MDD,
- previous premenstrual dysphoria,
- vulnerability to stressful life events during the perinatal period,
- poor social support,
- marital conflict,
- low income,
- immigrant status, and
- young maternal age.

Other factors identified that can increase the risk for developing depression include hormonal factors such as receiving progestogen within 48 hours of delivery (Dennis, Ross and Herxheimer 2008), the demands of new motherhood, and changes in sleep patterns as a result of the demand for lactation. (Friedman and Resnick 2009; Pearlstein, Howard, Salisbury and Zlotnick 2009) It is important not to identify normal experiences in the postpartum period as pathologic, and although the DSM discusses changes in sleep and appetite as criteria for depression, most women will experience changes in sleep patterns and appetite during the perinatal period. Depression during the perinatal period may range from mild to severe depending on the depressive symptoms and levels of impairment experienced by the women.

Also, women who have experienced severe depression at any time in their lives, including the postpartum period, may present with associated psychotic symptoms such as mood-congruent delusions, with content including maternal inadequacy, nihilism or feeling deserving of punishment. (Friedman and Resnick 2009)

2.7.6.2 Risks of not treating postpartum depression

The presence of depression during the perinatal period may have an impact on the new parents and can result in relationship issues. It can also impair maternal bonding (e.g. insecure maternal baby attachment), resulting in decreased cognitive skills and language development, as well as potentially long-term neuro-behavioural problems in the child. Depressed mothers may not respond to their infants' cues. (Reck, Hunt, Fuchs, Weis, Noon, Moehler et al 2004; Gunlicks and Weissman 2008; Dietz, Jennings, Kelley and Marshal 2009; Pawlby, Sahrp, Hay and O'Keane 2008; Hay, Palby, Sharp, Asten, Mills and Kumar 2001) A depressed mother's behaviour may include withdrawal, intrusiveness and hostility. She may perceive caring for her infant as being rather difficult. Her infant may experience emotional/social impairment, growth impairment, temperamental problems and decreased intellect. (Mian 2005)

Suicide and infanticide are risks associated with postpartum depression that require prompt attention. Suicide is a leading cause of postpartum death, accounting for up to a fifth of the deaths. (Lindahl, Pearson and Colpe 2005) Mothers who are suicidal are also at risk for committing infanticide (Friedman, Horwitz and Resnick 2005) as they may plan suicide with the belief that their child is better off dead than remaining alive and motherless. Depressed mothers may view the world as cruel and uncaring. (Resnick 1969) Some mothers experience recurrent thoughts of harming their infant and may not seek help or discuss their concerns with others; others may realize that they need help. (Barr and Beck 2008) One study of depressed mothers with children up to three years of age found that up to 41% of the mothers had experienced thoughts of harming their child. (Jennings, Popper, Ross and Elmore 1999)

Although suicide following childbirth is rare, the rate is higher than previously thought. Maternal deaths from suicide and psychiatric causes are the leading cause of maternal mortality in the United Kingdom and Australia.

In the UK, confidential enquiries into maternal deaths consistently found suicide to be the leading cause of maternal deaths from 1997–2002. (Oates 2003) This finding was ascertained through linkage with birth and death registration at the Office of National Statistics Linkage.

The study revealed more cases of suicide than those reported by the confidential enquiry into maternal deaths. (Lewis and Drife 2001; Lewis 2004) The ONS linkage was critical in the comprehensive examination of all maternal deaths because the majority of women who committed suicide within the first year following childbirth were not reported to the enquiry, as these women were no longer in contact with maternity services at the time of their deaths and their deaths were not coded as being due to maternal causes on the death certificate. Without the ONS linkage study, suicide was the second leading cause of maternal death and the leading cause of indirect maternal death. (Oates 2003) Eleven percent of the deaths reported to the enquiry were due to psychiatric causes. The majority of the coincidental psychiatric deaths were due to accidental drug overdose and 12% of the indirect deaths were due to suicide. 56% of all psychiatric deaths and 68% of suicides reported to the enquiry related to women who suffered from a serious mental illness, whilst 46% of the suicide cases had been admitted to a psychiatric hospital during a previous episode of illness. Of the women with a previous psychiatric history, half had been admitted to a psychiatric hospital following a previous pregnancy. (Oates 2003)

A study of a population sample in the United States reported a three times greater risk of a suicide attempt, as well as increased inpatient psychiatric admissions after foetal death or infant death in the first year postpartum. (Shiff and Grossman 2006) In the study, obstetric complications, preterm delivery, low birth weight and congenital malformations were not associated with an increased risk of suicide. A review of studies that confirmed suicide rates are lower during pregnancy and the postpartum period emphasized that perinatal women complete suicide by more violent means than women who were not in the perinatal period. (Lindahl et al 2005) Assessment of suicidality in the perinatal woman should include specific inquiry about depressed mood, substance abuse, current or previous psychiatric illness, previous suicide attempts, previous trauma and current intimate-partner violence. (Lindahl et al 2005; Comtois, Schiff and Grossman 2008)

2.7.7 Anxiety disorders in pregnancy

Anxiety symptoms during the perinatal period can adversely affect maternal wellbeing and influence pregnancy outcomes. Although postpartum depression is the most frequently studied psychiatric condition during the perinatal period, a number of authors have indicated the importance of distinguishing between postpartum depression and postpartum anxiety. (Mathey et al 2008; Pope 2000; Austin 2004; Heron, O'Connor, Evan, Golay and Glover 2004) Although anxiety and depression commonly co-exist in the postpartum period, anxiety is often included in the diagnosis of depression and not as a separate condition. Green (1998) reports that the concept of depression might limit the understanding of postnatal distress and suggests that broader indicators of negative mood need to be considered. Studies have indicated that the course of depression is longer and more severe in individuals who experience symptoms of anxiety compared to individuals who don't. (Corryell, Enicott and Winokur 1994) It appears that the burden of postpartum depression with sub-syndromal anxiety disorders is greater than it is for postpartum depression alone.

A study conducted by Stuart et al. which was based on a community sample, reported a point prevalence of 8.7% for anxiety at 14 weeks postpartum and 16.8% at 30 weeks postpartum. (Stuart, Couser, Schilder, O'Hara and Gorman 1998) The incidence of anxiety from 14–30 weeks postpartum was 10.3%. The authors concluded that there is a high prevalence of both postpartum depression and postpartum anxiety, and that it is common for anxiety cases to develop within 30 weeks of delivery.

Milgrom et al. emphasized the importance of distinguishing anxiety from depression to ensure that appropriate treatments are commenced, which specifically target the symptoms and aetiology of anxiety. (Milgrom, Martin and Negri 1999) Furthermore, Mathey et al (2003) found that not all anxious mothers are depressed, and studies with non-postpartum samples have shown that comorbidity of anxiety and depression may:

- present with more severe symptoms,
- be more difficult to treat than each disorder alone,
- be associated with poorer acute and long-term outcomes,
- increase the risk for suicide, and
- require specific treatment strategies that target both sets of symptoms. (Rivas-Vasquez, Saffa-Biller, Ruiz, Blais and Rivas-Vasquez 1998)

Matthey (2003) describes a hierarchical diagnostic system, where depression takes precedence even though anxiety symptoms are a prominent feature. This focus on depression can result in cases of anxiety being undetected and undertreated, and in cases where depression and anxiety co-occur, there is a risk that treatment strategies focus on the depressive symptoms, with limited or no attention paid to the symptoms of anxiety.

Ross et al (2003) indicated the importance of determining whether anxiety symptoms are part of a primary depression or another clinical entity, whilst Heron et al (2004) suggested that anxiety may be a precursor to depression due to altered physiological pathways, or a consequence of being unable to manage stress.

Furthermore, Miller et al (2006) proposed broader classification for postnatal distress that should include measures of depression, anxiety and stress. Lovibond and Lovibond (1995) described stress as a distinct negative emotional state, which includes chronic arousal and impaired functioning. Terry et al (1996) found evidence that linked high levels of stress and coping responses to depressive symptomatology. Some authors have suggested that many women experience distress in the postpartum period which may be missed if the criteria for depression alone are followed. They report that failure to identify and treat significant symptoms of anxiety and stress may leave women vulnerable to worsening symptomatology if the focus of postnatal distress is concentrated on depression alone.

The study examined symptoms of two anxiety disorders, panic and obsessive-compulsive disorder, in women who indicated high levels of dysphoria on a self-report depression measure. The study demonstrated that nearly 20% of postpartum women reporting dysphoria also experienced panic or obsessive-compulsive symptoms. It thus appears that anxiety is a common experience in women who are four to six months postpartum. However, only 1.5% and 3.9% of the women who were interviewed met DSM-4 criteria for panic and obsessive-compulsive disorder respectively. (Pinis, Cassano, Simonini and Savino 1997) Of the women who met criteria for major depressive disorder, the rates of comorbid panic disorder were 2.3% and 5.4% respectively. These rates are significantly lower than those reported in the literature. Pini et al (1997) indicated that 34.1% of individuals diagnosed with a non-postpartum major depressive episode were also diagnosed with obsessive-compulsive disorder.

Research on anxiety disorders related to childbirth has focused on two main areas, namely the prevalence and the predictors of peri-partum-related psychiatric morbidity and post-traumatic stress disorders. (Chandra and Ranjan (2007). Fears relating to childbirth-related have been a topic of interest for health professionals during the past few years.

Previous research indicates that nearly 25% of women report significant fear related to childbirth, which has been identified as a reason for the increase in the number of women requesting elective caesarean sections as well as for negative birth experiences. (Olde, van der Hart, Klever, van Son, Wijnen and Pop 2005; Söderquist, Wijma, and Wijma 2006) Over the years, research interest has focused on the changes in women's emotional reactions following delivery, rather than on their psychological state during pregnancy. (De Pinho and Hoffman 1998)

Descriptive and exploratory studies suggest that pregnant women may experience specific and intense fears such as fear of incompetence, concerns about pain and loss of control during delivery, fear for their own life and/or the life of their baby and worries about changes in their personal life due to pregnancy and childbirth. (Sjögren 1997) A study from Sweden reported that among 550 women and their spouses, 23% reported severe childbirth-related fears, with older primigravida women from urban areas, and those with a history of caesarean section, also reporting intense fear pertaining to childbirth. (Eriksson Westman and Hamberg 2005)

2.7.7.1 Panic disorder

Anxiety disorders cover a wide spectrum of conditions including panic disorders, which can present in women during the childbearing years. The occurrence of panic disorders during pregnancy poses a number of clinical challenges, including the effects of these diseases as well as exposure to psychotropic medication for the foetus (Roy-Byrne, Dager, Cowley Vitaliano and Dunner 1999; Cohen and Rosenbaum 1998; Erickson, Källen and Wilholm 1999) and mother during treatment of these conditions. (Cowley and Roy-Byrne 1998; Villeponteaux, Lydiard, Lavaia, Stuart and Ballenger 1992; George, Ladenhlim and Nut 1987; Klein, Skrobal and Garfinkel 1994)

Panic disorder has a chronic and recurrent course and the profile of physiological symptoms associated with postpartum panic attacks were similar to those associated with panic disorder in general, (Pollack, Otto, Rosenbaum, Sachs, O'Neil, Asher et al 1990; Cohen 1996; Williams, Koran 1997) as was confirmed in a study conducted by Metz et al. (1998) It therefore appears that postpartum panic disorder is not any different to instances of panic disorder that occur at other times.

Pregnancy may improve symptoms of panic in some patients, but other patients appear to experience persistence or exacerbation of symptoms. (Cohen 1996; Halbreich 2004) Psychiatric patients may be at a high risk for relapse during the perinatal period, especially if medications are discontinued, (Roy-Byrne et al 1999) and some studies have suggested adverse effects of untreated anxiety on neonatal outcome. (Istran 1996; Steer, School, Hediger and Fisher 1992; Orr and Miller 1995; Perkin, Bland, Peacock and Anderson 1993)

A study in Hungary showed that women with panic disorder had a higher risk for some pregnancy complications. The proportion of preterm birth was larger, though the symptoms of threatened preterm delivery were recorded less frequently in mothers with panic disorders than in mothers without panic disorders. The study also found a shorter gestational age in pregnant women with panic disorders, which may explain the larger proportion of preterm births. (Banhidy, Ács, Erzsèbet and Czeizel 2006)

Sichel et al (1993) speculated that rapidly changing hormonal levels and a predisposition to mental illness might be important risk factors in the development of postpartum anxiety disorders. Existing clinical studies of anxiety during the perinatal period indicate the specific conditions of panic disorder and obsessive-compulsive disorder. (Cohen, Sichel, Dimmock and Rosenbaum 1994) Cohen et al. (1994b) presented a retrospective case series of women with pre-existing panic disorder who were assessed for panic during pregnancy. They found that 20% of women experienced an exacerbation of panic symptomatology, with 35% of women experiencing exacerbation of symptoms at eight weeks postpartum.

Sholomskas et al (1993) concluded that even in the absence of a prior history of panic disorder, women are at significant risk for postpartum onset of panic disorder. Wisner et al (1999) obtained similar findings in their study, which suggested that women with histories of panic disorder may experience an exacerbation of their symptoms during pregnancy and the puerperium and that women without histories of panic disorder are more likely to develop the disorder during the perinatal period than during other time periods.

2.7.7.2 Obsessive-compulsive disorder

The postpartum period is considered to be one of risk for the development of obsessive-compulsive disorder. (OCD) Maina et al. (1993) observed that the birth of a child was an important precipitating event for OCD, and also that women with new onset of OCD had

significantly higher rates of aggressive obsessions, whilst Labad et al. (2005) observed that 50% of patients with OCD who had been pregnant reported worsening of symptoms postpartum.

The precise neurobiological mechanisms of postpartum OCD have not been identified. Fluctuating gonadal hormones during the postpartum period have been hypothesized to contribute to the increased risk of emotional disturbances in some women. Steroid hormones play an important role in brain functioning and can modulate neuronal transmission by affecting the synthesis and release of neurotransmitters (Steiner, Dunn and Born 2003) It has been hypothesized that changes in oestrogen and progesterone during the perinatal period may alter serotonergic function, thus predisposing some women to develop OCD. (Mc Evan 2002) Oxytocin has been hypothesized to play a role in the production of OC symptoms (Swedo, Leonard, Kruesi, Rettew, Listwak, Berrettini et al. 1992; Altemus, Swedo, Leonard, Richter, Rubinow, Potter et al1994; Leckman, Goodman, North, Chappel, Price, Pauls et al, 1994). Prolactin levels have been hypothesized to be negatively correlated with the duration and severity of OC symptoms in children. (Hanna, McCraken and Cantwell 1991) Research into the effects of hormones on OCD is preliminary and difficult to speculate on because of limited controlled prospective studies to identify clinical factors which predispose women to developing postpartum OCD. However, preliminary observations indicate that neuro-hormonal fluctuations may affect neurotransmitter activity that subsequently results in symptom presentation.

Although the role of recent life events in precipitating psychiatric disorders has been investigated, few empirical studies have specifically investigated the occurrence of stressful or potentially triggering events in the history of individuals with OCD. Conflicting results have been reported on the possible role of life events in triggering OCD onset. Pregnancy and/or delivery among life events appear to influence the OCD course and, in some cases, appear related to its onset. (Maina et al 1999) Obsessive patients reported a significant excess of events over the year prior to onset in comparison to healthy subjects, and the stressors were frequently serious illness in the subjects or their close relatives, arguments or the birth of a child. The occurrence of these incidents was, however, too infrequent to test for significance. (McKeon, Roa and Mann 1984)

Khanna et al (1998) on the other hand, reported that there was no difference between obsessive patients and healthy subjects over the year prior to symptom onset, despite the finding that there was an excess of events in the six months prior to the onset of the disorder.

Preliminary evidence supported the claim that exposure to pregnancy and or to delivery increases risk for OCD. It was further reported that either pregnancy or delivery was precipitants in 3.4% to 33.3% of the total sample of OCD patients and in 12.5% to 40% of female OCD patients (Pollitt 1957; Ingram 1961; Lo 1967; Diaz, Grush, Sichel and Cohen 1997). The results of the study by Maina et al. (1999) did not report on significant excess of life events in patients who develop OCD in the 6 and 12 months prior to onset. There was, however, a difference between the OCD patients and the comparison group when the type of event, rather than the actual number of events, was considered. The study revealed that, in all cases, the disorder occurred after delivery and within the first four weeks postpartum.

Data from the study are consistent with those of previous research that found women with OCD account for a higher percentage of postpartum onset of the disorder, with approximately a quarter of the cases developing during the puerperium. Assessment of obstetric complications in postpartum OCD have found that postpartum OCD appears to:

- occur more frequently in primiparae (75%),
- frequently follow a pre- and post-term pregnancy (62.5%), and
- often be associated with delivery by caesarean section without labour (62.5%).

The study failed to confirm the association between the occurrence and severity of life events and OCD as well as an association between pregnancy and onset of the disorder. The study did, however, confirm the high rate of OCD in the puerperium and its characteristic intrusive thoughts of harming the newborn, and suggests the possibility that the onset of the disorder after delivery is associated with several obstetric complications. (Maina et al 1999)

The lifetime prevalence of OCD in the general population is approximately 2%, but the prevalence of OCD in the postpartum sample is not well studied. . (Ashuler, Hendrick and Cohen 1998; Uguz, Akman, Kaya and Cili 2007; Abramowitz, Schwartz, Moore and Luenzmann 2003; Fairbrother and Abramowitz 2007) The data on incidence rates of postpartum OCD are limited, with available data generally based on case reports, case series or retrospective reports by females with OCD. Wenzel et al (2001) found that 2.6% of childbearing women in his sample met criteria for OCD at eight weeks postpartum, and that 5.4% of the women reported sub-syndromal levels of OCD. Obsessive-compulsive symptoms (OCS), especially intrusive thoughts of harming the baby, have been reported in postpartum depression and in the puerperium. Wisner et al (1999) observed that 57% of a sample of 37 women with postpartum depression, and 39% of 28 women without postpartum depression, had OCS.

Aggressive obsessive thoughts involving the baby are significantly more common in women with postpartum depression. In another study, Jenning et al. (1999) described unwanted aggressive thoughts in 41% of 100 women with postpartum depression, and in 6.5% of 46 women without psychiatric disorder.

As reported in cases of perinatal depression, maternal anxiety may have a negative developmental influence on children, and undiagnosed and untreated OCD and OCS can impair mother-baby bonding. (Brandes, Soares and Cohen 2004) Mothers with OCD and OCS can have fear of being alone with the baby and may avoid it, as well as expressing fear of being unable to care for the infant. (Fairbrother and Abrowitz 2007)

Maina et al (1999) suggested an association between perinatal OCD and preterm, post-term and caesarean delivery, whereas Labad et al (2005) found that none of the clinical variables examined, including primiparae, type of delivery, pregnancy or postpartum complication, were associated with the onset of or an increase in OCD.

In a sample of 59 women diagnosed with obsessive-compulsive disorder, Neziroglu et al (1992) found that 39% reported the onset of their disorder in pregnancy. In contrast, Williams and Koran (1999) reported that only 13% of 38 women with obsessive-compulsive disorder developed their disorder in pregnancy. These researchers also indicated that 17% of 29 women with pre-existing obsessive-compulsive disorder deteriorated in the postpartum period. Comorbid depression occurred in 37% of these women. Sichel, Cohen, Dimmock and Rosenbaum (1993) in a retrospective review, examined the symptoms of postpartum obsessive-compulsive disorder in fifteen women who developed the disorder in the puerperium. The mean time to onset was 2.2 weeks after delivery. Eight women had no previous history of psychopathology and seven women reported histories of either panic disorder or generalized anxiety disorder. It appears that obsessive-compulsive disorder, like panic disorder, is exacerbated in pregnancy and the puerperium in women with histories of anxiety disorders, and several cases of postpartum onset have been documented.

2.7.7.3 Pregnancy-related post-traumatic stress disorder and its implications for obstetric and mental health.

Despite the increasing amount of literature on PTSD related to childbirth, there is limited information pertaining to interventions and their efficacy. (Alder, Stadlmayr, Tshudin and Bitzer 2006).

Smith et al (2006) who examined symptoms of PTSD in a community sample of 948 low-income pregnant women found that 11.9% of women who experienced a traumatic event screened positive for PTSD in pregnancy. Thirty-three percent of the women reported thoughts of self-harm and more than 27% had comorbid substance use during pregnancy.

A study conducted in five health centres in Nigeria to assess the prevalence of PTSD and its association to childbirth-related experiences, marital satisfaction and social support reported a prevalence of PTSD of 5.9% among 876 women. (Adewuya and Afolabi 2005).

This was higher than the prevalence reported by Western data. The authors indicated that factors independently associated with PTSD include:

- hospital admission due to pregnancy-related complications,
- instrumental deliveries,
- emergency caesarean section,
- manual removal of the placenta, and
- poor maternal experience of control during childbirth.

The findings indicated the importance of the birth experience and antenatal care in influencing psychiatric morbidity associated with childbirth-related trauma. This is particularly relevant in the developing world, where women often do not receive adequate antenatal care and may be psychologically unprepared for the events related to pregnancy and delivery during the period of hospitalization.

Small et al. (2006) who studied the effectiveness of midwife-led interventions immediately following childbirth did not find any long-term benefits on anxiety or PTSD symptoms.

Previous research has shown that there is an association between early traumatic life events, particularly repeated physical or sexual abuse, and the subsequent development of post-traumatic disorder in adulthood. (Gnanadesikan, Novins and Beals 2005; Heinrichs, Wagner, Schoch, Soravia, Helhammer and Ehlert 2005; Yehuda 2002) Adults who were traumatized as children are, as a result of changes in their neurobiological systems, more vulnerable to the developing PTSD when exposed to subsequent re- traumatization (Loveland Cook, Flick, Homan, Campbell, Mc Sweeney and Gallagher 2004)

Past traumatic life events may be associated with increased pregnancy complications, including miscarriages, hyperemesis, preterm contractions (Yehuda, Spertus and Gollier 2001; Chang, Chang, Lin and Kuo 2002) and delivery complications (Glyn, Wadhwa, Dunkel-Schetter, Chicz-Demet and Sandman 2008), whilst female survivors of childhood

sexual abuse score higher in postpartum post-traumatic stress and depression. (Lev-Wiesel, Daphana-Tekoha 2007) Although the psychological effects of high-risk pregnancy (defined as any pregnancy in which medical factors, including maternal or foetal health factors, can adversely affect the outcome of the pregnancy and increase the likelihood of morbidity and mortality (Giurgescu, Penckhofer, Maurer and Bryant 2006; Maloni, Park, Anthony and Musil 2005; Turton, Hughs, Evans and Fainman 2001) are understood, there is limited of knowledge about postnatal psychological effects in terms of PTS symptoms. Studies have shown that physical and psychological aspects of a high-risk pregnancy are likely to be related to delivery complications as well as to pain and distress during delivery. (Maloni et al 2005)

Complicated pregnancy, and obstetrical and delivery complications such as stillbirth, pregnancy loss, premature birth and perinatal loss, may lead to the development of PTS symptoms and PTSD. (Olde et al 2005; Engelhard, Van den Hout, and Arntz 2001; Pierrehumbert, Nicole, Muller-Nix, Forcada-Guex and Ansermet 2003; Holdditc-Davis, Bartlett, Blickman and Isles 2003; Hunfeld, Wladimiroff and Passchier 1997).

Furthermore, 20% of all pregnancies are defined as high-risk and may include conditions such as maternal pre-pregnancy medical complications, pregnancy-induced medical complications, foetal and obstetrical delivery complications, which may be experienced as a traumatic event. (Gray 2006; Levy-Schiff, Lerman, Har-Even and Hod 2002; Smeltzer 2006). A higher percentage of high-risk pregnancy was found among women who reported a history of traumatic events. (Lev-Wiesel, Chen, Daphna-Tekoha and Hod 2009) Results from a study conducted in Israel showed that women suffering from chronic illness are no more prone to high-risk pregnancy than healthy women. It seems that high-risk pregnancy and traumatic childbirth following a history of previous traumatic events should be considered as significant risk factors for the development of adverse psychological consequences. Therefore, screening pregnant women for previous traumatic events, especially regarding their impact related to intrusion and avoidance, could help health care providers identify problems and initiate treatment at the initial stage of pregnancy. This may lower the risk for delivery complications and postpartum PTS. (Lev-Wiesel et al 2009)

While the incidence of PTSD is only 1.7% after an uneventful pregnancy, (Wijman, Söderquist and Wijma 1997) it is increased after pregnancy complicated by emergency cesarean section, preterm birth or term delivery of an infant with subsequent serious complications. (Ryding, Wijma and Wijma 1997) Stress conditions predisposing a woman to PTSD are typically unpredictable and uncontrollable. (Foa, Stektee, and Rothbau 1989)

Similarly, early-onset preeclampsia develops unexpectedly and, as a result of the potential risk for morbidity to mother and baby, surgical interventions like caesarean sections are conducted to expedite delivery. This can result in preterm deliveries, which may in turn result in the infant requiring prolonged treatment in a neonatal intensive care unit. Preeclampsia can potentially precipitate life-threatening events, which can adversely affect not only the mother but her family too. (Engelhard, van Rij, Boullart, Ekhart, Spaandeman van den Hout et al 2002)

A study investigated the incidence of PTSD in formerly preterm and term preeclamptics compared with two control groups of women matched for gestational age. One control group consisted of women who had a preterm birth, but no other complications, whilst the other control group consisted of women who had an uneventful pregnancy and term delivery.

Almost a quarter of patients met diagnostic criteria for PTSD in response to both preterm preeclampsia and preterm birth. The findings suggested that the physical strain of preeclampsia does not contribute to the psychological morbidity triggered by premature delivery. The prevalence of PTSD in the term preeclampsia group (17%) was not significantly lower than that of the preterm groups, but was substantially higher relative to the control group, suggesting that preeclampsia as such may be considered to be psychologically stressful.

In line with other studies, PTS symptoms were more strongly associated with psychological factors than with objective indicators of condition severity. Of the objective severity factors, only gestational age at admission was significantly negatively linked to PTSD symptoms. A stronger stressor dose response relationship might have been found with additional severity factors such as postnatal complications, (DeMier, Hynan, Harris and Manniello 1996) clinical course of the hospitalized newborn or persistent physical complaints. (Ehlers, Mayou and Bryant 1998) However, other PTSD research showed that the degree of peri-traumatic distress and dissociation strongly relates to PTSD severity, independently of objective stressor severity, which highlights the importance of distinguishing between subjective and objective indicators of stressor severity. (Ehlers et al 1998; Bernat, Ronfeldt, Calhoun and Arias 1998)

The data from the study suggest that the psychological sequelae of preeclampsia require more research and clinical attention. The authors recommended that future studies include longitudinal study designs and structured interviews to refine the prevalence, course and risk factors for PTSD. The findings further suggest the need for physicians to be aware of possible PTSD symptoms in response to preeclampsia or preterm birth.

This may be of importance, as one way of avoiding reminders of the condition might be to avoid a future pregnancy, or a subsequent pregnancy or delivery might reactivate unresolved PTSD when reminders of preeclampsia or preterm birth arise. (Foa et al 1989) Unresolved PTSD might also contribute to subsequent undesirable pregnancy outcomes, since symptoms of depression or anxiety are predictive of adverse obstetric and neonatal outcomes. (Levin and de Frank 1998) The data suggest that only a minority of patients develop PTSD. Furthermore, acute trauma interventions do not have established efficacy and sometimes even have adverse effects. (Chung, Lau, Yip, Chiu and Lee 2001) The authors suggest that short-term psychological support and follow-up should focus on individuals with intense acute distress and dissociative reactions, and that patients may also benefit from information about common responses and adaptive reactions. (Engelhard et al 2002)

2.8 MATERNAL NEAR MISS AND MENTAL HEALTH

The concept of maternal near miss and obstetric complications was highlighted in the previous chapter and will be elaborated upon in this section.

Severe obstetric complications are common in low-income countries. Women who develop acute complications, become critically ill or die from these complications may not have received prompt care due to a lack of accessible, good-quality emergency services. Furthermore, their babies may also suffer impairment or death. (Filippi et al 2010) It is recognized that severe obstetric complications may lead to long-term adverse consequences for women's health and socio-economic conditions, (Filippi et al 2010; Gill, Pandey and Malhotra 2007) yet postpartum interventions are belittled as a means to decrease maternal mortality (Hurt, Alam, Dieltens, Aktar and Ronsmans 2008) despite the risk of maternal death remaining high up to six months after delivery. There are few examples in developing countries of research on the health of recently delivered women, and more specifically the health of survivors of complications and their babies. (Van Ommeren, Saxena and Saraceno 2005)

Severe obstetric complications may lead to poor maternal health during the postpartum period, which can continue for up to 12 months or longer, with the burden increased for complications associated with perinatal deaths.

Near-miss women who experienced perinatal deaths were at a greater risk of developing mental disorders and of reporting poor health compared to women with uncomplicated childbirth. These near-miss women reported an increased use of postnatal services, although uptake remained low, below 50%. Women with a near miss who had given birth to a live baby were not different to women with uncomplicated childbirth in terms of postpartum health status, except for the presence of hypertension. Of concern, however, was the higher risk of death in babies born to mothers who experienced near-miss live births, as only 37% of the mothers in the group used postnatal services. (Filippi et al 2010)

Worldwide, approximately 1.5 million women a year suffer near-miss complications during pregnancy and childbirth (Filippi, Ronsmans, Campbell, Graham, Mills, Borghi et al 2006) that are so severe that they may threaten the woman's survival. (Mantel et al 1998; Filippi, Ronsmans, Gandaho, Graham, Alihonou and Santos 2000; Say et al 2009) The women who survive severe obstetric complications are vulnerable and can suffer from the physical, social, financial and psychological consequences of the near-miss event for up to one year postpartum. (Filippi, Ganaba, Baggaley, Marshall, Storeng, Sombie et al 2007)

However, the health and subsequent experiences of women who survive these severe complications is underexplored in all countries.

As mentioned previously, studies (Saurel-Cubizolles, Romito, Lelong and Ancel 2000; Waterstone, Bewley and Wolfe 2001) describing postpartum experiences of women who survived life-threatening experiences over a significant period of time are rare. (Filippi et al 2000) A study conducted in Benin found near-miss women with potential loss suffered to a greater extent than those who had a live baby. Women who had experienced a near miss were troubled by the childbirth experience, describing their postpartum period as emotionally challenging and attributing feelings of sadness, worry and discouragement to their near-miss event, especially when interviewed soon after birth. Near-miss women who continued to be sad struggled to cope with the effects of life events that occurred following the near-miss event compared to women whose symptoms decreased over time. These included financial debt relating to the cost of birth, inability to resume employment, emotional and physical fatigue, marital uncertainty, and strained relations with family and in-laws. (Filippi et al 2000) Some women described feeling pressured to have another pregnancy as soon as possible after the event. The women mentioned that the traumatic birth and subsequent social, personal and economic instability made them feel desperate.

Quantitative analysis of the study showed that near miss was not associated with greater psychological distress at 6 and 12 months postpartum when women give birth to live infants as compared with women who had uncomplicated deliveries. However, the presence of a perinatal loss precipitated symptoms of psychological distress, as was found when the near miss group was compared to the other groups. (Filippi et al 2000)

Women's health during the postpartum period was adversely affected as a result of experiencing a near-miss event and perinatal loss. Some women who experienced perinatal loss also reported that spousal abuse began in the six months following delivery. The rates of abuse were similar to lifetime prevalence rates of intimate partner violence reported in other studies. (WHO 2005; Kishor and Johnson 2004) The evidence from the study conducted in Benin was that a near-miss complication associated with perinatal loss increases the risk of abuse and indicates an increased vulnerability of women with adverse pregnancy outcomes. Significant associations between marital conflict and depression in diverse countries have been shown. (Patel et al 2002; WHO 2005; Dennis and Ross 2006) The importance of marital conflict in the aetiology of psychological distress may relate to the specific socio-cultural context where gender identities and values are defined by fertility. (Bernazzini and Bifulco 2003; Gijsels, Mgall and Wambura 2001)

Studies in Africa have shown that infertility and perinatal loss have adverse social consequences for women because bearing children is not only a personal experience for them, it is a family and social obligation, and may be the only way women can acquire social status and recognition within their community. (Grossman-Kendall, Filippi, De Koninck and Kanhonou 2001)

Women with near miss and perinatal death were at higher risk of developing psychological distress and were likely to be in need of further mental health care Fottrell et al 2010), this was especially true for mothers who had experienced perinatal loss. A high index of suspicion in this group may reduce the risk of negative consequences and allow early detection of clinical symptoms and prompt treatment. Evidence for the effectiveness of interventions to prevent of postpartum mood disorders in low- and middle-income countries is weak, although strategies such as support groups have been shown to be acceptable to mothers and can lead to reduced morbidity and psychological distress. (Nhiwatiwa, Patel and Acuda 1998)

Although improved access to emergency obstetric and neonatal care, as well as good-quality antenatal and delivery services, may play an important role in the prevention of psychological distress in the postpartum period, there is also a role for general postpartum

services in the management of postpartum mood disorders. Mental health needs to be integrated into maternal health care in low-income settings. As there is a shortage of mental health workers, the role of care may need to be met initially by nurses, midwives, gynaecologists and paediatricians during routine postnatal visits (Patel et al 2002; Rojas, Fritsch, Solis, Jadresic, Castilla, Gonzàlez et al, 2007; Rahman, Malik, Sikander, Roberts and Creed 2008), as these are often the professionals who have close contact with the women. It may be unlikely that postpartum women who are psychologically distressed as a result of perinatal loss would want to meet in a group, and these women may require more intensive one-on-one care using a combination of behavioural, social, reproductive and pharmacological interventions. (Rojas, Lozano and Rojas 2007)

Two previous longitudinal studies described the health effects of near-miss complications. Waterstone et al (2001) showed that women who experienced severe morbidity in the UK were more likely to report sexual health problems and made increased use of health services up to 12 months postpartum, compared to controls with uncomplicated childbirth. The authors explained the sexual health problems reported by some of the near-miss women as resulting from their fear of falling pregnant again, given the traumatic event they had experienced.

A study conducted in Burkina Faso (Filippi et al 2007) found that women in the near miss perinatal group were more likely to experience mental health problems, as expressed by more suicidal ideation. The study also found that babies born to mothers who had a near miss were more likely to die post discharge. There was also an increased rate of mortality among the women who experienced a near miss in the postpartum period. The study further reported that women in the near miss group expressed more negative feelings and lack of self-esteem up to a year postpartum, used services more than the uncomplicated group, and were under pressure to have another pregnancy quickly.

The psychological distress found in the perinatal death group has been documented in developed countries and is often associated with physical symptoms. The majority of deaths, complications and their sequelae may be avoidable if women have access to skilled birth attendance and emergency obstetric care. (Sichel et al 1993) Studies have shown that some of the women may present with symptoms at a later stage and can be diagnosed with or report health problems at 6 and 12 months postpartum.

There appears to be limited recognition of the difficulties faced by women who have suffered severe obstetric complications or perinatal death. This is may be because postnatal care in developing countries primarily focuses on child health and on reducing child mortality, with

limited focus on maternal health and survival. (Warren, Daly, Toure and Mongi 2006) Research shows that some women and their babies may experience problems that persist beyond the traditional 42 days postpartum period, and that these problems were either not identified during routine visits or were deemed too difficult to resolve. Filippi et al (2007) highlighted in their study that it is important to reach women who have lost their babies as they were neglected by traditional postnatal services. There is only one published intervention trial that tested the provision of postnatal care in a developing country with a primarily woman-centred approach, (Ransjo-Arvidson, Chintu, Ng'andu, Ericsson, Susu, Christensson et al 1998) but women with complications were excluded. Filippi et al (2007) concluded that women with near miss complications might benefit from active screening for symptoms or signs of adverse emotional and physical wellbeing during the postnatal visits or other contacts with health professionals in the postpartum period.

Finally, there is a need for an understanding of the reasons for the relatively low uptake of postnatal services after a complication, and whether outreach services such as those using community health workers would be beneficial to women who have had a complication. Women in developing countries face a high risk of severe complications during pregnancy and delivery, which can adversely affect their own health and that of their children.

Furthermore, resources to ensure that pregnant women receive adequate routine and emergency care before, during and after discharge from hospital are needed. Near-miss women with a perinatal death appear to be a particularly high-risk group. However, the longer-term outcome for women who experience near-miss mortality in pregnancy has received very limited attention to date. A significant degree of physical and psychological morbidity is experienced, especially among young women who lose their fertility potential as a result of life-saving obstetrical care. In contrast, there is a high chance of successful pregnancy outcome among women who retain their fertility potential and choose to have a further pregnancy. (Murphy and Charlett 2002)

2.9 SUMMARY

This chapter focused on various factors that influence maternal mortality and morbidity, with special attention paid to the woman, who forms the nucleus around which various interventions are targeted. Furthermore, the Millennium Development Goals, which highlight the problem of maternal mortality, were addressed.

The health systems, particularly those of South Africa, with various policies aimed at promoting maternal wellbeing, were reviewed. Lastly, women's mental health was reviewed, with specific reference to psychiatric conditions in the postpartum period and especially psychiatric conditions in women who have experienced life-threatening stressors in pregnancy. As mentioned earlier, the literature contains limited studies pertaining to this specific group of patients.

3 RESEARCH METHODOLOGY

3.1 INTRODUCTION

Prior to embarking on this study, the main question was that of what approach would best capture its essence, as a purely quantitative approach wouldn't capture the "humanness", personal or emotional aspects sufficiently, and a purely qualitative approach wouldn't suffice either. Thus, the decision was made to marry the two and have the "best of both worlds" by adopting a mixed methods approach.

Before continuing, it is important to differentiate between the terms methodology and methods, as this is a potential area of confusion.

- **Research methodology** is a broad approach to scientific inquiry specifying how research questions should be asked and answered, and includes worldview considerations, general preferences for designs, sampling logic, data collection and analytic strategies, guidelines for making inferences, and the criteria for assessing and improving quality.
- **Research methods** include specific strategies and procedures for implementing research design, including sampling, data collection, data analysis and interpretation of the findings. Specific research methods are determined by the overall methodological orientation of the researchers. (Teddlie and Tashakkori 2003:21)

3.2 HISTORICAL PERSPECTIVE

Protagoras said, "Man is the measure of all things".

Debates about singular or universal approaches to viewing the world versus multiple or relative truths date back to ancient Western philosophy. Similar debates pertain to knowledge and how it is viewed, to what is sought and found in this process of seeking knowledge, and finally to how the "knowledge" is justified. (Johnson, Onwuegbuzie and Turner 2007) The traditional research methods consisted of qualitative and quantitative methods that were used independently, and researchers chose whichever method they deemed most appropriate to answer the research question at hand.

Researchers thus positioned their research in a selected paradigm, or worldview, which was defined by distinct elements including epistemology (how we know what we know), ontology (the nature of reality), axiology (the value system) and methodology (the process of research). (Howe 1985; Hanson, Creswell, Plano Clark and Creswell 2005)

Paradigm differences influence how we know what we know, our interpretation of reality, our values and methodology in research, the influence that the paradigm or philosophy will have on the research questions formulated, and the methods used to answer the questions. (Morgan 2007)

Allen-Meares and Lane (1990) wrote about differences between the qualitative and quantitative paradigms, or ways of thinking. These paradigms can also be referred to by their philosophical labels, namely, naturalistic/interpretivistic (qualitative) and positivistic (quantitative). (Morgan 2007; Guba 1990)

Qualitative and quantitative debates have resulted in the illusion that the two approaches are mutually exclusive. Most scientists considered qualitative research approaches inferior to quantitative research until the 1980s (Johnson & Onwuegbuzie, 2004; Johnstone, 2004; Morgan, 2007). The styles of research approaches were modified and expanded over the years and a third paradigm was constructed. Mixed methods research is guided by the philosophical assumptions that enable mixing of qualitative and quantitative approaches throughout the research process. Mixed methods research is positioned between the extremes of quantitative research and qualitative, with attempts made to respect the wisdom of both viewpoints while looking for solutions to many research problems of interest. Mixed methods research is an approach to knowledge of both theory and practice that attempts to consider multiple viewpoints, perspectives, positions and standpoints. (Johnson et al 2007)

3.3. MIXED METHODS RESEARCH

3.3.1 Definition of mixed methods research

Mixed methods research may be defined as research in which the investigator collects and analyses data integrates the findings and draws inferences using both qualitative and quantitative approaches and methods in a single study. (Tashakkori and Cresswell 2007)

As a methodology, it involves philosophical assumptions that guide the direction of the collection, analysis and combination of qualitative and quantitative approaches in many parts of the research process.

As a method, it focuses on collecting, analysing and mixing both quantitative and qualitative data in a single study or series of studies. The rationale is that the use of quantitative and qualitative approaches, in combination, provides a better understanding of research problems than either approach alone. (Teddlie and Tashakkori 2009)

Johnson et al (2007) define mixed methods research as:

- The type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration. Mixed methods can be conceptualized as the use or blending of research methods from both qualitative and quantitative traditions. Considerable complexity exists in how these methods may be used together.

3.3.2 Evolution of mixed methods research as the third research movement (Cresswell and Plano Clark 2007)

A number of periods in the evolution of mixed methods as the third form of research inquiry were identified. These include:

- **The formative period**, which began in the 1950s and continued until the 1980s, was the period where the interest in using more than one method in a study started. Mixed research in the social and behavioural or human sciences started with researchers and methodologists who believed that quantitative and qualitative viewpoints and methods were useful when combined to address their research questions.
- A number of factors have contributed to the evolution of mixed methods research, such as the complexity of research problems that require answers, which extend beyond numbers in the quantitative sense and beyond words in the qualitative sense, and where a combination of the data provides a comprehensive analysis of the

problems. “Mixed research” can be seen in the work of cultural anthropologists and in the fieldwork of sociologists dating back to the early decades of the 20th century.

Campbell and Fiske (1959) described the inclusion of multiple sources of quantitative information in the validation of psychological traits. Denzin and Lincoln and Campbell (2014) amongst others, advocated for the inclusion of qualitative data in quantitative experimental studies.

- **The paradigm debate period** occurred in the 1970s and 1980s when qualitative researchers believed that the foundations for qualitative and quantitative research differed. There was an assumption that the research paradigms were not compatible because it was not possible to combine the ontological and epistemological perspectives of both traditions.
- **The procedural development period** occurred in the 1980s, when the focus shifted to development of procedures in the history of mixed methods, particularly regarding methods of data collection, data analysis, research design, and the reasons for conducting a mixed methods study.
- **The advocacy and expansion period** occurred when many advocated for mixed methods research as a separate methodology, method or approach to research, and interest in mixed methods had extended to many disciplines and countries.
- **The reflective period** occurred in the last five to seven years, when mixed methods research has been characterized by an assessment of the field and a look into the future. Constructive criticisms challenging the emergence of mixed methods have also been put forward.

3.3.3 Theory of mixed methods research

Mixed methods research design is one of the fastest growing areas in research methodology. (Mendlinger and Cwikel 2008) This research methodology views qualitative and quantitative research methods on a continuum rather than as separate entities. The combination of two methods affords researchers the ability to explore multiple ways of viewing a complex problem. The quantitative method allows for deductive thinking, testing of hypotheses, standardized data collection and statistical analysis, whereas the qualitative method emphasizes inductive thinking and exploring complex issues in depth, using materials from different types of data collection, for example, through in-depth interviews.

Cresswell and Tashakkori (2007) identified four different perspectives on the use of the term "mixed model":

- As a method or strategy for collecting, analysing and interpreting qualitative and quantitative data
- As a new philosophical or paradigm shift in research thought
- As an approach that allows one to view knowledge and the nature of reality with a different perspective
- As a new strategy for finding answers to research questions.

Greene and colleagues have made significant contributions to the theory of mixed methods research. (Greene, Caracelli and Graham 1989) They have identified five purposes for mixed methods research, namely:

- Triangulation, which allows for checking sets of findings across the different methods.
- Complementarity, which clarifies specific findings from one method by using the other.
- Development, which uses results in a sequential manner from one part of the research process to develop methods for the next stage of the research process.
- Initiation, which develops new perspectives by highlighting missing, conflicting or paradoxical findings.
- Expansion, which refers to extending the study by using different methods for various research components.

According to the literature, mixed methods research is becoming increasingly common in the social sciences and health sciences.

According to Hines (1993), combining qualitative and quantitative designs provides a way to improve the quality and integrity of cross-cultural research. It also provides a means to ensure that the findings are culturally relevant and accurate. The purpose of mixing approaches is to afford the researcher an opportunity to gain a comprehensive understanding of research problems, with researchers anticipating that mixing methods will allow them to capture and understand the complexity of human phenomena.

The combination of the methods allows the researcher to oscillate between the qualitative, subjective data using inductive reasoning, and the quantitative numeric data, analysed using deductive reasoning.

Deduction is a “form of reasoning in which conclusions is formulated about particulars from general or universal premises” (Eriksson & Kovalainen, 2008: 304), whereas in “induction”, reasoning from the observed cases is widened to general claims about the issue under inspection. (Eriksson and Kovalainen, 2008:306; Stake 2006; Tashakkori and Cresswell 2007)

Mixed methods research within healthcare remains an emerging field and its use is subject to much debate, which therefore necessitates that researchers clearly state their use of the approach and the conclusions made to improve transparency and quality within mixed methods research.

3.3.4 Advantages of mixed methods research (Pole 2007)

- Mixed methods approaches can sometimes be superior to single method designs.
- This research method can answer questions that other single paradigms cannot, where methods that the researcher uses to answer questions can sometimes not be answered effectively by either method alone. By combining approaches, findings can be verified, approaches may complement each other, or one method can lay the groundwork for the other.
- Mixed methods research enables the researcher to simultaneously answer confirmatory and exploratory questions.
- A researcher may use qualitative methodology to generate a theory and quantitative methods to test it.
- This type of research can provide for stronger inferences because the data is viewed from multiple perspectives, thus providing greater breadth and depth in studies.

3.3.5 Limitations of mixed methods research (Doyle, Brady and Byrne 2009)

- Criticism of mixed methods research focuses on the incompatibility thesis, namely, the belief that qualitative and quantitative research methods cannot be mixed in a single study due to the differing ontological and epistemological origins. Methodological purists believe in the dichotomy of paradigms and research methods,

and argue against the combination of methods; (Doyle et al 2009) however, Onwuegbuziie (2002) suggest that positivist and non-positivist philosophies lie on a continuum, with mixed methods occupying the middle ground.

- Other practical criticisms or weaknesses refer to the difficulties that a single researcher may encounter when carrying out mixed methods studies, especially those that are undertaken concurrently. (Johnson and Onwuegbuzie 2004
- Other methodologists identify sequential studies as having limitations with regard to the time and resources required to undertake distinct phases of the study. (Ivankova, Cresswell and Stick 2006)
- Another limitation or requirement is that researchers undertaking this type of study must have an understanding of both quantitative and qualitative research methods independently and how to mix methods appropriately to achieve good study outcomes.

3.3.6 Major mixed methods designs

Subsequent to the decision to undertake a mixed methods study, decisions pertaining to the design of the study are made and include the following: (Cresswell and Plano Clark 2007)

- **Fixed or emergent design**

  Fixed mixed methods designs are studies where the use of qualitative and quantitative methods is predetermined and planned at the start of the research process, whereas the emergent design occurs when a second approach (either qualitative or quantitative) is added after the study has commenced because one method was found to be inadequate (Morse and Niehaus, 2009). According to Creswell and Plano Clark (2007:54) the two categories, namely fixed and emergent designs, are not considered as a dichotomy but as the endpoints of a continuum. Many mixed methods designs will fall somewhere in the middle, with both fixed and emergent aspects to the design.

- **Typology-based or dynamic approach** (Cresswell and Plano Clark 2007)

  The typology-based approach emphasizes the classification of useful mixed methods designs with the selection and adaptation of a particular design to a study's purpose

and questions. A wide range of available classification of types of mixed methods designs has been identified.

The dynamic approach to mixed methods design focuses on a design process that considers and interrelates multiple components of research design rather than placing emphasis on selecting an appropriate design from an existing typology.

The approaches to mixed methods design may differ, but each design emphasizes the overall problem, purpose and research questions that guide the study.

- **Identify the reason or reasons** for mixing quantitative and qualitative methods within a study, as combining methods is a challenging endeavour.
- **Determine the level of interaction** between the quantitative and qualitative strands in the study, and the extent to which the two strands are kept independent or interact with each other. Greene (2007) noted two options for this interaction, namely independent and interactive. The independent interaction occurs when the quantitative and qualitative strands are implemented independently during the data collection and analysis phase, and the integration occurs at the time of drawing conclusions during the overall interpretation at the end of the study.

  The interactive level of interaction occurs when a direct interaction exists between the qualitative and quantitative strands of the study. The interaction occurs at different points in the study and in different ways.

- It is necessary to **determine the priority** or relative importance (either explicitly or implicitly) of the quantitative and qualitative strands within the design. The study may have an equal priority, a quantitative priority or a qualitative priority. (Cresswell and Plano Clark 2007)
- **The temporal relationship** or timing between the quantitative and qualitative strands within a study must also be taken into consideration. They can by concurrent, sequential, or use multiphase combination timing. (Cresswell and Plano Clark 2007)
- Lastly, **decisions about mixing of the data** can occur during interpretation, during data analysis, during data collection or at the level of the research design.

3.3.7 Typology-based design

Selecting a typology-based design provides the researcher with a framework to guide the implementation of the research methods, thereby ensuring that the resulting design is rigorous, persuasive and of high quality.

The major mixed methods research designs include the following:

- **Convergent parallel design** occurs when the researcher uses concurrent timing to implement the quantitative and qualitative strands during the same phase of the research process, prioritizes the methods equally, and keeps the strands independent during analysis, then mixes the results during the interpretation.
- **Explanatory sequential design** occurs in two distinct interactive phases. The design starts with the collection and analysis of quantitative data, which has priority. This phase is followed by the subsequent selection and analysis of qualitative data.
- **Exploratory sequential design** begins with and prioritizes the collection and analysis of qualitative data in the first phase, and building from the exploratory results, the researcher conducts a second, quantitative phase to test or generalize the initial findings.
- **Embedded design** occurs when the researcher collects and analyses both quantitative and qualitative data within a traditional quantitative or qualitative design. The researcher may add a qualitative strand within a quantitative design, with the supplemental strand being added to enhance the overall design.
- **Transformative design** is a mixed methods design that the researcher shapes within a transformative theoretical framework. The decisions with regard to the interaction, priority, timing and mixing are made within the context of the transformative design.
- **Multiphase design** combines both sequential and concurrent strands over a period of time that the researcher implements within a programme of study, addressing an overall programme objective. This approach is often used in programme evaluation, where quantitative and qualitative approaches are used over time to support the development, adaptation and evaluation of specific programmes.

3.4 PHILOSOPHICAL APPROACH

It is important at this point to discuss the philosophical approaches encountered in mixed methods studies. Three of the most common philosophical approaches used in mixed methods research are pragmatism, transformative-emancipatory and multiple-paradigm position.

The philosophy of pragmatism focuses on the outcomes of the research, namely the actions, situations and consequences of inquiry. The pragmatic approach to research is informed by the belief that the practicalities of research cannot be guided by data or theory alone, and thus a process of abduction is required to allow interaction between induction and deduction through a process of enquiry. (Onwuegbuzie 2002) Johnson and Onwuegbuzie (2004) explain that taking a pragmatic position allows a researcher to design research studies that combine methods that will offer the best chance of answering their specific research questions. Maxcy (2003) suggests that pragmatic researchers make a "unique contribution to open up inquiry to all possibilities while tying that search to all possible ends."

Morgan (2007) views the pragmatic approach as a new paradigm that can act "as a basis for supporting work that combines qualitative and quantitative methods and as a way to redirect our attention to methodological rather than meta-physical concerns."

Cherrylholmes (1992) and Murphy (1990) discuss the ideas that:

- pragmatism is not committed to any single system of philosophy,
- researchers have freedom of choice,
- pragmatists do not see the world as an absolute unity and would thus have multiple approaches, and
- pragmatists look to the "what" and "how" of research.

The second most common mixed methods paradigm is known as the transformative-emancipatory, where diverse views on social realities are held and need to be placed in a social, historical, political and economic value system in an attempt to understand the differences. This paradigm assumes that repression (racial, gender, ethnic, disability) is the root of social problems. These researchers' goal is to improve conditions for the groups being studied. (Pole 2007)

Multiple-paradigm position states that the researcher uses methods that are most likely to answer the research question, and the methods vary according to the study at hand. The philosophical approach used in this study is centred in pragmatism, in that multiple approaches have been used to answer the research question.

3.5 STUDY DESIGN

The design selected in this study was that of a convergent parallel mixed methods design. The study design was implemented in such a manner that data collection of both arms occurred concurrently during the same phase of the research process.

The quantitative arm occurred with the completion of demographic questionnaires, completion of the Level 1 and Level 2 crosscutting questionnaires, and the completion of relevant psychiatric scales according to the prominent symptoms that were found with the Level 1 and 2 questionnaires. The qualitative phase entailed conducting the semi-structured interviews with the research participants and the subsequent interviews with participants that were purposefully sampled for the case studies. The results were analysed separately and independently using quantitative and qualitative procedures. The two sets of results were merged during the overall interpretive phase to create a better understanding of the study at hand. Furthermore, the data validation variant, which is a variant of the convergent design, will be used, as both interview and instrumentation were employed and will provide emergent themes and quotes that will be used to validate the data and complement the quantitative survey findings.

The convergent parallel design was considered as the appropriate study design to answer the research questions as both arms of the study were given equal priority. Also, a group of the study participants were women who were severely ill with life-threatening complications and this study design enabled data collection to occur concurrently, whereas a sequential design would have required prolonged engagement over a period of time to complete the different phases as well as follow-up over four time intervals over a six month period would have required a greater level of commitment form study participants.

Furthermore, the sequential design was used “to obtain different but complimentary data on the same topic” (Morse 1991:120) and provide a thorough understanding of the research problem.

As has been described by mixed methodologists, “the intent in using the design is to bring together the differing strengths and non-overlapping weaknesses of quantitative methods with those of qualitative methods.” Another purpose for using this design is to combine the quantitative and qualitative results to develop a comprehensive understanding of the study.

3.5.1 **Strengths of the convergent design** (Johnson et al 2007)

- The convergent design makes intuitive sense and has become a popular approach for thinking about mixed methods research.
- It is an efficient design in which both types of data are collected during one phase of the research at about the same time.
- Each type of data is collected and analysed independently using techniques traditionally associated with each data type.

3.5.2 **Challenges in using the convergent design** (Cresswell and Plano Clark 2007)

- Great effort and expertise are required because of the concurrent data collection and the equal priority given to each strand.
- Having different samples and different sample sizes may result in disparities when merging the two sets of data.
- The merging of two sets of very different data and their results in a meaningful way poses a challenge.
- Researchers may face the question of what to do if the quantitative and qualitative results do not agree. Contradictions may provide new insights into the topic, but these differences can be difficult to resolve.

3.6 STUDY METHODS

3.6.1 Study setting

The study was conducted in the Department of Obstetrics at two hospitals namely; Steve Biko Academic Hospital which is a tertiary referral hospital, and Kalafong Hospital, which is a secondary referral hospital. These are public hospitals affiliated with the University of Pretoria. These hospitals serve the greater area of the City of Tshwane, which has approximately 1.98 million inhabitants, and an average population growth of 1.7%. The City of Tshwane forms one of three metropolitan municipalities of the Province of Gauteng. The other two municipalities include the City of Johannesburg and City of Ekhuruleni. The rationale for including participants from two hospitals is that it provides a wider sample distribution of urban women from diverse socio-economic strata. Many of the patients who use the health services of the two hospitals are either self-referral or referred from the surrounding maternal obstetric units and district hospitals. Surrounding provinces such as Mpumalanga, Limpopo and North West Province also refer to Steve Biko Academic Hospital. Ethical approval to conduct the study was obtained from the Research Ethics Committee of the Faulty of Health Sciences at the University of Pretoria. (353/2013)

3.6.2 Study population

The study population consisted of two groups of women, namely those who had uneventful pregnancies and those who had life-threatening complications. Recently delivered women who fulfilled the criteria for a near-miss event according to the WHO criteria were identified. Please refer to (Appendix B) for the WHO criteria for near miss. Although the research participants were selected if they met the criteria for a near-miss event, the term near miss will not be used henceforth in this dissertation as the instruction from the Faculty of Health Sciences Research Ethics Committee of the University of Pretoria was to replace the term “near miss” with “life-threatening”.

The recruitment of participants was done in collaboration with colleagues from the Department of Obstetrics at the two hospitals. Near miss case identification form part of the daily routine audit by a team of consultants, registrars and medical officers in the department.

The afore-mentioned colleagues informed the investigator of the near-miss cases. The investigator then approached these women and informed them of the nature of the study and provided an information leaflet about the study. These women were given an opportunity to ask questions and if they were interested in participating in the study, written informed consent was obtained from them. A copy of the signed informed consent document was also given to the participant.

The second group of women were those with uneventful pregnancies and consisted of women who were classified as having had normal deliveries according to the birth registers of the two hospitals. These women were approached if they were still admitted in the labour ward on the day of the interviews. They were informed about the study and given an opportunity to ask questions. If they indicated an interest to participate in the study, written informed consent was then obtained. A copy of the signed informed consent was also given to the participant.

Some women with uneventful pregnancies who declined to participate cited they had no "psychological problems", others informed of the inability to commit to the follow-up appointments.

For the women with life-threatening complications who elected not to participate in the study, the reason was once again that they had medical problems and not "psychological problems" and for women who had a pregnancy loss, they felt that talking about their problems would not return what they had lost or undo the suffering

Inclusion criteria:

- Women over the age of 16 years
- Women who have been identified, according to criteria, to have suffered a life-threatening (near-miss) event
- A basic level of literacy that would enable the participants to write a journal

Exclusion Criteria:

- Women unable to speak English, Afrikaans or Northern Sotho

3.6.3 DATA COLLECTION

- An initial contact session with the research participants occurred soon after delivery when the women were able to converse. The nature of the study and a description of how the study would be executed were explained to potential participants. If they indicated an interest, informed consent to participate in the study was obtained from the study participants. Women who were, for reasons of medical or psychiatric conditions, unable to give consent initially were approached at a later stage during their hospitalisation and informed about the study. Consent for participation in the study was obtained when they had recovered from the acute episode.
- Comprehensive information pertaining to the socio-demographic, psychiatric, medical and obstetric history was obtained during interviews that took place in a designated room in the labour ward or obstetric outpatient clinic on the hospital premises.
  Women who had previously been diagnosed with psychiatric conditions were not exempted from taking part in the study.
- As mentioned previously, the study design was that of a convergent parallel mixed methods design. It consisted of two arms, namely, a quantitative arm and a quantitative arm. The quantitative arm consisted of data collected in the form of questionnaires and validated instruments such as rating scales to identify the presence of psychiatric symptoms.
- The qualitative arm of data collection occurred concurrently and consisted of semi-structured interviews with the research participants, as well as a subset of patients who were selected for the case studies.
- Research participants were initially selected over a period of six months, from January 2014 to July 2014, with three follow-ups at six weeks, three months and six months after the initial interview. Contact with these women thus occurred four times.
- At the end of July 2014, a total of 30 women in the “life-threatening” group and 30 women in the “uneventful pregnancy” group were enrolled. However, the follow-up of the participants in the “uneventful pregnancy” group did not occur as initially envisaged, as a number of participants were unavailable or withdrew consent to continue with the study. After consultation with my research supervisor and statistician, it was decided to continue with participant enrolment for another six months. Thus, a total of 89 research participants – 46 with “life-threatening” complications and 43 with “uneventful pregnancies” – were enrolled by the end of August 2015.

3.6.3.1 Quantitative arm

This study set out to compare “life-threatening” and “uneventful pregnancy” groups over a period of time with respect to the emergence of psychiatric symptoms. Data collection included comprehensive psychiatric interviews conducted prior to discharge from hospital (after delivery), then six weeks, three months and six months post-delivery.

The aim of the quantitative arm was not to prove causality. Associations between symptoms and exposure variables, time and delivery groups, adjusted for potential confounders (age, parity, mode of delivery), are of importance. Here, 8(2x4) delivery groups by time combinations are of interest, and hence, by convention, approximately (8-10X4=+/- 40) subjects were included in the study for each combination.

The aim was to enrol the women in approximately a 1:1 ratio, as recommended by the statistician; therefore, +/- 80 subjects were required for recruitment.

At each interview, self-administered questionnaires were completed by research participants, namely the Adult DSM-5 Self-Rated Level 1 Cross-Cutting Symptom Measure, and the WHO Disability Assessment Schedule 2.0. The schedule is an instrument, which was developed by the World Health Organization in order to assess behavioural limitations and restrictions to participation experienced by an individual, independent of a medical diagnosis.
The instrument is designed to evaluate the functioning of the individual in six activity domains, namely, understanding and communicating, getting around, self-care, getting along with people, life activities and participation in society.

As the DSM-5 is the current classification system used to diagnose psychiatric conditions, the view that psychiatric disorders occur along a dimension rather than as categorical entities has been considered. Research and clinical evidence have illustrated that the categorical system does not accurately reflect the scope of clinical concerns in many patients, especially the presence of sub-threshold symptoms. Thus, the integration of dimensional assessments of psychiatric symptoms may be clinically useful in providing information to assist in understanding mental disorders, as well as comorbid symptoms and conditions. The DSM-5 Task Force and Work Groups developed the DSM-5 Crosscutting Symptom measures as dimensional measures to address the issue of co-morbidities in mental disorders.

The measures were developed to serve as a “review of mental systems” in patients and were considered as adjunctive tools ‘to give clinicians quantitative ratings that that characterize patients in a simple, useful and clinically meaningful manner.” The test-retest reliabilities of the crosscutting symptoms were found to be good to excellent during the DSM-5 field trials conducted to assess the development and reliability testing of a cross-cutting symptom assessment for DSM-5. (Narrow, Clarke, Kuramoto, Kraemer, Kupfer et al 2013; Clarke and Kuhl 2014)

The Level 1 crosscutting symptom measure was used to broadly identify psychiatric symptoms and was scored and interpreted for the presence of psychiatric symptoms. The scales were completed using the English version of the Level1 and Level 2 symptom measures. These scales were not available in Afrikaans or any of the Balck languages. In the event of a participant not understanding any questions asked on the symptom measure, a nursing sister assisted in translating the question to aid participant understanding. In the presence of symptoms, a Level 2 crosscutting symptom measure, consisting of Patient-Reported Outcomes Measurement Information System (PROMIS) scales, was then completed to obtain information on significant symptoms of psychiatric illness. (Appendix D)

In the presence of mild-to-severe symptoms identified on the Level 1 crosscutting symptom measures, relevant Level 2 scales were completed, which included the following:

- Anxiety
- Depression
- Mania
- Substance abuse
- Repetitive thoughts and behaviours
- Sleep disturbances
- Anger
- Somatic symptoms

Subsequent to completing the Level 1 and 2 measures, appropriate validated rating scales, as identified according to the symptomatology, were completed, for example:

- Brief Psychiatric Rating Scale, for psychotic symptoms. A total score of 31 may indicate “mildly ill”, score of 41 “moderately ill” and a score of 53 “markedly ill”
- Hamilton Anxiety Scale, for anxiety symptoms. The comprehensive score of the scale will be in the range of 0-56, with a score of 17 or less indicating mild

anxiety, 18-24 mild to moderate anxiety and a score of 25-30 indicative of moderate to severe anxiety.

- Becks Depression Inventory for depressive symptoms

The Beck Depression Inventory was used to assess the intensity of depression in psychiatric patients and has been validated for use in an obstetric population. The standardized cut-off scores are 0-13, which indicate minimal depression, 14-19 mild depression, 20-28 moderate depression, and 29-63 indicating severe depression. (Holcomb, Stone, Lustman, Gavard and Mostello 1996). The Edinburgh Postnatal Depression Scale in postpartum women was not included in this study, as although it is a validated screening measure, the Level 1 and Level 2 crosscutting measures were already used as adjuncts for symptom identification.

3.6.3.2 Qualitative arm

Semi-structured in-depth interviews were conducted in English with each research participant after delivery. As there were 89 interviews in total, it was felt that some of the "richness" of the qualitative data in such a sample would be lost, as described by Cresswell. (Cresswell and Plano Clark 2007) A case study was chosen as the design of inquiry in the qualitative arm. Prior to elaborating on data collection in the qualitative arm of the present study, a brief introduction to a case study as method of inquiry is given.

3.6.3.2.1 Case study inquiry

Case studies have a long history in qualitative research (Collins and O'Cathain 2009; Faegin Orum and Sjoeberg 1996; Stake 2005; Yin 2004) and the term is used to refer to an approach, a method and a product.

Snow and Andersen (1991) describe case studies as studies of "bounded systems of action", as these studies draw on the ability of the qualitative researcher to extract depth and meaning in context through multiple perspectives and data sources to produce contextually rich and meaningful interpretation.

Case study methods are not as explicitly described as grounded theory, thus leaving more analytic discretion to the researcher, as seen in multiple case studies where the challenge is one of collection across the cases but also maintaining the distinctive nature of each case (Stake 2005; Campbell and Arens 1998; Ragin 1987; Yin 2008). . The case study research involves the study of a case within a real-life context or setting (Yin 2008). Case study research is a qualitative approach in which the investigator explores a bounded system or systems over time, through detailed, in-depth data collection involving multiple sources of information (observations, interviews, audio-visual material, documents and reports) and presents a case description and case themes.

3.6.3.2.2 Characteristics of case studies

Case studies begin with identification of a specific case, which may be a concrete entity, such as an individual, an organization or a partnership.

The intent of conducting case studies is important in that it can be used to illustrate a case, or aspects that need to be identified and illustrated. This is referred to as an intrinsic case study. On the other hand, the case study may be used to understand a specific issue, problem or concern, and this is called an instrumental cases study. In a collective case study, the issue or concern is selected by the inquirer, who then selects multiple case studies to illustrate the issue. The hallmark of a good qualitative case study is that it presents an in-depth understanding of the case. (Cresswell 2013)

As mentioned previously, semi-structured, in-depth interviews were conducted in English with each research participant after delivery. As there were 89 interviews in total, it was felt that some of the "richness" of the qualitative data in such a sample would be lost. Therefore, 16 participants were purposefully sampled in an attempt to provide a representative sample.

The sample sizes for qualitative research are smaller than those used in quantitative studies. A point of diminishing return is considered, in that more data does not necessarily mean more information. As qualitative research is concerned with meaning, an occurrence of a piece of data may be sufficient to become part of the study, and one piece of information may be useful in the process of understanding. (Mason 2013) Furthermore, the sample size should generally follow the concept of saturation. (Fossey, Harvey, McDermott and Davidson 2012)

Theoretical saturation occurs when no new themes or new insights are identified. Furthermore, theoretical saturation occurs as a result of theoretical sampling, where the focus is less on the sample size and more on the sampling adequacy. Data saturation occurs when adding new participants does not add new information. (Bowan 2008)

Several factors can influence saturation: amongst others, the aims of the study will determine sample size, as a small study may achieve saturation sooner. (Charmaz 2006) The skill of the researcher, and thus the quality of interaction between the researcher and participant, is also an important factor, as this can have an effect on the quality of the study and the data saturation. (Mason 2010; Morse 2008)

- Purposeful sampling of participants from both study groups, namely those who experienced “life-threatening” complications and those with “uneventful pregnancies”, occurred. Attempts were made to recruit at least one woman in each group who had experienced a perinatal loss. Purposeful sampling in qualitative research occurs when the researchers intentionally select participants. These participants are selected because they have experienced the central phenomenon or key concept that is being studied. In this study, 16 participants were purposefully selected; nine participants were women who experienced life-threatening complications. The nine women included in this sample were participants who represented the common life-threatening complications identified by the criteria, such as postpartum-haemorrhage, hysterectomies, septicaemia, diverse medical-complications which fulfilled the criteria of life-threatening complications, and pregnancy losses. Seven participants chosen were women who experienced uneventful pregnancies and were of similar age to the group with life-threatening complications.
- In-depth, open-ended recorded interviews were conducted with these women at birth and at six weeks. These interviews provided an opportunity to become familiar with the women, establish a rapport, observe them and gain an insight into their worlds.
- Subsequent to the initial interview, these women were requested to keep a journal of their experiences post the event upon discharge from the hospital and to continue with this for a period of time.
- The aim of these journals was to gain insight into the women’s experiences and their life away from the hospital environment during this period of their lives. The journals provided information that was utilized to establish questions relevant to their experiences that would be put to them in interviews.

- Of particular importance to this study was the participants' mental health during this period, as well as the psychosocial components that may have had an influence on their mental health.
- Information gathered from these journals allowed me to identify potential difficulties or problems that may have influenced the mental health of these women in the postpartum period.
- Problems that the women experienced in accessing mental health services and the role that the health care system played in providing these services were identified.

3.6.3.2.3 Other sources of data

- Documents: hospital records and clinical notes, personal journals and other relevant documents. These may be solicited, such as the journals, or unsolicited, which can include diaries.
- Field notes were compiled after each interview.
- A project journal the researcher will keep during the research process.

3.6.4 DATA RECORDING

Permission was sought from the participants for voice recordings to be made during the interviews, which were later transcribed by an independent transcriber. The transcripts were read and corrected according to the notes taken at the time of interview. The recordings were listened to and omissions and mistakes were corrected. The interviews were then coded. The same process was repeated after the subsequent three interviews per patient.

Field notes were made after each interview and a recording of all the processes during the interviews was kept for referral. Field notes are a "written account of what the researcher hears, sees, experiences and thinks in the course of collecting and reflecting on the data in a qualitative study" (Bogdan & Biklen, 2007, p. 119).

The field notes included:

- Observational notes, which included the details of what happened during the interview, including the date, time and setting of the meeting. Important aspects of the interview process were noted, for example, the non-verbal cues of the participants.
- Theoretical notes, which included data from the interviews that were later interpreted and reflected upon during data analysis.
- Methodological notes, which served as reminders of specific steps that were taken at specific times during the process of data collection.
- Analytical memos, which consisted of summaries made at the end of an interview session and included the emotional reaction to the interview as well as impressions of specific moments that occurred during the interview process.

3.6.5 DATA ANALYSIS

Mixed methods data analysis consists of seven phases, which can be used, in combination during the analysis process.

These are:

- Data reduction, where quantitative data is analysed using descriptive statistics and qualitative data categorized as descriptive themes.
- Data display, where data pertaining to both strands are organized and presented visually in graphs and matrices.
- Data transformation, where quantitative data can be converted into narrative codes (qualitized) and analysed using qualitative techniques, and qualitative data converted into numerical codes (quantitized) and analysed using quantitative techniques.
- Data correlation, where quantitative data is correlated with qualitized data or vice versa.
- Data comparison of the two sources.
- Data integration, where both sets of data are integrated into a coherent whole and that will be analysed and interpreted simultaneously as a single data set or two sets that will be analysed separately. (Collins and O'Cathian 2009)

3.6.5.1 QUANTITATIVE ARM

3.6.5.1.1 Statistical considerations

Data analysis for the quantitative arm compared near miss and normal pregnancy groups over a period of time (delivery, six weeks, three months and six months post-delivery) with respect to symptom distribution, categorized broadly into groups (psychotic, mood and anxiety disorders).

For each patient, these symptom groups were followed up four times (delivery, six weeks, three months and six months post-delivery) in each of the research groups. The quantitative data in this study was analysed using the computer software programme SPSS version 24.0

The statistical analysis and considerations were discussed with Prof P Bekker, statistician at the Medical Research Council, during the initial stages of data collection. Subsequent to the completion of the first round of data collection, the data were discussed with Dr D van Zyl at the Department of Informatics at Unisa.

Data analysis of the qualitative arm consisted of a combination of data analysis methods used in grounded theory and case study research.
Stake advocates four forms of data analysis and interpretation in case studies, namely: (Stake 2005)

- categorical aggregation, where the researcher seeks a collection of instances from the data, in the hope that issue-relevant meanings will emerge;
- direct interpretation, where the researcher looks at a single instance and draws meaning form it;
- establishing patterns and looking for correspondence between two or more categories; and
- naturalistic generalizations after the data is analysed and generalizations made, that people can learn from the cases, either for themselves or to apply to a population of cases.

3.6.5.2 QUALITATIVE ARM

According to Fossey et al (2002), sampling, data collection, data analysis and interpretation are interwoven in qualitative research. The following steps were employed during data analysis of the qualitative arm in this study.

- Intermittent analysis of data occurred during the data collection phase, which provided some insights that helped in the subsequent phases of the study.
- The field notes, transcripts of the interviews, and observations aided in reflexivity. A large amount of data was generated through the interviews and the journals kept by the participants, as well as the field notes and the reflective journal.
- Reading and re-reading the transcripts provided an opportunity to become familiar with the data, to become immersed in the data, and also allowed for analysis of data to occur. Initially, open coding occurred.

  Using the constant comparative method, line-by-line coding occurred. After coding the transcripts, the codes were aligned and checked for replication. The codes were then grouped together, creating families of codes or themes. Categories created in this process, which were integrated and refined, are also referred to as axial coding.
- Both manual coding and the qualitative data analysis software program Atlas.ti were used to manage and organize the data.
- Holistic analyses of the cases occurred and themes were subsequently analysed. The analysis of themes, according to Cresswell (2013), is not to generalize beyond the case, but to understand the complexity of the case.
- A within-case analysis was conducted, where issues within each case were identified, followed by a cross-case analysis, where thematic analysis across the cases occurred.
- Data were analysed using grounded theory.

3.6.5.2.1 Grounded theory

Glaser and Strauss originated grounded theory (Glaser and Strauss 1967), which is a way of generating new theory grounded in the field but also set in context of existing theory. It does not set out to test an existing hypothesis, but rather seeks to generate theory from the research situation in the field. (Kennedy and Lingard 2006)

Although grounded theory is considered to be a qualitative approach, it can incorporate both qualitative and quantitative methods. (Duhscher and Morgan 2004) The fundamental aspect of grounded theory is inductive-deductive interplay that commences with a research situation, as researchers start with a topic of interest, collect data and allow relevant ideas to develop. This process requires open-mindedness to ensure that data are not ignored if they do not fit in with a preconceived notion. (McGee, Marland and Atkinson 2007) The grounded theory approach is not linear, but concurrent, iterative and integrative. Data collection, analysis and conceptual theorizing occur in parallel and from the outset of the research process. (Duhscher and Morgan 2004) The process continues until the theory generated explains every variation in the data. The resulting theory then becomes a theoretical explanation of the subject that is under investigation. (Benton 1992) This process of analysis is known as the constant comparison method, in that themes are grounded in the data rather than derived from a preconceived conceptual framework. (Glaser and Strauss 1967) According to Strauss and Corbin, grounded theory is a methodology for theory development that is grounded in narrative data that are systematically gathered and inductively analysed, and Patton describes it as "inductive analysis that involves discovering patterns, themes and categories in data in contrast to deductive analysis where the data are analysed according to an existing framework". (Strauss 1998; Patton 1990)

The place of the literature review is an aspect of debate and controversial when a grounded theory approach is considered in a study. Some researchers believe that the initial review of the literature allows the readers to identify the researcher's perspective at the initial stages of the study and provides justification for the use of a grounded theory study. (Antle May 1986). The researcher then does a second review of the literature that links existing research and theory with constructs and concepts that emerge from the new theory. (Hutchinson 1993) However, Glaser and Strauss the pioneers of the grounded theory approach disagreed with this need to conduct an initial review.

Strauss promoted an initial review of the literature in that he reasoned that it not only stimulates theoretical sensitivity, but that it also provides a secondary source of data, whilst it also stimulates questions and provides supplementary data. Glaser (1992) on the other hand disagreed with this view and considered that a number of levels of literature may be required in a grounded theory study. These include professional literature that are linked to a study which he considered must not be examined until the researcher was in the field and codes and categories start to emerge from the data.

The stance as a researcher in this mixed method study is that an initial review of the literature was conducted to present the current context of the concept of maternal health, maternal mortality and morbidity, psychiatric conditions and various aspects that are involved. As mentioned previously, maternal health is a complex construct that not only involves biological processes but psychological and sociocultural aspects too. The initial literature review presented in Chapter 2 addressed these issues pertaining to the quantitative arm of the study. However, for the qualitative arm of the study the grounded theory method for data analysis was considered and this method is a way of generating theory from the data obtained in the field and not from a pre-existing theory or conceptual framework. As the grounded theory method involves an inductive-deductive process, the literature was reviewed only after the themes were identified from the existing data that was obtained in the qualitative arm. References to the literature were made to compare and contrast the themes that had evolved from the data.

3.7 STRATEGIES TO ENSURE QUALITY OF DATA

3.7.1 Mixed methods research

Data validation refers to the implementation of appropriate steps or procedures to assure legitimation by establishing a process of examining inference quality in terms of design quality and interpretive rigor of the study's outcomes, (Onwuegbuzie and Johnson 2006) thus leading the researcher to formulate appropriate generalizations, termed "inference transferability". (Teddlie and Tashakkori 2003)

Legitimation has been defined as a recursive process in which the researcher evaluates the quality of the inferences drawn from the quantitative and qualitative phases at each stage of the study, and across the research programme.

Therefore, decisions pertaining to both the quantitative and the qualitative phases impact the researcher's ability to draw appropriate inferences and generalizations.

Onwuegbuzie and Johnson (2006) describe a legitimation model, and Dellinger and Leech (Dellinger and Leech 2007) a validation framework, providing the researcher with two alternatives to evaluate inferences on the basis of study findings.

Validity differs in quantitative and qualitative research, but in both approaches it serves the purpose of checking on the quality of the data, the results and the interpretation.

3.7.2 Quantitative arm

Quantitative researchers would agree that social science research should meet the following criteria: (i) internal validity, (ii) external validity or representativeness, (iii) reliability and (iv) objectivity. Very few qualitative researchers would regard these as suitable to ascertain the "truth value" of a qualitative study.

In quantitative research, the concern about the issues of validity occurs at two levels, the quality of the scores that are derived from the instruments used and the quality of the conclusions that can be drawn from the results of the quantitative analysis. Quantitative validity means that the scores received from the participants are meaningful indicators of the construct being measured. The standards are drawn from an external source to the researcher and the participants, statistical procedures or external experts. Researchers look for content validity, assessed according to whether the items or questions are representative of possible items; criterion-related validity, assessed according to whether the scores relate to some external standard, such as scores on a similar instrument; or construct validity – whether what was intended to be measured is measured.

Quantitative researchers also consider the validity of the conclusions that are drawn from the results. This means that studies need to be designed in such a manner so as to reduce the threats to internal and external validity. Internal validity is the extent to which the investigator is able to conclude that there is a cause-and-effect relationship among the variables. These cause-and-effect inferences can only be drawn if threats such as participant attrition and selection bias are accounted for in the design. External validity is the extent to which the investigator can conclude that the results apply to a larger population, which is usually of concern in survey design.

Quantitative researchers also consider issues of reliability. Quantitative reliability requires that scores received from participants are consistent and stable over time. Reliability of scores from past uses assessed in terms of reliability coefficients and instrument test-retest results, need to be addressed In a study, researchers need to check for the reliability of scores and any test-retest comparisons while exploring the data.

The reliability of scores needs to be established before assessments of their validity are addressed. (Cresswell and Plano Clark 2007)

3.7.3 Qualitative arm

The challenge confronting a qualitative researcher is how to assure the readers of the ***quality*** or ***trustworthiness*** of the research (Schurink, 2009). This has led to a highly contentious debate, which has in turn given rise to the development of various checklists and frameworks to assess qualitative research (Flick, 2006). Of particular importance here is Lincoln and Guba's (1985) classical contribution, since these scholars successfully matched the traditional evaluation terminology to more qualitative-appropriate terms.

3.7.3.1 Methods to ensure quality of research

- **Credibility**, which requires that the research be carried out in a responsible way and in line with what is considered to be good practice. Steps to improve credibility include prolonged engagement and persistent observation in the field, triangulation of different methods, and formalized qualitative methods such as grounded theory. The following strategies may be used to improve the credibility of qualitative research:
    - **Peer debriefing**, where the researcher's views of the findings will be discussed with peers, namely the supervisor and co-supervisor, as well as colleagues who are knowledgeable, to critique and discuss the interpretations.
    - **Triangulation**, which refers to the use of a combination of methods to explore one set of research questions. For example, a strategy to avoid recall bias would be to obtain information from clinical records in hospital files.
    - **Member checks**, which include returning the life history accounts of the research participants for their approval, to ensure that the way the information was understood and interpreted is a representative reflection of the data/information.

- **Transferability**, which depends on the degree to which the findings can be generalized. The aim in this research is to produce qualitative data that is rich in detail collected in a transparent process. This transparency will enable others to judge whether or not the results of this study have more general applications.
- **Dependability**, which is determined by the "auditing" process.
  The researcher will keep a comprehensive record of the complete research process – including field notes, transcripts of interviews, decisions on data analysis and other records such as peer audits.
- **Confirmability**, which requires that the researcher acknowledges that scientific objectivity is not absolute and that the researcher will act in good faith without allowing personal values and convictions to influence the participants.

Other procedures for establishing the validity of qualitative research have been described by Creswell and Miller, and it is recommended that qualitative researchers use at least two in any given study. (Cresswell 2013)

- **Prolonged engagement** and persistent observation: includes building trust with the participants, learning the culture and checking for misinformation that stems from distortions introduced by the researcher or informants.
- **Triangulation**: occurs where researchers make use of multiple and different sources, methods investigators and theories to provide corroborating evidence.
- **Peer review** or debriefing: provides an external check of the research process.
- **Negative case analysis**: whereby the researcher refines working hypotheses as the inquiry advances.
- **Researcher reflexivity**: refers to the researcher reporting on personal beliefs, values or biases that may shape their enquiry.
- **Member checking**: whereby the researcher seeks participants' views on the credibility of the findings.
- **Rich, thick descriptions**: allow readers to make decisions regarding transferability.
- **External audit**: whereby an external consultant or auditor to examines the process and the product of the account, assessing for accuracy.

3.8 RESEARCH ETHICS

Ethical approval to conduct the study was obtained from the Faculty of Health Sciences Research Ethics Committee of the University of Pretoria (353/2013). A recommendation of the Ethics Committee was that the phrase “near miss” be replaced with “severe, life-threatening” in the study.

The principles of medical ethics – namely beneficence, non-maleficence, respects for autonomy, and justice – were acknowledged in the study and efforts were made to adhere to these principles.

Participation in the study was totally voluntary and participants were not coerced in any manner to consent to participation. Furthermore, participants had the autonomy to withdraw consent to participation in the study at any time. Study participants who were identified as having psychiatric pathology during interviews were referred to mental health care services for psychiatric intervention.

- **Informed consent**: The study was explained to prospective participants and a patient information leaflet pertaining to the aims of the study was provided to them.

  Upon agreeing to participate in the study, written informed consent was obtained from the participants, each of whom were given a copy of the informed consent document. Each participant was given an opportunity to ask questions about the study. In the event where women had difficulty understanding the informed consent information leaflet due to language difficulties, nursing staff who spoke the participants’ language were asked to serve as interpreters during the informed consent process. Women who were identified as having experienced life-threatening stressors according to the criteria but were unable to give consent for example those who were intubated and ventilated, were approached at a later stage during their hospitalisation and informed about the study. Consent for participation in the study was then obtained when they had recovered from the acute episode. (Appendix C)

- **Confidentiality:** Research participants were informed that the researcher would strive to ensure confidentiality and anonymity. The names and file numbers of the patients were handled with utmost confidentiality.

A study number was assigned to each participant to maintain confidentiality, but the names and file numbers of patients were documented separately for future reference, follow-up and verification of information. Telephonic communication was initiated prior to the follow-up appointment to ensure compliance with appointments. A budget was allocated for transport costs incurred by the study participants for each interview.

A confidentiality agreement was signed by the transcriber to ensure confidentiality of research participants was maintained during the process of transcription.

Data is stored according to the Policy for the Preservation and Retention of Research Data (Rt 306/07) of the University of Pretoria.

3.9 SUMMARY

This chapter focused on the rationale for conducting a mixed methods study, and presented the historical perspectives and theory of mixed methods studies. Research paradigms, theory of mixed methods research, design classification and the type of design used in the study were described. The study was conducted at two hospitals in Pretoria, South Africa, namely Steve Biko Academic Hospital, a tertiary hospital, and Kalafong Hospital, a secondary hospital.

The study design chosen was a mixed methods study that consisted of two arms, namely a qualitative and a quantitative arm.

The study was conducted in a parallel convergent manner. The convergent parallel design was considered as the appropriate study design to answer the research questions as both arms of the study were given equal priority.

Also, a group of the study participants were women who were severely ill with life-threatening complications and this study design enabled data collection to occur concurrently, whereas a sequential design would have required prolonged engagement over a period of time to complete the different phases as well as follow-up over four time intervals over a six month period would have required a greater level of commitment form study participants.

Data collection for the two arms occurred concurrently, and merging of the data occurred at the level of interpretation. Participants in the study consisted of two groups of women, namely those who experienced a life-threatening complication in pregnancy and those with uncomplicated pregnancies. Prospective participants were approached soon after delivery, and in the case of participants with life-threatening stressors, only once they were medically stable. Written informed consent was obtained from women if they agreed to participate and a copy of the consent document was given to the participants. The women with life-threatening complications were selected if they met the WHO criteria for a “near-miss” pregnancy, and the women in the uncomplicated group were randomly selected from the birth registers kept in the respective labour wards of both hospitals.

Eighty-nine participants were selected, including 46 participants who experienced a life-threatening stressor and 43 who had uneventful pregnancies.

Participants were interviewed four times: shortly after delivery, at six weeks, at three months and at six months postpartum. At the initial contact, a comprehensive psychiatric interview was conducted and obstetric and medical history was obtained.

Socio-demographic information was obtained that included age, race, level of education, employment status, current living circumstances. Pregnancy outcome, services accessed and future fertility intention were also recorded. Furthermore, social support structure and religious status were enquired about.

The quantitative arm consisted of the completion of validated Level 1 and Level 2 crosscutting symptom measures. The Level 1 crosscutting symptom measure was completed by all participants, and in the presence of mild-severe symptoms, the investigator completed a relevant Level 2 questionnaire. The following symptom domains were identified from the questionnaires: depression, anxiety, sleep and cognitive disturbances, dissociative symptoms, thoughts of self-harm, psychotic and manic symptoms, post-traumatic and obsessive symptoms, as well as substance abuse. As the Level 1 questionnaire was used, which served as a screening tool, other scales that were validated for use in pregnant women were used and included the Beck Depression Inventory, the Hamilton Anxiety Scale, the Brief Psychiatric Rating Scale, and the Yale-Brown Obsessive Compulsive Scale.

Furthermore, the WHO Disability Assessment was completed and impairments in personal, social and occupational functioning were identified.

The qualitative arm consisted of in-depth, semi-structured interviews with research participants. Sixteen participants were purposefully sampled to provide a rich description and fully representative sample. Seven of the participants had uneventful pregnancies, whilst nine were women who experienced life-threatening stressors, and in some cases also foetal losses. The narratives were coded and prominent themes were analysed using grounded theory. Finally, research validity pertaining to mixed methods, as well as the qualitative and quantitative arms respectively, were described, and ethical considerations with regard to the study were presented.

SECTION 2

"THE FINDINGS OF THE STUDY"

In this section:

Chapter 4: Findings of the quantitative arm

Chapter 5: Findings of the qualitative arm

4 FINDINGS OF THE QUANTITATIVE ARM

4.1 INTRODUCTION

A total of 89 participants provided informed consent to participate in the study, 43 of whom had uncomplicated pregnancies and 46 of whom experienced a life-threatening stressor and met the WHO criteria for a near miss pregnancy. Subsequent to obtaining informed consent from the participants, a comprehensive interview was conducted, which included a psychiatric, medical, obstetric and social history. A detailed structured questionnaire was used to elicit information on demographic and socio-economic characteristics of the participants, including age, race, marital status, educational status, current living circumstances, employment history, pregnancy and antenatal history, previous and current pregnancy history, pregnancy outcome and future pregnancy plans, as well as medical and psychiatric history (including a substance history). Enquiry was made about their social support structure and the role of religion in their lives. Following the completion of the demographic questionnaire, subjects were also asked to complete the WHO Disability Assessment Schedule (WHODAS) 2.0 and the DSM-5 Self-Rated Level 1 cross-cutting symptom measure to identify the presence of psychiatric symptomatology. The interviewer depending on the results of Level 1 questionnaire completed relevant Level 2 scales. The Level 1 and Level 2 questionnaires, as well as the WHODAS were completed at each of the subsequent interviews, which took place at six weeks, three months and six months. (APPENDIX D) Fifty-three participants followed up at six weeks, 32 participants followed up at three months and 20 participants at six months. Simple descriptive statistics were used to present the data as a statistical limitation was the small sample sizes, which restricted group comparisons.

4.2 SOCIO-DEMOGRAPHIC RESULTS

A total of 89 subjects were recruited, 43 with uneventful pregnancies and 46 who fulfilled the criteria for a life-threatening event. The age distribution was as follows 14.8% were between the ages of 16 and 20 (n=13), the 21–25 and 26–30 age groups each consisted of 23.9% (n=21), and participants of advanced maternal age made up 18.2% (n=16) of the group, with 14.8% (n=13) falling in the 36–40 age group and 3.4% (n=3) in the 41–45 age group. (Table 1: Age distribution of study participants)

Table 1: Age distribution of study participants

Age group	U n (%)	LT n (%)	Total (%)
11-15	0(0.0 %)	0(0.0%)	0(0.0%)
16-20	7(16.3%)	6(13.3%)	13(14.8%)
21-25	10(23.3%)	11(24.4%)	21(23.9%)
26-30	10(23.3%)	11(24.4%)	2 (23.9%)
31-35	8(18.6%)	9(20.0%)	17(19.3%)
36-40	6(14.0%)	7(15.6%)	13(14.8%)
41-45	2(4.7%)	1(2.2%)	3(3.4%)
46-50	0(0.0%)	0(0.0%)	0(0.0%)
Total	43(100%)	46(100%)	89(100%)

Key: U- uncomplicated pregnancies LT-life-threatening complications

With regard to the different population groups, 91% (n=81) were of black race, whilst 6.7% were white, 1.1% was of mixed race and 1.1% was of Indian race. (Table 2: Population Distribution of study participants). Approximately a quarter of the total participants (24,7%)(n=22) were non South Africans.

Table 2: Population distribution of study participants

Population group	U n (%)	LT n (%)	Total (%)
Black	37(86.0%)	44(95.7 %)	81(91,0%)
Coloured	0(0.0%)	1(2.2%)	1(1.1%)
Asian/Indian	0(0.0%)	1(2.2%)	1(1,1%
White	6(14.0%)	0(0.0%)	6(6.7%)
Other	0(0.0%)	0(0.0%)	0(0.0%)
Total	43(100.0%)	46(100%)	89(100%)

Key: U- uncomplicated pregnancies LT-life-threatening complications

Approximately a third of the participants (n=29, 32.6%) were married and 31.5% were single. A quarter of them described themselves as living together like married partners, whilst 10%

of the women described themselves as being in a non-exclusive relationship. (Table 3: Relationship status of study participants)

Table 3: Relationship status of study participants

Relationship status	U n (%)	LT n (%)	Total n (%)
Married	13(30.2%)	16(34.8%)	29(32.6%)
Single	13(30.2%)	15(32.6%)	28(31.5%)
Living together	15(34.9%)	8(17.4%)	23(25.8%)
Never married	0(0.0%)	0(0.0%)	0(0.0%)
Widowed	0(0.0%)	0(0.0%)	0(0.0%)
Divorced	0(0.0%)	0(0.0%)	0(0.0%)
Non-exclusive relationship	2(4.7%)	7(15.2%)	9(10.1%)
Total	43(100%)	46(100%)	89(100%)

All the participants had attended school, with 36% (n=32) having some secondary schooling, and 33.7% (n=30) having completed matric. Seven (7.9%) of the women had post-matric certifications and a further 7.9% (n=7) had university degrees, whilst 13.5% (n=12) of the women had obtained a Technicon diploma. The distribution of level of education was similar between the two groups. (Table 4: Level of Education) of study participants)

With regard to employment status a third of the women (32.6%, n=29) were employed on a full-time basis, and a greater number of women who had experienced a life-threatening stressor worked on a full-time basis (37%, n=17). Thirteen (14.6%) of the participants were employed on a part-time basis, whilst approximately a third of the study participants (31.5%, n=28) were unemployed. Eleven (12.4%) of the women described themselves as housewives, and 9% (n=8) were scholars, five of whom made up 11.6% of the women who had uncomplicated pregnancies. (Table 5: Employment status of study participants)

Table 4: Level of Education of study participants

Highest level of education	U n %)	LT n (%)	Total n (%)
No schooling	0(0.0%)	0(0.0%)	0(0.0%)
Some primary schooling	0(0.0%)	1(2.2%)	1(1.1%)
Primary school completed	0(0.0%)	0(0.0%)	0(0.0%)
Some high school	15(34.9%)	17(37.0%)	32(36.0%)
Matric (Gr12)	16(37.2%)	14(30.4%)	30(33.7%)
Post-matric certificate	3(7.0%)	4(8.7%)	7(7.9%)
Technicon diploma	6(14.0%)	6(13.0%)	12(13.5%)
University degree	3(7.0%)	4(8.7%)	7(7.9%)
Total	43(100%)	46(100%)	89(100%)

Key: U- uncomplicated pregnancies LT-life-threatening complications

The living circumstances of the participants were as follows 44.9% (n=40) lived in houses and almost a third (n=28) lived in an informal settlement. 34.8% (n=16) of women who experienced a life-threatening stressor lived in informal settlements, which was greater than the proportion that lived in houses. (Table 6: Living circumstances of study participants) Furthermore, 78.7% and 83.1% of the participants had access to running water and electricity respectively. (Table7: Amenities)

Table 5: Employment status of study participants

What applies to you at the moment	U n %)	LT n (%)	Total n (%)
Working full-time	12(27.9%)	17(37.0%)	29(32.6%)
Working part-time	6(14.0%)	7(15.2%)	13(14.6%)
Not-working (housewife)	6(14.0%)	5(10.9%)	11(12.4%)
Student/Scholar	5(11.6%)	3(6.5%)	8(9.0%)
Unemployed	14(32.6%)	14(30.4%)	28(31.5%)
Total	43(100%)	46(100%)	89(100%)

Table 6: Living Circumstances of study participants

Type of dwelling	U n (%)	LT n (%)	Total n (%)
Stand alone house/structure	20(46.5%)	20(43.5%)	40(44.9%)
Townhouse/cluster	0(0.0%)	0(0.0%)	0(0.0%)
Flat in block of flats	5(11.6%)	5(10.9%)	10(11.2%)
House/flat/room in backyard	6(14.0%)	5(10.9%)	11(12.4%)
Informal dwelling/shack	12(27.9%)	16(34.8%)	28(31.5%)
Shared dwelling	0(0.0%)	0(0.0%)	0(0.0%)
Other	0(0.0%)	0(0.0%)	0(0.0%)
Total	43(100%)	46(100%)	89(100%)

Key: U- uncomplicated pregnancies LT-life-threatening complications

Table 7: Amenities available to study participants

Amenities	U n (%)	LT n (%)	Total n (%)
Access to running water			
Yes	36(83.7%)	34(7.9%)	70(78.7%)
No	7(16.3%)	12(26.1%)	19(21.3%)
Access to electricity			
Yes	37(86.0%)	37(80.4%)	74(83.1%)
No	6(14.0%)	9(19.6%)	15(16.9%)
Total	43(100%)	46(100%)	89(100%)

Less than a third (n=27) of the participants had been pregnant at least two times, with 27% of women (n=24) having one and three pregnancies respectively. Nine (10%) of the women had been pregnant at least four times and approximately 5.6% (n=5) had been pregnant five times or more. More than two thirds of the women (n=61) had either one or two children, and approximately one third had three or more children. Of note was that 6.5% (n=3) of women who experienced life-threatening stressors had no children at the time of first interview and the same number had experienced pregnancies but later lost their children. (Table 8: Obstetric History of study participants).

Table 8: Obstetric history of study participants

Number of pregnancies	U n (%)	LT n (%)	Total n (%)
1	10(23.3%)	14(30.4%)	24(27.0%)
2	15(34.9%)	12(26.1%)	27(30.3%)
3	12(27.95)	12(26.1%)	24(27.0%)
4	3(7.0%)	6(13.0%)	9(10.1%)
5	2(4.7%)	1(2.2%)	2(2.2%)
6	1(2.3%)	1(2.2%)	2(2.2%)
Total	43(100%)	46(100%)	89(100%)
Current pregnancy outcome			
Alive	42(97.7%)	29(6.0%)	71(79.8%)
Intrauterine foetal death	1(2.3%)	15(32.6%)	16(18.0%)
Miscarriage	0(0.0%)	0(0.0%)	0(0.0%)
Stillbirth	0(0.0%)	2(4.3%)	2(2.2%)
Therapeutic abortion	0(0.0%)	0(0.0%)	0(0.0%)
Total	43(100%)	46(100%)	89(100%)
Pregnancy status			
Planned	12(27.9%)	13(28,3%	25(28.1%)
Unplanned	31(72.1%)	33(71.7%)	64(71.9%)
Total	43(100%)	46(100%)	89(100%)
Wanted	37(86.0%)	38(82.6%)	75(84.3%)
Unwanted	6(14.0%)	8(17.4%)	14(15.7%)
Not wanted at all	0(0.0%)	0(0.0%)	0(0.0%)
Total	43(100%)	46(100%)	89(100%)

Twenty (22.5%) of the total sample of women either experienced a stillbirth, miscarriage or had a pregnancy that ended with an abortion. Of these, 71% (n=15) of the respondents experienced a miscarriage and 19% (n=4) a stillbirth. These were all women who experienced a life-threatening stressor, and 9.5% had abortions. Only a third of the women mentioned that the pregnancies were planned and more than 71% (n=64) described the most recent pregnancy as unplanned, with more than 15% of women expressing that the pregnancy was unwanted as well.

Almost 80% of the women had live births, with 18% experiencing intrauterine foetal demise. Almost a third of these intrauterine deaths occurred in women who had experienced a severe, life-threatening stressor, whilst 4.3% of the women with a life-threatening stressor had stillbirths.

Furthermore, 12.4% (n=11) of women reported not attending any antenatal care at all. (Table 9: Antenatal care attendance by study participants) More than 60% of the participants reporting that they had accessed the local community clinic for antenatal care, 16.9% of them, the local government hospital and 14.6% had initial contact with a general practitioner. 4.5% of the respondents both attended the community clinic and visited a general practitioner for antenatal care. No participants reported visiting a traditional healer for antenatal care. (Table 10: Services accessed by study participants)

Table 9: Antenatal care attendance by study participants

Antenatal care attendance	U n (%)	LT n (%)	Total n (%)
Yes	38(88.4%)	40(87.0%)	78(87.6%)
No	5(11.6%)	6(13.0%)	11(12.4%)
Total	43(100%)	46(100%)	89(100%)

Key: U- uncomplicated pregnancies LT-life-threatening complications

Only half of the respondents mentioned that they were informed of the signs of pregnancy complications, and 20% of the participants mentioned that they were not informed of any potential complications of pregnancy, whilst a quarter reported that they didn't know if they had received any information. Furthermore, more than 70% (n=64) of the respondents were aware of the processes to follow should they experience any complications. Approximately 18% (n=16) said that they didn't know where to go in the event of experiencing complications. (Table 11: Information pertaining to potential pregnancy complications)

Table 10: Services Accessed by study participants

Government hospital	**7(16.3%)**	**8(17.4%)**	**15(16.9%)**
Clinic/community health centre	25(58.1%)	30(65.2%)	55(61.8%)
Private hospital	0(0.0%)	0(0.0%)	0(0.0%)
GP	7(16.3%)	6(13.0%)	13(14.6%)
Traditional healer	0(0.0%)	0(0.0%)	0(0.0%)
Other	0(0.0%)	0(0.0%)	0(0.0%)
Clinic/community health care & GP	3(7.0%)	1(2.2%)	4(4.5%)
Clinic/community healthcare & traditional healer	1(2.3%)	0(0.0%)	1(1.1%)
Clinic/community healthcare & private hospital	0(0.0%)	1(2.2%)	1(1.1%)
Total	43(100%)	46(100%)	89(100%)

Table 11: Information pertaining to potential pregnancy complications

Complications	U n (%)	LT n (%)	Total n (%)
Yes	22(51.2%)	26(56.5%)	48(53.9%)
No	7(16.3%)	11(23.9%)	18(20.2%)
Don't know	14(32.6%)	9(19.6%)	23(25.8%)
Total	43(100.0%)	46(100.0%)	89(100.0%)
Services available in event of complications			
Yes	31(72.1%)	33(71.7%)	64(71.9%)
No	7(16.3%)	9(19.6%)	16(18.0%)
Don't know	5(11.6%)	4(8.7%)	9(10.1%)
Total	43(100.0%)	46(100.0%)	89(100.0%)

Key: U- uncomplicated pregnancies LT-life-threatening complications

With regard to having other children and future family planning, more than 70% (n=64) of the respondents planned on having other children and 95% (n=85) of the participants were planning on using some form of contraceptive method to delay pregnancy. (Table 12: Future pregnancy intention of study participants)

The injectable formulation was the contraceptive method of choice for more than 40% of the participants, with 21% of women preferring the contraceptive implant. 17.6% of the participants chose surgical interventions as a permanent contraceptive method. (Table 13: Contraceptive Methods of choice of study participants)

Table 12: Future pregnancy intention of study participants

Future pregnancy intention	U n (%)	LT n (%)	Total n (%)
Yes	28(65.1%)	36(78.3%)	64(71.9%)
No	15(34.9%)	10(21.7%)	25(28.1%)
Total	43(100.0%)	46(100.0%)	89(100.0%)
Delay/avoidance of pregnancy			
Yes	42(97.7%)	43(93.5%)	85(95.5%)
No	1(2.3%)	3(6.5%)	4(4.5%)
Total	43(100.0%)	46(100.0%)	89(100.0%)

Key: U- uncomplicated pregnancies LT-life-threatening complications

Table 13: Contraceptive methods of choice of study participants

Contraceptive method employed	U n (%)	LT n (%)	Total n (%)
Pill	5 (11.9%)	1(2.3%)	6(7.1%)
IUD	1(2.4%)	4(9.3%)	5(5.9%)
Injectable	16(38.1%)	20(46.5%)	36(42.4%)
Implant	12(28.6%)	6(14.0%)	18(21.2%)
Male condom	0(0.0%)	2(4.7%)	2(2.4%)
Female condom	0(0.0%)	0(0.0%)	0(0.0%)
Lactational method	0(0.0%)	0(0.0%)	0(0.0%)
Periodic abstinence	0(0.0%)	0(0.0%)	0(0.0%)
Withdrawal	0(0.0%)	0(0.0%)	0(0.0%)
Female sterilization	8(19.0%)	7(16.3%)	15(17.6%)
Male sterilization	0(0.0%)	1(2.3%)	1(1.2%)
Other	0(0.0%)	2(4.7%)	2(2.4%)
Total	42(100.0%)	43(100.0%)	85(100.0%)

Key: U- uncomplicated pregnancies LT-life-threatening complications

Pertaining to medical conditions, 82% (n=38) of the women who had experienced a life-threatening stressor during pregnancy had received treatment for medical conditions in the past compared to 14% in the uncomplicated pregnancy group. (Table 14: Medical History of study participants)

The common medical conditions that they received treatment for were hypertensive disorders, diabetes mellitus and HIV. Approximately one fifth of the total study participants were HIV-positive, with more than 28% of the women who experienced life-threatening stressors being HIV-positive. Only 2.3% of women with uncomplicated pregnancies reported that they were unaware of their HIV status.

Table 14: Medical History of study participants

Previous treatment	U n (%)	LT n (%)	Total n (%)
Yes	6(14.0%)	38(82.6%)	44(4.4%)
No	37(86.0%)	8(17.4%)	45(50.6%)
Don't know	0(0.0%)	0(0.0%)	0(0.0%)
Decline to comment	0(0.0%)	0(0.0%)	0(0.0%)
Total	43(100.0%)	46(100.0%)	89(100.0%)
HIV tested			
Yes	43(100.0%)	46(100.0%)	89(100.0%)
No	0(0.0%)	0(0.0%)	0(0.0%)
Total	43(100.0%)	46(100.0%)	89(00.0%)
HIV status			
Positive	4(9.3%)	13(28.3%)	17(19.1%)
Negative	38(88.4%)	33(71.7%)	71(79.8%)
Unknown	1(2.3%)	0(0.0%)	1(1.1%)
Decline	0(0.0%)	0(0.0%)	0(0.0%)
Total	43(100.0%)	46(100.0%)	89(100.0%)

Key: U- uncomplicated pregnancies LT-life-threatening complications

A total of 12.4% (n=11) of participants had received treatment for a psychiatric illness in the past. Of these, 17.4% (n=8) were women who experienced a life-threatening stressor compared to 7% (n=3) of women with uncomplicated pregnancies.

More than a third of the total study subjects admitted to having previously used substances, with approximately 62.5% of the women admitting to using alcohol and 21.9% of women admitted to using both alcohol and cigarettes. (Table 15: Psychiatric and substance history of study participants)

Table 15: Psychiatric and Substance history of study participants

Previous treatment	U n (%)	LT n (%)	Total n (%)
Yes	3(7.0%)	8(17.4%)	11(12.4%)
No	39(90.7%)	38(82.6%)	77(86.5%)
Don't know	1(2.3%)	0(0.0%)	1(1.1%)
Decline to comment	0(0.0%)	0(0.0%)	0(0.0%)
Total	43(100.0%)	46(100.0%)	89(100.0%)
Substance use			
Yes	18(41.9%)	14(30.4%)	32(36.0%)
No	25(58.1%)	32(69.6%)	57(64.0%)
Total	43(100.0%)	46(100.0%)	89(100.0%)
Type of substance use			
Alcohol	10(55.6%)	10(71.4%)	20(62.5%)
Illicit drugs	2(11.2%)	1(7.1%)	3(9.4%)
Prescription drugs	0(0.0%)	0(0.0%)	0(0.0%)
Cigarettes	1(5.6%)	0(0.0%)	1(3.1%)
Alcohol and cigarettes	4(22.2%)	3(21.4%)	7(21.9%)
Decline to comment	1(5.6%)	0(0.0%)	1(3.1%)
Total	18(100.0%)	14(100.0%)	32(100.0%)

Participants were asked about the role that religion played in their lives and 28% (n=25) of the subjects considered religion to be very important in their lives, with more than a third (n=33) considering religion to be somewhat important.

More than 35% (n=31) did not consider religion to be of importance. Twenty (43.5%) of the women who experienced a life-threatening stressor felt that religion was important in their lives, whilst approximately 42% (n=18) of women from those with uncomplicated pregnancies reported that religion did not have any importance in their lives. (Table 16: Religious Orientation of study participants)

Table 16: Religious Orientation of study participants

Importance of religion	U n (%)	LT n (%)	Total n (%)
Very important	12(27.9%)	13(28.3%)	25(28.1%)
Important	13(30.2%)	20(43.5%)	33(37.1%)
Not so important	15(34.9%)	9(19.6%)	24(27.0%)
Not important at all	3(7.0%)	4(8.7%)	7(7.9%)
Total	43(100.0%)	46(100.0%)	89(100.0%)

With regard to social support in women's lives, more than 37% (n=33) of the study participants reported that they would speak to their spouses or partners if they had a problem, with less than a third (n=25) reporting that they would speak to family members. However, more than 11% (n=10) of women reported that they had nobody to talk to, and of these, more than 15% (n=7) were women who experienced a life-threatening stressor. (Table 17: Sources of support available to study participants)

Table 17: Sources of support available to study participants

Sources of support	U n (%)	LT n (%)	Total n (%)
Spouse/partner	15(34.9%)	18(39.1%)	33(37.1%)
Family	15(34.9%)	10(21.7%)	25(28.1%)
Friends	7(16.3%)	6(13.0%)	13(14.6%)
Members of church	(2.3%)	3(6.5%)	4(4.5%)
Members of community	1(2.3%)	0(0.0%)	1(1.1%)
Others	1(2.3%)	2(4.3%)	3(3.4%)
Nobody to talk to	3(7.0%)	7(15.2%)	10(11.2%)
Total	43(100.0%)	46(100.0%)	89(100.0%)

4.3 RESULTS OF THE WHO DISABILITY ASSESSMENT

Participants were asked at each interview about their ability to function according to the WHO Disability Assessment in the following domains: understanding and communicating, getting around, self-care, getting along with people, household/school/work activities, and participation in society. Although women in both groups experienced impairments in functioning, those who experienced life-threatening complications presented with a greater variation in their levels of functioning as compared to women with uneventful pregnancies. The trend with regard to functional impairment was however similar in both groups in that the participants experienced impairments in levels of functioning around the time of delivery and some of the participants continued to experience difficulties in their functioning at six weeks. The levels of functioning in all spheres however, improved during the subsequent appointments. (Tables18 a, b, c, d: Results of WHO Disability Assessment) and (Figure 1a,b: Functional Impairment)

Table 18a: Results of WHO Disability Assessment at Delivery

	Group									
	Uncomplicated					Life-threatening				
	Valid n	Mean	Minimum	Maximum	Standard Deviation	Valid n	Mean	Minimum	Maximum	Standard Deviation
WHODAS at P! Understanding and communicating	43	1,10	1,00	2,17	0,233	46	1,46	1,00	4,00	0,636
WHODAS P1 Getting around	43	2,19	1,00	3,20	0,652	46	2,58	1,00	4,00	0,773
WHODAS P1 Self-care	43	1,07	1,00	2,50	0,246	46	1,51	1,00	4,00	0,635
WHODAS P1 Getting along with people	43	1,19	1,00	2,40	0,293	46	1,56	1,00	4,00	0,714
WHODAS P1 Life activities - Household	37	2,18	1,00	3,25	0,714	43	2,63	1,00	5,00	0,933
WHODAS P1 Life activities - School/Work	22	2,20	1,25	5,00	0,950	30	2,25	1,00	4,00	0,801
WHODAS P1 Participation in society	43	1,30	1,00	2,63	0,412	46	1,76	1,00	3,50	0,601
WHODAS P1 TOTAL	43	1,54	1,00	2,38	0,322	46	1,95	1,00	3,91	0,596

Key: P1- Delivery P2- Six weeks P3- Three months P-4 Six months

Table 18b: Results of WHO Disability Assessment at six weeks

	Group									
	Uncomplicated					Life-threatening				
	Valid n	Mean	Minimum	Maximum	Standard Deviation	Valid n	Mean	Minimum	Maximum	Standard Deviation
WHODAS P2 Understanding and communicating	24	1,38	1,00	3,33	0,639	29	1,79	1,00	4,00	0,812
WHODAS P2 Getting around	24	1,47	1,00	3,00	0,589	29	1,72	1,00	3,60	0,848
WHODAS P2 Self-care	24	1,10	1,00	2,50	0,329	29	1,47	1,00	3,75	0,687
WHODAS P2 Getting along with people	24	1,38	1,00	3,00	0,711	29	1,77	1,00	3,40	0,831
WHODAS P2 Life activities - Household	23	1,76	1,00	3,25	0,915	29	2,27	1,00	4,00	1,018
WHODAS P2 Life activities - School/Work	8	2,22	1,00	4,00	1,064	12	1,94	1,00	4,00	0,989
WHODAS P2 Participation in society	24	1,54	1,00	2,75	0,656	29	1,98	1,00	3,38	0,783
WHODAS P2 TOTAL	24	1,46	1,00	2,62	0,499	29	1,84	1,00	3,43	0,696

Key: P1- Delivery P2- Six weeks P3- Three months P-4 Six months

Table 18c: Results of WHO Disability Assessment at three months

	Group									
	Uncomplicated					Life-threatening				
	Valid n	Mean	Minimum	Maximum	Standard Deviation	Valid n	Mean	Minimum	Maximum	Standard Deviation
WHODAS P3 Understanding and communicating	11	1,23	1,00	1,83	0,291	21	1,46	1,00	2,60	0,522
WHODAS P3 Getting around	11	1,02	1,00	1,20	0,060	21	1,23	1,00	3,00	0,503
WHODAS P3 Self-care	11	1,02	1,00	1,25	0,075	21	1,08	1,00	2,00	0,242
WHODAS P3 Getting along with people	11	1,33	1,00	2,00	0,458	21	1,49	1,00	3,00	0,665
WHODAS P3 Life activities - Household	10	1,35	1,00	2,00	0,474	21	1,77	1,00	3,00	0,707
WHODAS P3 Life activities - School/Work	6	1,00	1,00	1,00	0,000	14	1,63	1,00	3,25	0,870
WHODAS P3 Participation in society	11	1,45	1,00	2,25	0,543	21	1,59	1,00	3,13	0,620
WHODAS P3 TOTAL	11	1,22	1,00	1,60	0,269	21	1,46	1,00	2,46	0,469

Key: P1- Delivery P2- Six weeks P3- Three months P-4 Six months

Table 18d: Results of WHO Disability Assessment at six months

	Group									
	Uncomplicated					Life-threatening				
	Valid n	Mean	Minimum	Maximum	Standard Deviation	Valid n	Mean	Minimum	Maximum	Standard Deviation
WHODAS P4 Understanding and communicating	8	1,04	0,80	1,33	0,155	12	1,26	1,00	2,67	0,529
WHODAS P4 Getting around	8	1,00	1,00	1,00	0,000	12	1,10	1,00	2,00	0,289
WHODAS P4 Self-care	8	1,00	1,00	1,00	0,000	12	1,02	1,00	1,25	0,072
WHODAS P4 Getting along with people	8	1,03	1,00	1,20	0,071	12	1,20	1,00	1,60	0,270
WHODAS P4 Life activities - Household	8	1,19	1,00	2,00	0,372	12	1,44	1,00	2,25	0,501
WHODAS P4 Life activities - School/Work	5	1,20	1,00	2,00	0,447	5	1,00	1,00	1,00	0,000
WHODAS P4 Participation in society	8	1,13	1,00	1,38	0,177	12	1,28	1,00	2,38	0,430
WHODAS P4 TOTAL	8	1,08	1,00	1,29	0,103	12	1,22	1,00	1,84	0,251

Key: P1- Delivery P2- Six weeks P3- Three months P-4 Six months

Figure 1a: Functional impairment as per results of WHODAS of all participants at four time intervals

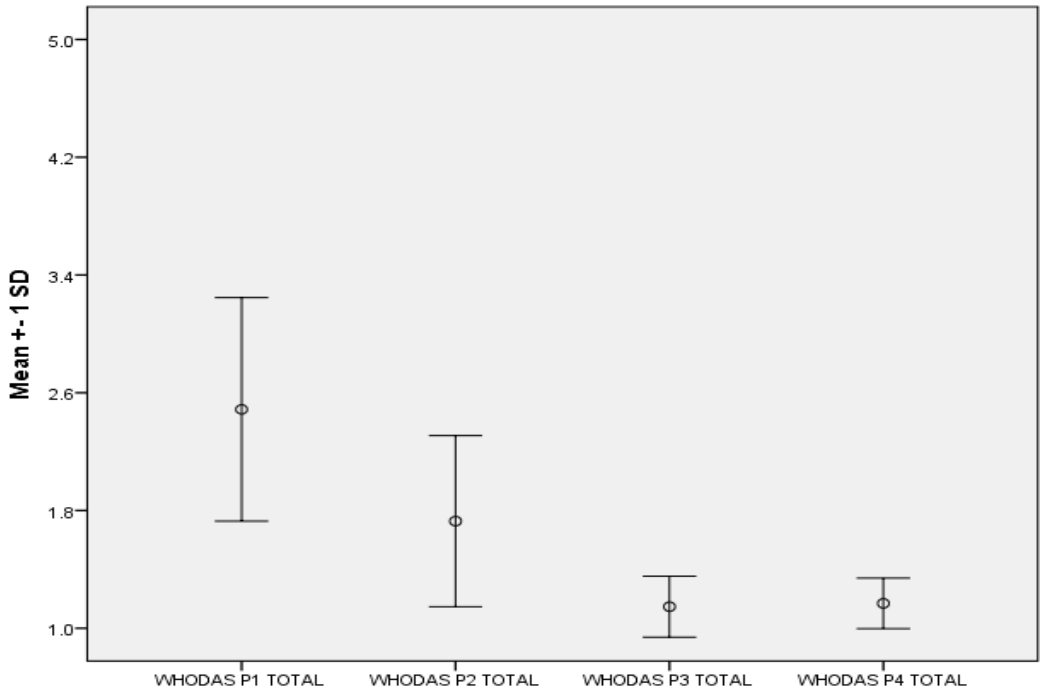
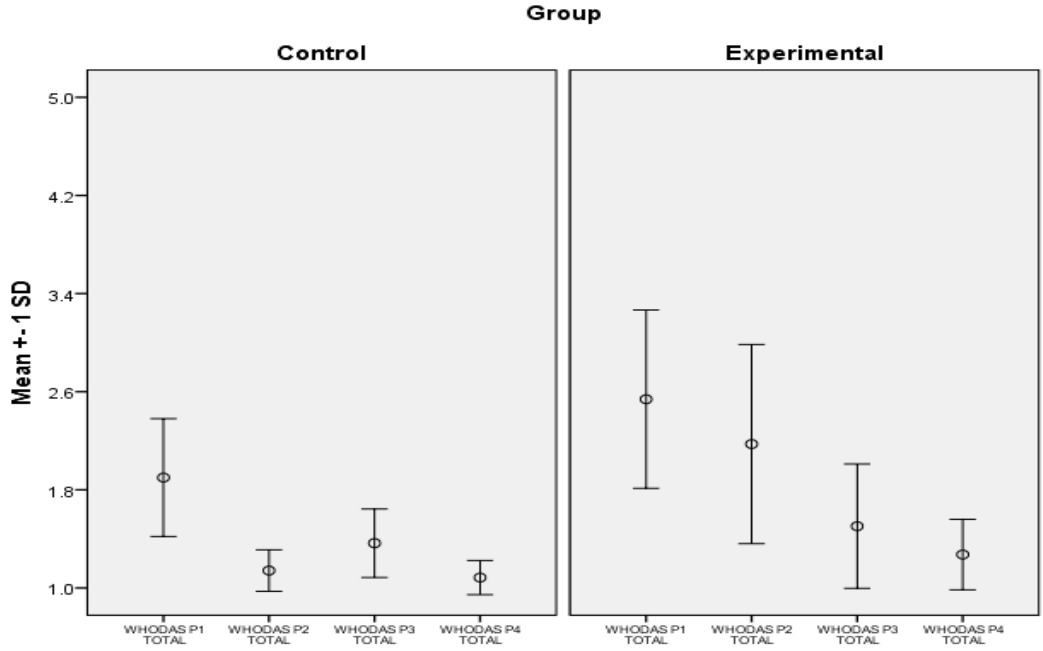


Figure 1b: Functional impairment as per results of WHODAS of women with life-threatening complications and uncomplicated pregnancies at four time intervals



4.4 PSYCHIATRIC SEQUELAE

At each interview, study participants completed a Level 1 crosscutting questionnaire. The questionnaire served as a screening tool for psychiatric symptomatology and included identifying symptoms of depression, mania, anxiety, sleep disturbances, memory, psychotic symptoms, obsessive-compulsive symptoms, dissociative symptoms, as well as substance use. The symptoms were graded according to a five-point scale, with possible grades of none, slight, mild, moderate and severe in the preceding two weeks (Appendix D). Subjects reporting symptoms in the mild to severe categories had a corresponding scale in the Level 2 crosscutting symptom measure completed by the interviewer. In addition, a Beck Depression Inventory, Hamilton Anxiety Scale, Young Mania Rating Scale, Brief Psychotic Rating Scale, or Yale-Brown Obsessive Compulsive Scale was completed, depending on the symptoms identified in the Level 1 questionnaire. As mentioned in Chapter 3, the additional scales were validated for use in obstetric populations.

4.4.1 Depressive symptoms

At delivery, 24.7% (n=22) (Table 19a, Figure 2) of study participants reported mild to severe symptoms of depression. Of these 63.6% (n=14) were those who had experienced life-threatening stressors. When the two groups of women namely those with life-threatening complications (n=46) and those with uneventful pregnancies (n= 43) are compared, then 30.4% of women who had life-threatening complications presented with symptoms whilst 18.6% of women with uneventful pregnancies presented with mild to severe symptoms (p-value 0,196). (Participants with life-threatening stressors had odds ratios of 1.91(95% confidence interval) as compared to women with uncomplicated pregnancies. At six weeks, 49.1% (n=26) of the participants reported significant depressive symptoms that warranted completion of the Level 2 questionnaire. Seventy-three percent of the sample was women who had experienced a life-threatening stressor.

When the two groups are compared, then, 65.5% of women with life-threatening complications experienced mild to severe symptoms of depression whilst 29.2% of women with uneventful pregnancies developed symptoms. (p=0.08)(OR 4.91, 95% CI for women with life-threatening complications.

The number of women experiencing depressive symptoms decreased during the three-month follow-up with 37.5% (n=12) of the subjects presenting with symptoms, of whom 83.3%were women who had experienced a life-threatening event. Within the two groups, 47.6% of women with life-threatening stressors continued to experience symptoms as compared to 18.2% of women with uncomplicated pregnancies. (p=0,102)(OR 4.09 at 95% CI) At the six months, 15% of women continued to experience symptoms, with two-thirds of the sample being women who had a life-threatening complication.

Within the individual groups, 16.7% of women with life-threatening complications and 12.5% with uncomplicated pregnancies continued to experience mild to severe symptoms. (p-value0, 798)(OR 1,40 at 95% CI).

At delivery 13.5% of subjects had a Becks depression score (BDI score) of more than 18, and of these 10.1% (n=9) were women who experienced a life-threatening stressor. The number of women who had a BDI score of more than 18 increased at the six-week appointment with 39,6% of women experiencing severe symptoms. Of these, 62.1% were women who had experienced a life-threatening complication. At the three month follow-up 21.9% of women had a BDI score of more than 18 and of these 23,8% were women who had a life-threatening complication. At the 6-month follow-up none of the subjects had a BDI score of more than 18.

Figure 2: Depressive symptoms per group at four time intervals

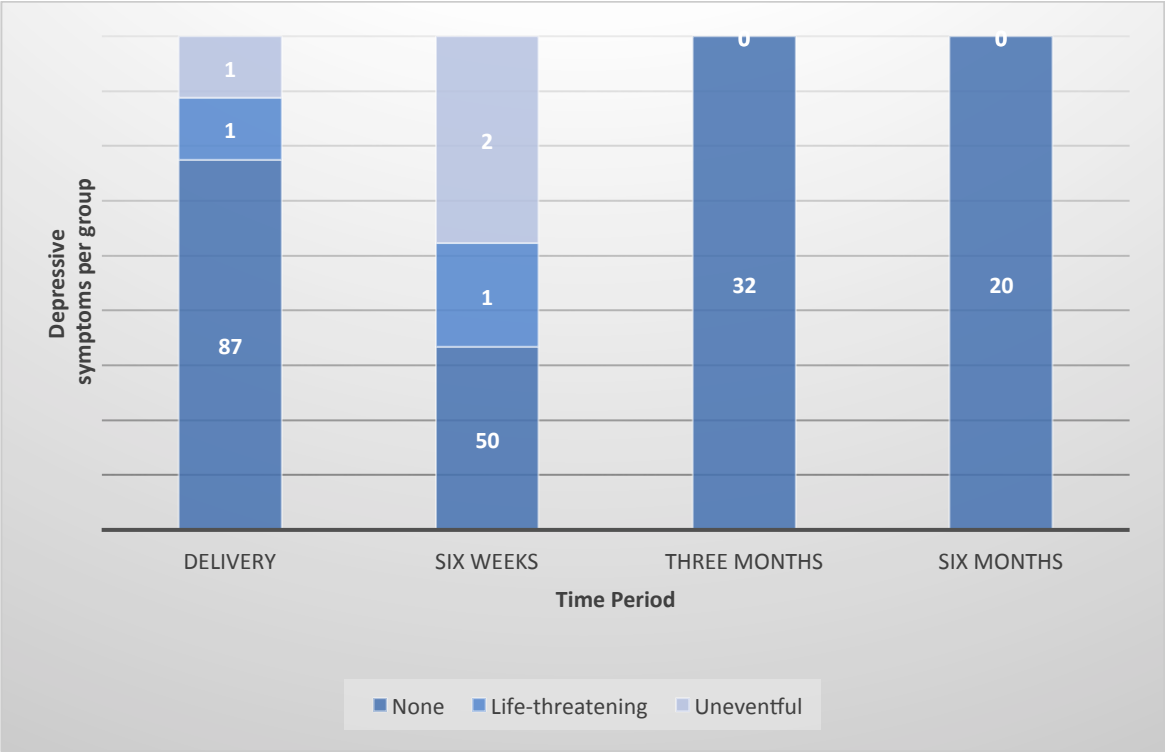


Table 19a: Depressive symptoms per group at four time intervals

Depression	None		Mild/Moderate/Severe				Total	
	n	%	n		%		n	%
Delivery	67	75.3	22		24.7		89	100
			LT	U	LT	U		
			14	8				
Total per group			46	43	30.4	18.6		
p-value	0.196							
Six weeks	27	50.1	26		40.9		53	100
			LT	U	LT	U		
			19	7				
Total per group			29	24	65.5	29.2		
p-value	0.008							
Three months	20	62.5	12		37.5		32	100
			LT	U	LT	U		
			10	2				
Total per group			21	11	47.6	18.2		
p-value	0.102							
Six months	17	85	3		15		20	100
			LT	U	LT	U		
			2	1				
Total per group			12	8	16.7	12.5		
p-value	0.798							

4.4.2 Manic symptoms

At delivery, 2.2% (n=2) (Table 19b, Figure 3) of the subjects reported mild to moderate manic symptoms at delivery. A woman from each group, namely 2.2% with life-threatening complications and 2.3% with uncomplicated pregnancy presented with manic symptoms respectively. (p=0,962)(OR of 1.07 for women with uncomplicated pregnancies, 95% CI)

Approximately, 5.7% (n=3) of women presented with symptoms at six weeks. Two-thirds of them were women who had uneventful pregnancies. These were women who had relapse due to an existing psychiatric condition. When the two groups are compared, then 8.3% of women with uneventful pregnancies and 3.4% of women with life-threatening complications presented with manic symptoms respectively. (p-value-0,444)(OR of 2,56 for women with uncomplicated pregnancies at 95% CI) These women were subsequently lost to follow-up.

Figure 3: Manic symptoms per group at four time intervals

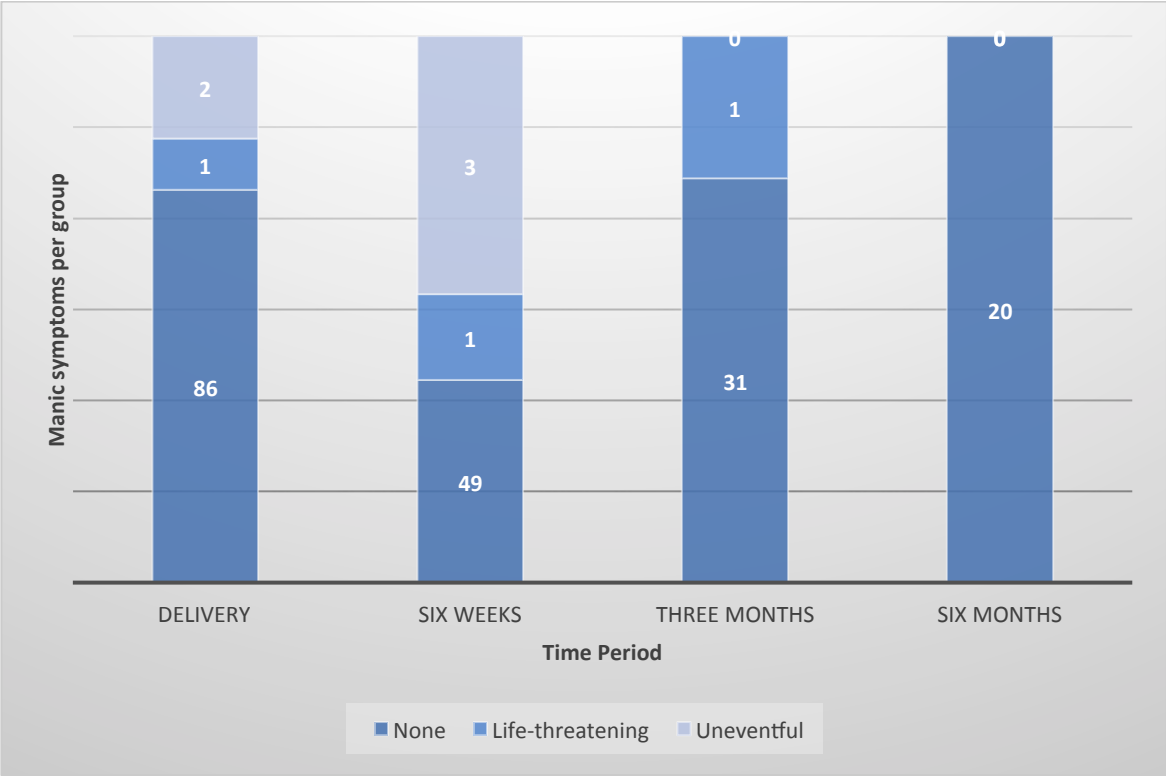


Table 19b: Manic symptoms per group at four time intervals

Mania	None		Mild/Moderate/Severe				Total	
	n	%	n		%		n	%
Delivery	87	97.8	2		2.2		89	100
			LT	U	LT	U		
			1	1				
Total per group			46	43	2.2	2.3		
p-value	0.962							
Six weeks	50	94.3	3		5.7		53	100
			LT	U	LT	U		
			1	2				
Total per group			29	24	3.4	8.3		
p-value	0.444							
Three months	32	100	0		0.0		32	100
			LT	U	LT	U		
			0	0				
Total per group			21	11	0.0	0.0		
p-value	0							
Six months	20	100	0		0		20	100
			LT	U	LT	U		
			0	0				
Total per group			12	8	0.0	0.0		
p-value	0							

4.4.3 Anxiety symptoms

Seventeen (19.1%) (Table 19c, Figure 4) of the subjects presented with anxiety symptoms in the mild to severe category at delivery, with 82% (n=14) of the sample being women who had a life-threatening complication.

When the two groups are compared, then, 30.4% of women who had a life-threatening event presented with symptoms of anxiety, whilst 7% of women with uncomplicated pregnancies had symptoms. (p=0.005)(OR of 5.83 at 95 % CI) The number of women who experienced symptoms at six weeks increased to 39.6% (n=21), with 76.2% of the group being women who experienced life-threatening stressors.

Significant differences with regard to symptom presentation was found between the two groups with 55.2% of women who experienced life-threatening complications experiencing anxiety symptoms at six weeks as compared to 20.8% of women with uneventful pregnancies. (p=0,011) (OR of 4.68 for women with life-threatening complications at 95% CI) The number of women who experienced anxiety symptoms at three months decreased to 34.4% (n=11).

More than 80% of the sample was women who had a life-threatening complication. Within the individual groups, 42.9% of women with life-threatening complications continued to experience symptoms of anxiety as compared to 18.2% of women with uncomplicated pregnancies. (p=0,163)(OR of 3.38 for women with life-threatening complications at 95%CI)

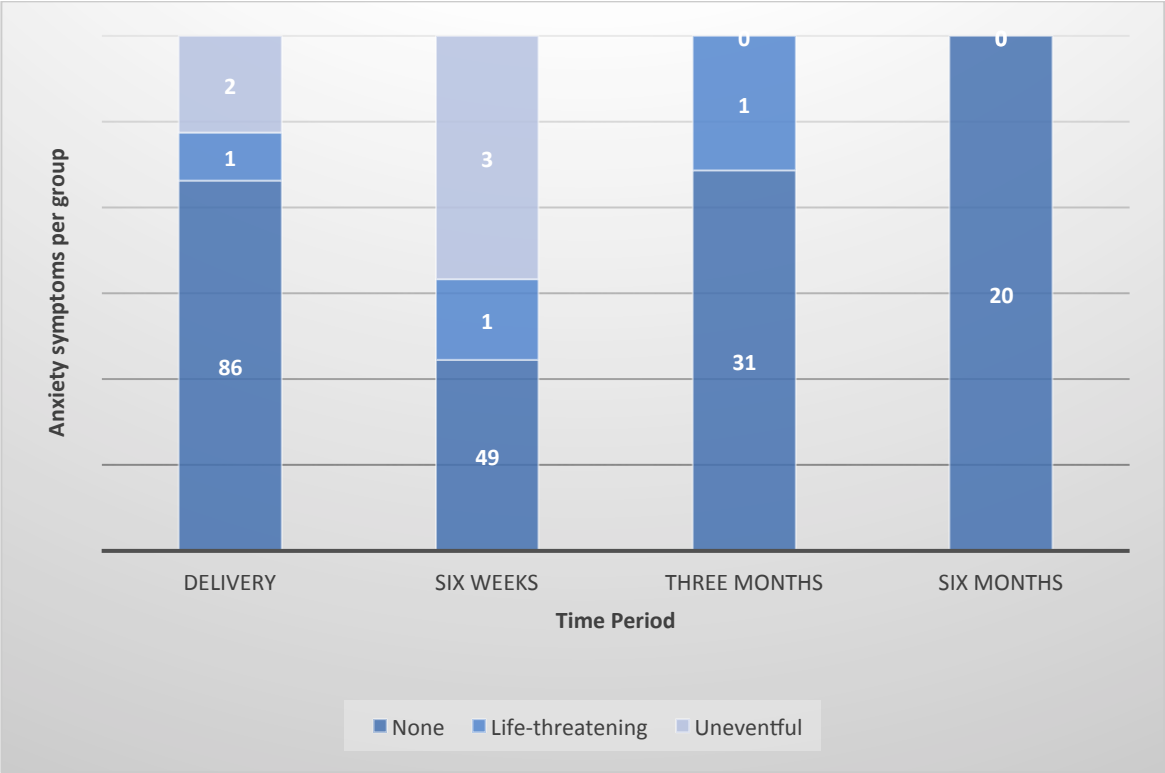
At six months, 10 % (n=2) of the participants had residual anxiety symptoms with 8.3% of women within the life-threatening group and 12.5% of women with uncomplicated pregnancies experiencing residual symptoms respectively (p=0,761) (OR of 1.57 for women with uneventful pregnancies at 95% CI). With regard to obsessive-compulsive symptoms, only 2.2% of the subjects reported mild intrusive thoughts at the six-week follow up, whilst 4.5% of subjects reported experiencing some dissociative symptoms at delivery, 5.6% at six weeks and 2.3% at three months.

At delivery, 17.6% of women had moderate to severe symptoms of anxiety with a score of more than 18 on the Hamilton Anxiety Scale (HAM-A). At 6 weeks 321% of women had a score of more than 18, of these 75% were women who had a life-threatening complication. At three months 36.4% of women experienced moderate to severe symptoms of anxiety according to the HAM-A scale. None of the subjects experienced symptoms in moderate to severe degree at six months.

Table 19c: Anxiety symptoms per group at four time intervals

Anxiety	**None**		**Mild/Moderate/Severe**				**Total**	
	n	%	n		%		n	%
Delivery	72	80.9	17		19.1		89	100
			LT	U	LT	U		
			14	3				
Total per group			46	43	30.4	7.0		
p-value	0.005							
Six weeks	32	60.4	21		39.6		53	100
			LT	U	LT	U		
			16	5				
Total per group			29	24	55.2	20.8		
p-value	0.011							
Three months	21	65.6	11		34.4		32	100
			LT	U	LT	U		
			9	2				
Total per group			21	11	42.9	18.2		
p-value	0.163							
Six months	18	90	2		10		20	100
			LT	U	LT	U		
			1	1				
Total per group			12	8	8.3	12.5		
p-value	0.761							

Figure 4: Anxiety symptoms per group at four time intervals



4.4.4 Anger symptoms

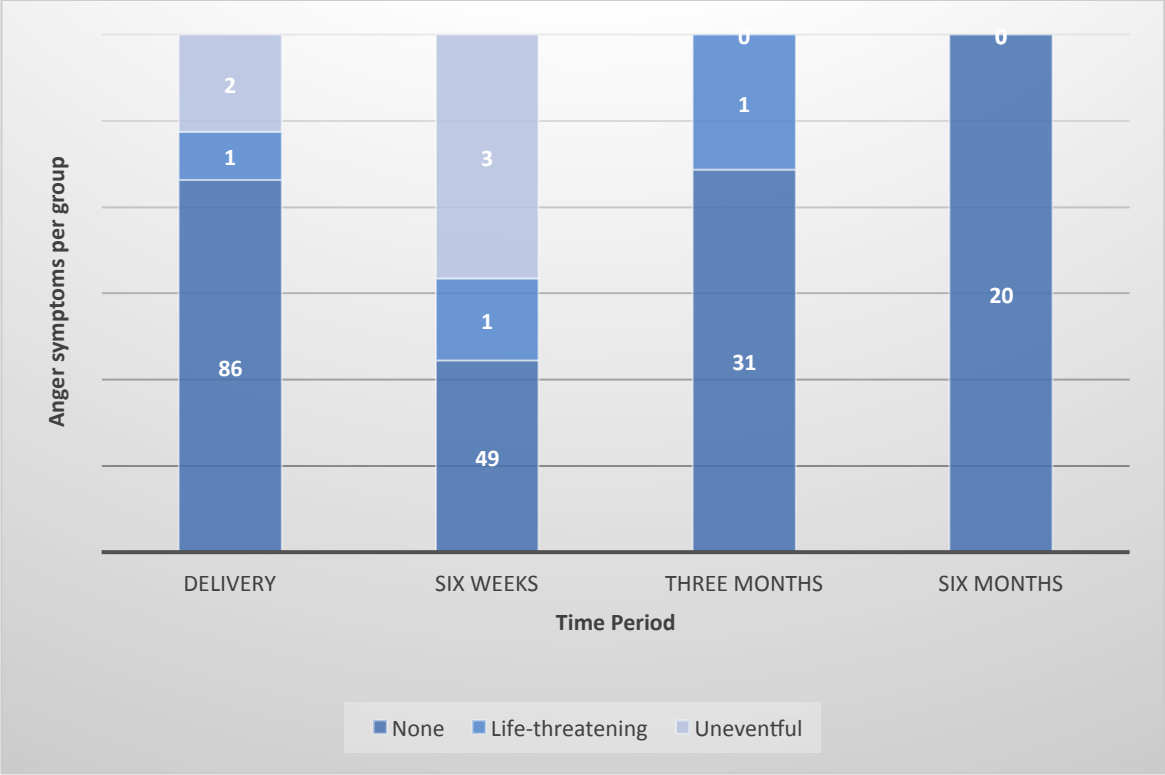
At delivery, less than 1% (n=3) of women presented with symptoms of anger. Of the women who experienced life-threatening complications, 4.3% expressed symptoms of anger as compared to 2.3% of women with uncomplicated pregnancies. (p=-0,597)(OR of 1.91at 95% CI). Furthermore, 11.32% (n=6) of women expressed symptoms of anger at six weeks.

More than 80% of the group were women who experienced life-threatening complications. Within individual groups, 17.2% of women with life-threatening complications and 4.2% of women with uncomplicated pregnancies presented with symptoms of anger respectively (p=0.135) (OR of 4.79 for women with life-threatening complications at 95% CI)(Table 19d, Figure 5) There was a downward trend to 9,3% (n=3) at three months with the entire sample representing women with life-threatening complications (14.3%)(p=0.188) and none of the women presented with symptoms of anger at six months.

Table 19d: Anger symptoms per group at four time intervals

Anger	None		Mild/Moderate/Severe				Total	
	n	%	n		%		n	%
Delivery	86	96.6	3		3.4		89	100
			LT	U	LT	U		
			2	1				
Total per group			46	43	4.3	2.3		
p-value	0.597							
Six weeks	47	88.7	6		11.3		53	100
			LT	U	LT	U		
			5	1				
Total per group			29	24	17.2	4.2		
p-value	0.135							
Three months	29	90.6	3		9.4		32	100
			LT	U	LT	U		
			3	0				
Total per group			21	11	14.3	0.0		
p-value	0.188							
Six months	20	100	0		0		20	100
			LT	U	LT	U		
			0	0				
Total per group			12	8	0.0	0.0		
p-value	0							

Figure 5: Anger symptoms per group at four time intervals



4.4.5 Somatic symptoms

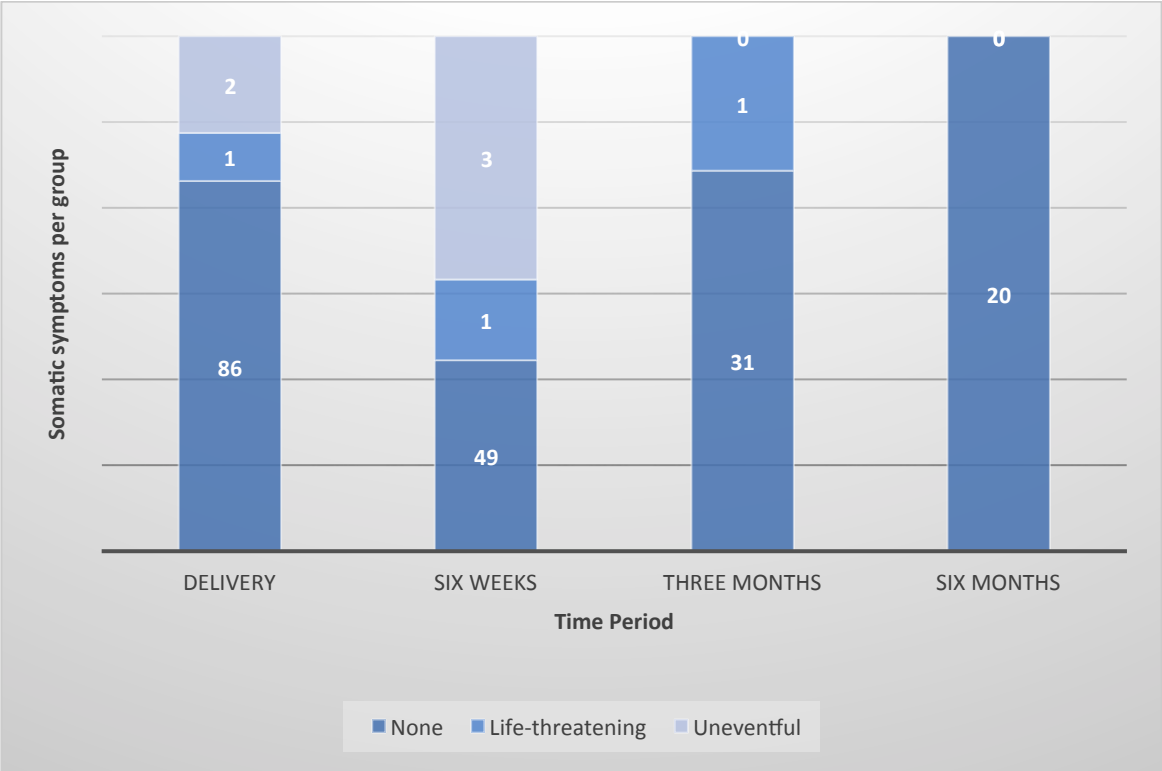
Participants also reported somatic symptoms (Table 19e, Figure 6) that were in the mild to moderate category of which 16.9% (n=15) presented at delivery. More than 80% of the sample was women who experienced a life-threatening complication. There was a significant difference between the two groups with respect to symptom presentation in that 28.3% of women were those who had life-threatening complications compared to 4.7% of women with uneventful pregnancies. (p= 0.003)(OR of 8.08 for women with life-threatening complications at 95% CI) The number increased to 26.4% of women who experienced symptoms at six weeks with women who had life-threatening complications representing more than 78% of the group. Within the individual groups, 37.9% of women with complications and 12.5% with uneventful pregnancies experienced symptoms at six weeks (p=0.037) (OR of 4.28 for women with life-threatening complications at 95%CI). At three months, only 6.3% (n=2) of women continued to experience residual somatic symptoms.

Within each group, 4.8% of women with life-threatening complications and 9.1% with uncomplicated pregnancies expressed somatic symptoms. (p=0,631) (OR of 2.0 for women with uneventful pregnancies at 95% CI) Women with uneventful pregnancies appeared to experience more somatic symptoms than those with life-threatening complications. None of the women who followed up at six months reported any somatic symptoms.

Table 19e: Somatic symptoms per group at four time intervals

Somatic	**None**		**Mild/Moderate/Severe**				**Total**	
	n	%	n		%		n	%
Delivery	74	83.1	15		16.9		89	100
			LT	U	LT	U		
			13	2				
Total per group			46	43	28.3	4.7		
p-value	0.003							
Six weeks	39	73.6	14		26.4		53	100
			LT	U	LT	U		
			11	3				
Total per group			29	24	37.9	12.5		
p-value	0.037							
Three months	30	93.7	2		6.3		32	100
			LT	U	LT	U		
			1	1				
Total per group			21	11	4.8	9.1		
p-value	0.631							
Six months	20	100.0	0		0.0		20	100
			LT	U	LT	U		
			0	0				
Total per group			12	8	0.0	0.0		
p-value	0							

Figure 6: Somatic symptoms per group at four time intervals



4.4.6 Sleep disturbances

Approximately 18% (n=16) (Table 19f, Figure 7) of women reported significant sleep disturbances at delivery with women who had life-threatening complications representing more than 80 % of the sample. Within each group, 28.3% and 7.0% of women who had life-threatening complications and uneventful pregnancies respectively experienced symptoms. (p= 0,009) (OR of 5.25 for women with life-threatening complications at 95% CI)

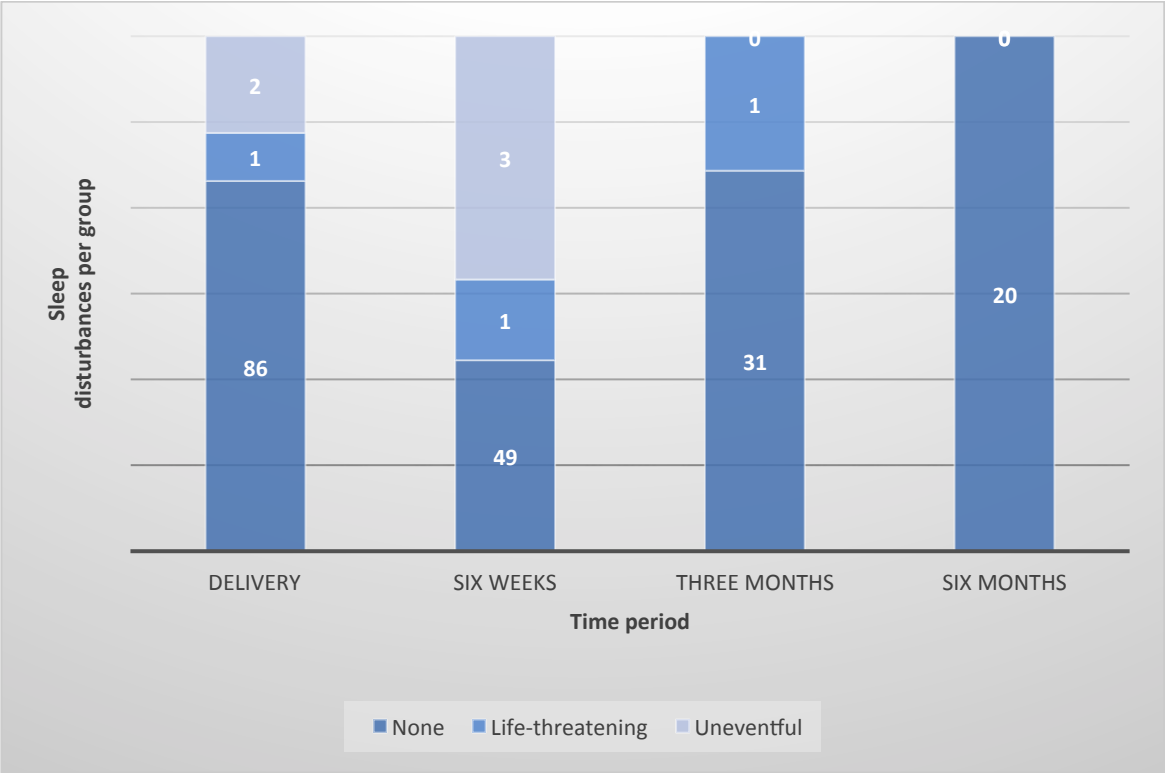
At six weeks, 41.5% (n=24) of women expressed sleep disturbances with more than three-quarters of the women representing those who had life-threatening complications. Within each group, a quarter of women with uncomplicated pregnancies and 62% of women with life-threatening complications experienced sleep disturbances. (p= 0,007)(OR of 4.91 for women with life-threatening complications at 95% CI) The sleep disturbances improved over time decreasing to 31% (n=10) at three months, with more than 80% of the sample being women who had a life-threatening complication.

Furthermore, within each group, 38.1% of women with life-threatening complications and 18% of women with uneventful pregnancies experienced residual symptoms. (p=0,248) (OR of 2.77 at 95% CI). At six months only 5% (n=1) of subjects still reported significant sleep disturbances, with 8.3% of women with life-threatening complications experiencing symptoms. (p=0,402)

Table19f: Sleep disturbances per group at four time intervals

Sleep	None		Mild/Moderate/Severe				Total	
	n	%	n		%		n	%
Delivery	73	82.1	16		17.9		89	100
			LT	U	LT	U		
			13	3				
Total per group			46	43	28.3	7.0		
p-value	0.009							
Six weeks	29	54.7	24		45.3		53	100
			LT	U	LT	U		
			18	6				
Total per group			29	24	62.1	25.0		
p-value	0.007							
Three months	22	68.8	10		31.2		32	100
			LT	U	LT	U		
			8	2				
Total per group			21	11	38.1	18.2		
p-value	0.248							
Six months	19	95	1		5		20	100
			LT	U	LT	U		
			1	0				
Total per group			12	8	8.3	0		
p-value	0.402							

Figure 7: Sleep disturbances per group at four time intervals



4.4.7 Cognitive and memory disturbances

Subjects also reported memory disturbances (Table 19g, Figure 8), with a total of 9% (n=8) of women reporting some memory problems at delivery. More than 85% of the sample was women who had a life-threatening complication. Significant differences with regard to memory disturbances were found between the two groups, with 15.2% of women with life-threatening complications and 2.3% with uneventful pregnancies experiencing symptoms respectively. (p= 0,034) (OR of 7.54 for women with life-threatening complications at 95% CI)

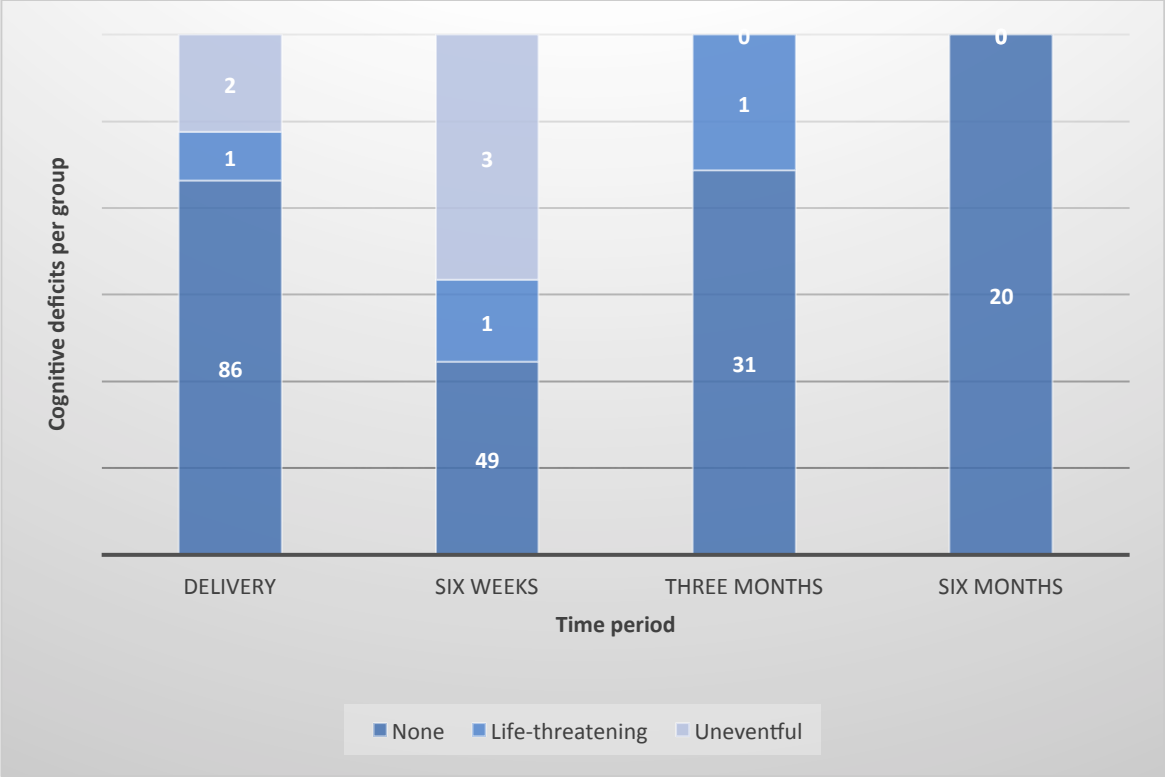
At six weeks, 22.6% (n=12) of women complained of memory impairments. Within each group, 34.5% and 8.3% of women with life-threatening complications and uneventful pregnancies respectively presented with significant memory disturbances. (p-value-0.024) (OR of 5.79 for women with life-threatening complications at 95% CI) The number of women expressing cognitive difficulties decreased at three months with approximately 18% (n=6) of women presenting with residual symptoms.

The women in each group who had residual symptoms were 23.8% and 9.2 % respectively. (p=0,311)(OR 3.13 for women with life-threatening complications at 95% CI) None of the women complained of memory deficits at six months.

Table 19g: Cognitive and Memory deficits per group at four time intervals

Memory	None		Mild/Moderate/Severe				Total	
	n	%	n		%		n	%
Delivery	81	91.1	8		8.98		89	100
			LT	U	LT	U		
			7	1				
Total per group			46	43	15.2	2.3		
p-value	0.034							
Six weeks	41	77.4	12		22.6		53	100
			LT	U	LT	U		
			10	2				
Total per group			29	24	34.5	8.3		
p-value	0.024							
Three months	26	81.2	6		18.8		32	100
			LT	U	LT	U		
			5	1				
Total per group			21	11	23.8	9.1		
p-value	0.311							
Six months	20	100	0		0		20	100
			LT	U	LT	U		
			0	0				
Total per group			12	8	0.0	0.0		
p-value	0							

Figure 8: Cognitive and Memory deficits per group at four time intervals



4.4.8 Psychotic symptoms

Less than 5% (n=4) (Table 19h, Figure 9) of participants presented with mild to severe psychotic symptoms at delivery. Three- quarters of the sample were women who had a life-threatening stressor.

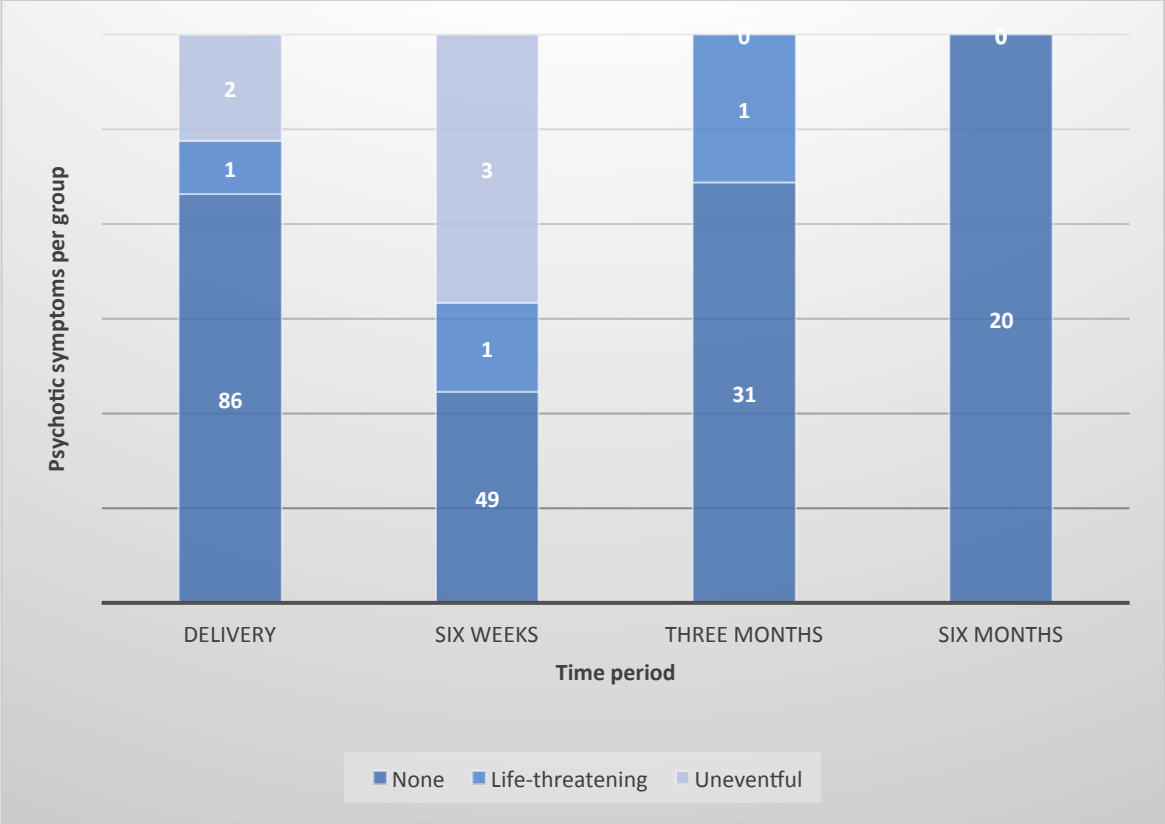
Within the individual groups, 6.5% of women with life-threatening complications and 2.3% with uneventful pregnancies experienced psychotic symptoms (p-value-0, 340) (OR of 2.93 for women with life-threatening compilations at 95% CI). At six weeks 5.7% (n=3) of women continued to experience psychotic symptoms. Of these, 6.9% were women who had a life-threatening complication, whilst 4.2% of women with uncomplicated pregnancies experienced symptoms. (p=0,669)(OR of 1.70 for women with life-threatening complications at 95% CI) However, only 3.1% (n=1) presented with residual psychotic symptoms at three months. The sample was representative of a woman who had an uneventful pregnancy (9.1%)(p-value=0.160) At the six-month follow-up, none of the patients in the sample presented with symptoms suggestive of a psychotic illness.

At delivery, 4.5% of women presented with a Brief psychiatric rating score of more than 31, which corresponds with being moderate to markedly ill. At 6 weeks, 3.7% of women were moderate to markedly ill and at three months 3.1% of subjects were moderately ill with a BPRS score of 38.

Table 19h: Psychotic symptoms per group at four time intervals

Psychosis	None		Mild/Moderate/Severe				Total	
	n	%	n		%		n	%
Delivery	85	95.5	4		4.5		89	100
			LT	U	LT	U		
			3	1				
Total per group			46	43	6.5	2.3		
p-value	0.340							
Six weeks	50	94.3	3		5.7		53	100
			LT	U	LT	U		
			2	1				
Total per group			29	24	6.9	4.2		
p-value	0.669							
Three months	31	96.9	1		3.1		32	100
			LT	U	LT	U		
			0	1				
Total per group			21	11	0.0	9.1		
p-value	0.160							
Six months	20	100	0		0.0		20	100
			LT	U	LT	U		
			0	0				
Total per group			12	8	0.0	0.0		
p-value	0							

Figure 9: Psychotic symptoms per group at four time intervals



4.4.9 Substance abuse

Approximately 3.4% (n=3) of participants admitted to substance use (Table 19i, Figure 10) at delivery, with more than two-thirds of the sample representing women who had uneventful pregnancies. When the two groups are compared, then 2.2% (n=1) of women with life-threatening complications and 4.7% of women with uneventful pregnancies presented with substance abuse. (p=0,518) (OR of 2.20 for women with uneventful pregnancies at 95% CI).

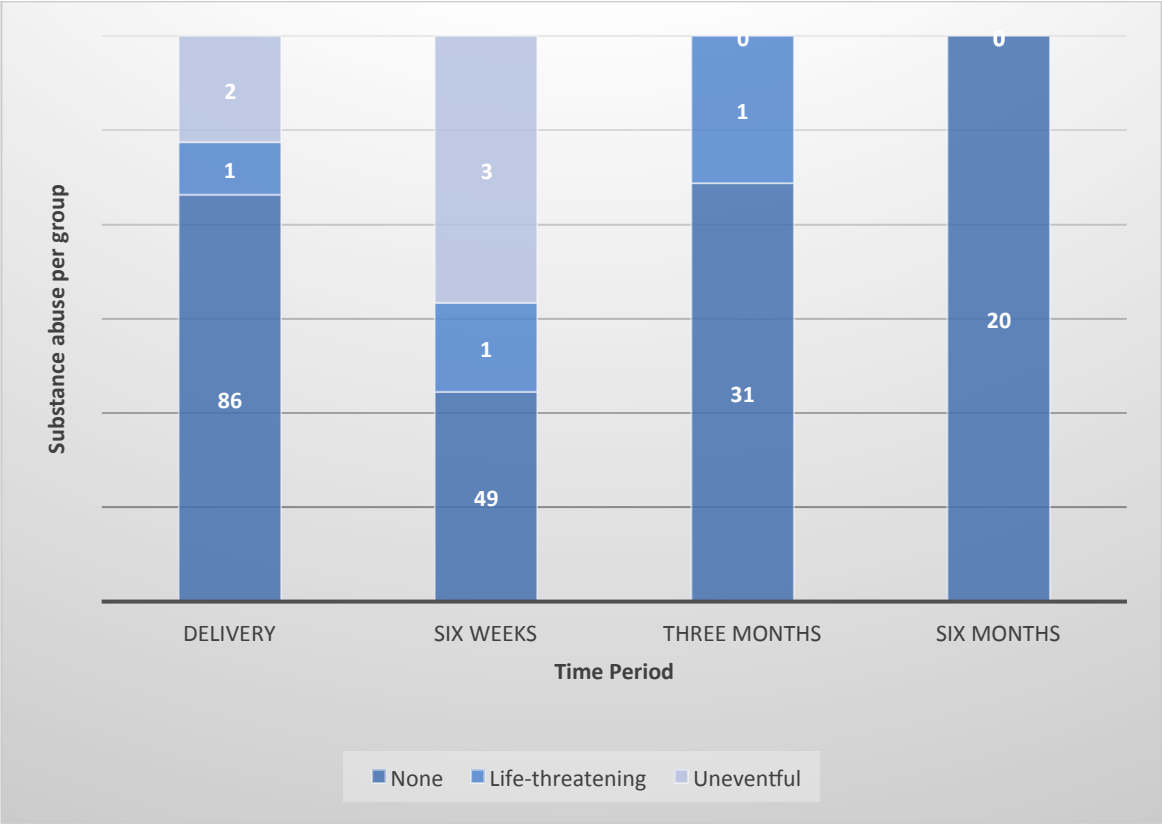
At six weeks, 7.5% of participants continued to present with substance abuse, with 75% if the sample representing women with uneventful pregnancies. Within the individual groups, 3.4% and 12.5% of women with life-threatening complications and uneventful pregnancies respectively presented with symptoms. (p=0.214)(OR of 4 for women with uncomplicated pregnancies at 95% CI)

Only 3.1% (n=1) of the women followed up at three months. This sample was representative of a woman who had a life-threatening complication. (4.8%) (p= 0.462)

Table 19i: Substance abuse per group at four time intervals

Substances	None		Mild/Moderate/Severe				Total	
	n	%	n		%		n	%
Delivery	86	96.6	3		3.4		89	100
			LT	U	LT	U		
			1	2				
Total per group			46	43	2.2	4.7		
p-value	0.518							
Six weeks	49	92.5	4		7.5		53	100
			LT	U	LT	U		
			1	3				
Total per group			29	24	3.4	12.5		
p-value	0.214							
Three months	31	96.9	1		3.1		32	100
			LT	U	LT	U		
			1	0				
Total per group			21	11	4.8	0.0		
p-value	0.462							
Six months	20	100	0		0.0		20	100
			LT	U	LT	U		
			0	0				
Total per group			12	8	0.0	0.0		
p-value	0							

Figure 10: Substance abuse per group at four time intervals



4.5 SUMMARY

In summary, 89 women signed informed consent to participate in the study. 46 were women who experienced a severe, life-threatening event in pregnancy, whilst 43 had uneventful pregnancies. Fifty-three participants followed-up at the six-week appointment. (29 with life-threatening complications and 24 with uneventful pregnancies) Furthermore, at three months, 32 women followed-up (21 and 11 respectively) whilst during the six month follow-up, 20 women attended the appointments. (12 with life threatening and 8 with uneventful pregnancies) More than two thirds of the participants were between the ages of 21 and 35, and a third of the participants reported that they were married. Approximately a third of the participants had matriculated and a similar proportion was employed. Almost a third of the participants lived in informal settlements with basic amenities.

A third of the participants had been pregnant at least twice, and is noteworthy that 6.5% of women who experienced a life-threatening stressor had no children at the first interview.

More than 71% of the participants reported that their most recent pregnancy was unplanned, with more than 15% reporting that the pregnancy was unwanted as well. Only 12.4% of participants did not attend any antenatal care, and a fifth of the participants reported that they were uninformed of the signs of potential pregnancy complications.

Almost a third of the women who experienced a severe, life-threatening stressor experienced an intrauterine foetal demise. The contraceptive method preferred by more than 42% of participants was the injectable contraceptive. Approximately 12% of women received treatment for a psychiatric illness in the past and a fifth of the participants were HIV-positive at the first interview.

Participants in both groups experienced psychiatric complications in the following symptom domains namely; depressive symptoms, anxiety, sleep, somatic symptoms, memory deficits and anger. When the two groups of women namely those with life threatening complications and those with uneventful pregnancies were compared with regard to psychiatric complications, then women with complications experienced greater distress than those with uneventful pregnancies. These symptoms were most pronounced at the six-week follow-up.

Approximately 30.4% of women who had life-threatening complications and 18.6% of women with uneventful pregnancies presented with mild to severe symptoms at delivery. (p-value 0,196)(OR of 1,91 at 95% confidence interval). At six weeks, almost two-thirds (65,5%) of women with life-threatening complications experienced symptoms of depression whilst 29,2% of women with uneventful pregnancies developed symptoms. (p-value 0,08 (OR of 4,91 at 95% CI).

The number of women experiencing depressive symptoms decreased at three months and within the two groups, 47,6% of women with life-threatening stressors continued to be symptomatic as compared to 18,2% of women with uncomplicated pregnancies. (p-value 0,102) (OR of 4,09 at 95% CI). At the six months, 15% of women continued to experience symptoms and within the individual groups, 16,7% of women with life-threatening complications and 12,5% with uncomplicated pregnancies were symptomatic. (p-value-0,798) (OR of 1,40 at 95% CI).

Furthermore at delivery, 2.2% (n=2) of the subjects reported mild to moderate manic symptoms with similar percentages of women in both groups presenting with symptoms. (2.2% of women with complications and 2,3% in women with uncomplicated pregnancies) (p-value-0, 962) (OR of 1.07 for women with uncomplicated pregnancies, 95% CI)

The number of women experiencing manic symptoms increased at six-weeks to 5,7% (n=3) of whom two-thirds were women who had uneventful pregnancies. These were women who had relapse due to an existing psychiatric condition. These women were subsequently lost to follow-up.

Anxiety symptoms in the mild to severe category were present in 19.1%(n=17) of the study subjects. Within the two groups, 30,4% of women who had a life-threatening event and 7% of women with uncomplicated pregnancies had symptoms. (p-value 0,005) (OR of 5,83 at 95 % CI). The number of women who experienced symptoms at six weeks increased to 39,6%. (n=21) Significant differences with regard to symptom presentation were found between the two groups with 55,2% of women who experienced life-threatening complications being symptomatic compared to 20,8% of women with uneventful pregnancies. (p=0,011) (OR of 4,68, 95% CI) The number of women who experienced anxiety symptoms at three months decreased with 42,9% of women with life-threatening complications continuing to be symptomatic compared to 18,2% of women with uncomplicated pregnancies. (p-value-0, 163) (OR of 3,38, 95%CI)

An interesting observation at six months, was that 12,5% of women with uncomplicated pregnancies presented with residual symptoms of anxiety as compared to 8,3% of women with life-threatening complications. (p-value-0, 761) (OR of 1,57 for women with uneventful pregnancies at 95% CI). With regard to obsessive-compulsive symptoms, only 2.2% of the subjects reported mild intrusive thoughts at the six-week follow up, whilst 4.5% of subjects reported experiencing some dissociative symptoms at delivery, 5.6% at six weeks and 2.3% at three months.

At delivery, less than 1%(n=3) of women presented with symptoms of anger and within each group, 4,3% of women with complications and 2,3% of women with uncomplicated pregnancies were symptomatic. (p-value-0, 597) (OR of 1,91 at 95% CI). During the six-week appointment, 17,2% of women with life-threatening complications and 4,2% of women with uncomplicated pregnancies presented with symptoms of anger respectively. (p-value-0, 135) (OR of 4,79, 95% CI) A downward trend was observed at three months with the entire sample representing women with life-threatening complications (14,3%)(p-value-0, 188) and none of the women reported symptoms at six months. Participants also presented with somatic symptoms that were in the mild to moderate category. There was a significant difference between the two groups with respect to symptom presentation at the first interview in that there were 28,3% of women with complications and 4,7% of women with uneventful pregnancies experiencing symptoms. (p-value= 0,003) (OR of 8,08 at 95% CI)

An increase and significant difference between the two groups was observed at six weeks with 37,9% of women with complications and 12,5% with uneventful pregnancies presenting with symptoms (p=0,037) (OR of 4,28 at 95%CI). At three months, a greater percentage of women with uneventful pregnancies appeared to experience somatic symptoms than those with life-threatening complications. (9,1% compared to 4,8%). (p-value-0, 631) (OR of 2,0 for women with uneventful pregnancies at 95% CI) None of the women who followed up at six months reported any somatic symptoms.

Furthermore, at the initial interview, 28,3% and 7,0% of women who had life-threatening complications and uneventful pregnancies respectively, reported disturbances in sleep. (p-values= 0,009) (OR of 5,25 at 95% CI) The number of women that were symptomatic increased at the six-week interview with a quarter of those with uncomplicated pregnancies and 62% with life-threatening complications experiencing sleep disturbances. (p-value = 0,007) (OR of 4,91 at 95% CI) The sleep disturbances improved over time with 38,1% of women with life-threatening complications and 18% of women with uneventful pregnancies having residual symptoms. (p-value-0, 248) (OR of 2,77 at 95% CI). At six months 8,3% of women with life-threatening complications presented with residual sleep disturbances. (p-value-0, 402)

Significant differences with regard to memory disturbances were found between the two groups, with 15,2% of women with complications and 2,3% with uneventful pregnancies expressing symptoms at the initial interview respectively. (p-value= 0,034) (OR of 7,54 at 95% CI) An upward trend was observed at six weeks with, 34,5% and 8,3% of women with life-threatening complications and uneventful pregnancies respectively presenting with significant memory disturbances. (p-value-0.024) (OR of 5,79 at 95% CI) The number of women expressing cognitive difficulties decreased at three months to 23,8% of women with complications and 9,2 % with uneventful pregnancies respectively. (p-value-0, 311) (OR 3,13 at 95% CI).

At the initial interview, 6,5% of women with life-threatening complications and 2,3% with uneventful pregnancies experienced psychotic symptoms (p-value-0, 340) (OR of 2,93 at 95% CI).

At six weeks, 6,9% of women with complications and 4,2% with uncomplicated pregnancies experienced symptoms. (p-value-0, 669) (OR of 1,70 at 95% CI) However, only 3,1%(n=1) presented with residual psychotic symptoms at three months. The sample was representative of a woman who had an uneventful pregnancy. (9,1%)(p-value-0, 160)

Approximately, 2,2%(n=1) of women with life-threatening complications and 4,7% of women with uneventful pregnancies presented with substance abuse at the initial interview. (p-value-0, 518)(OR of 2,20 for women with uneventful pregnancies at 95% CI).

At the six week follow-up, 3,4% of women with life threatening complications and 12,5% of women with uneventful pregnancies presented with symptoms. (p-value-0, 214) (OR of 4,00 for women with uncomplicated pregnancies at 95% CI). A participant (4,8%) (p-value- 0,462) with a life-threatening complication that followed up at three months continued to abuse substances. Women who presented with symptoms were subsequently referred to their local clinics for further management. These symptoms were found to have improved with treatment at the subsequent visits at three months and six months.

Table 20: Summary of psychiatric sequelae

Condition	P1			P2			P3			P4		
	LT (46)	U(43)	p-value	LT(29)	U(24)	p-value	LT(21)	U(11)	p-value	LT(12)	U(8)	p-value
Depression	14 (30.4%)	8 (18.6%)	0.196	19 (65.5%)	7 (29.2%)	0.008	10(47.6%)	2 (18.2%)	0.102	2 (16.7%)	1 (12.5%)	0.798
Mania	1 (2.2%)	1 (2.3%)	0.962	1 (3.4%)	2 (8.3%)	0.444	0	0		0	0	
Anxiety	14 (30.4%)	3 (7.0%)	0.005	16 (55.2%)	5 (20.8%)	0.011	9 (42.9%)	2 (18.2%)	0.163	1 (8.3%)	1 (12.5%)	0.761
Anger	2 (4.3%)	1 (2.3%)	0.597	5 (17.2%)	1 (4.2%)	0.135	3 (14.3%)	0	0.188	0	0	
Somatic	13 (28.3%)	2 (4.7%)	0.003	11 (37.9%)	3 (12.5%)	0.037	1 (4.8%)	1 (9.1%)	0.631	0	0	
Sleep	13 (28.3%)	3 (7.0%)	0.009	18 (62.1%)	6 (25.0%)	0.007	8 (38.1%)	2 (18.2%)	0.248	1 (8.3%)	0	0.402
Memory	7 (15.2%)	1 (2.3%)	0.034	10 (34.5%)	2 (8.3%)	0.024	5 (23.8%)	1 (9.1%)	0.311	0	0	
Psychosis	3 (6.5%)	1 (2.3%)	0.34	2 (6,9)	1 (4.2%)	0.669	0	1 (9.1%)	0.16	0	0	
Substance	1 (2.2%)	2 (4.7%)	0.518	1 (3.4%)	3 (12.5%)	0.214	1 (4.8%)	0	0.462	0	0	

Key: P1: Delivery P2: Six weeks P3: Three months P4: Six months

5 FINDINGS OF THE QUALITATIVE ARM

5.1 INTRODUCTION

Eighty-nine participants were interviewed and 16 subjects were purposefully sampled for the case studies. As mentioned previously, these women were interviewed four times: shortly after delivery, at six weeks, at three months and at six months. These women were requested to keep a diary of their lived experiences. The holistic approach to patient care is often dictated by the bio psychosocial approach, but the focus is very often directed almost entirely on the biological processes of illness. The psychosocial aspects are either under-investigated or not given adequate recognition. The purpose of requesting a diary was to gain an understanding and insight into their world outside the hospital environment, and avoid viewing them merely as patients in the hospital environment.

5.2 PARTICIPANT EXPERIENCES

5.2.1 Summaries of 16 purposefully sampled case narratives

5.2.1.1 Participants with uneventful pregnancies

TSM

22-year-old student with two children: a three-year-old and a newborn. She has been in a stable relationship for eight years. TSM lives in an informal settlement, in a shack with amenities, with her mom, brother and her son. The pregnancy was unplanned and unwanted, but an abortion was not an option as it was against her principles. She did not divulge news of her pregnancy to anybody other than her boyfriend. TSM made an appointment at the clinic at 23 weeks, had two subsequent visits and described no problems during her pregnancy, apart from receiving iron supplementation. She had no medical or psychiatric history of note and denied any illicit substance history.

TSM grew up in a single-parent family, attended school and was enrolled at a tertiary facility. She describes a supportive structure that included her mom, her boyfriend and his family.

With regard to her religious beliefs, she was not a regular churchgoer, her mother was a traditional healer and her boyfriend had received a calling from the ancestors to become a traditional healer as well. TSM's pregnancy was uneventful and she delivered her baby vaginally without any complications. She reported that she was not considering falling pregnant in the near future and planned on using the implant as a contraceptive method. TSM was found to be friendly and cooperative during the interview and a rapport was easily established.

EM

25-year-old mother of two children: a four-year-old son and the newborn daughter. She reported that she was traditionally married and had been living with her husband in an informal settlement, in a shack with amenities. Her eldest child lives with her parents in Limpopo. She describes having an unplanned pregnancy, and admitted that when she found out that she was pregnant, she felt somewhat guilty because her first child was still young and they had not planned on having another baby so soon. She also admitted that she had not been using any form of contraception prior to conception. Her pregnancy was confirmed at five months when she made an appointment at the antenatal clinic. She attended two subsequent appointments prior to delivery. EM describes an uneventful pregnancy and had no complications during this or her previous pregnancy. She had not received treatment for any medical conditions and had no psychiatric history of note. She denied any illicit drug or alcohol use. She admitted that she didn't attend church very often but felt that religion was important to her for salvation. EM had a tertiary education and was formally employed prior to her pregnancy. She was not planning on returning to work after maternity leave and said that her husband would be providing for the family financially. EM described experiencing abdominal pains prior to going to the primary hospital. After physical examination she was referred to the secondary hospital for surgery due to a breech presentation. She was re-examined at the secondary hospital and was told that no surgery was required due to cephalic presentation of the baby, and she subsequently had a normal vaginal delivery. EM was a pleasant young woman who was friendly and cooperative during the interview, and volunteered information happily.

JOS

42-year-old mother of three children who was in a stable relationship for three years. She was employed, as a teacher's assistant and lived with her mother and children in a house with all the amenities. Her partner was employed and provided financially for her two children. JOS described an unplanned pregnancy as she had been using the injectable contraceptive and had amenorrhea as a result. JOS discovered that she was pregnant after an accident when she was bitten by a dog and attended a clinic for treatment. Her pregnancy was then confirmed and she was referred to the secondary hospital for further management as she was of advanced maternal age. She was referred to the maternal and foetal unit for further investigation but describes an uneventful pregnancy. She reported no medical or surgical complications during the present pregnancy, or in her previous pregnancies. She had a normal vaginal delivery and was planning on undergoing sterilization in the postpartum period. JOS denied any previous psychiatric history and was not receiving any chronic medication. She describes a supportive system, and although she describes herself as not particularly religious, she does believe in God and says that prayer helps her when she has any problems. JOS was also found to be friendly and cooperative during the interview.

PM

38-year-old, married mother of three children. PM lived with her husband and children in a flat that they shared with other families. She was the provider for the family and had been temporarily employed, as her husband was chronically ill and had been intermittently admitted to hospital. The pregnancy was unplanned, but she had not used any contraceptive methods. She believed that the baby was a blessing from God. PM was late in booking an appointment at the clinic and only had two visits. She did not report any problems during the pregnancy, which progressed uneventfully, and had a normal delivery. She did not report any previous medical or psychiatric problems and denied any illicit drug or alcohol use. She had been pregnant five times but had two spontaneous abortions prior to the last pregnancy. She had decided to undergo sterilization after delivery. PM was born and raised in the Democratic Republic of the Congo. She had secondary schooling, and after completing school she started working. She came to South Africa after her husband found employment here. She described not having many friends, but said she believed that having too many friends comes with problems.

She describes being rather lonely in South Africa, as the rest of her family were still in the DRC. She is religious and attends church weekly. She says her faith gives her the strength to continue and that she knows God has a plan for everything. She sometimes wonders how her family will survive, but believes that everything will be all right one day. PM was cooperative during the interviews and a rapport was easily established and maintained throughout, although it was somewhat difficult to understand her due to her accent.

SN

23-year-old mother of three children who was in a stable relationship for seven years. She lived with her family in rented accommodation with all the amenities. She described herself as religious and attended church on a weekly basis. SN was gainfully employed and at the time of the interview was on maternity leave. She reported that the pregnancy was unplanned and that the only contraceptive method she and her partner were using was the condom. She denied having any previous chronic conditions, past psychiatric history or history of illicit substance use. She reported that at her initial visit to the clinic she was diagnosed with HIV and was administered antiretroviral medication. She described an uneventful pregnancy and was planning to use the depot contraceptive in the future.

5.2.1.2 Participants with life-threatening complications

TR

23-year-old female who was unemployed. She was pregnant with her first child and reported being in a long-term relationship of five years. The father of the baby was not permanently employed and subsisted by doing piece jobs. TR lives with her mother and younger sisters in an informal settlement, in a shack with no amenities. The pregnancy was unplanned but wanted. She reported using the oral contraceptive pill, but had been erratic in compliance and thus fell pregnant. She confirmed her pregnancy through a home pregnancy test, made an appointment at the antenatal clinic at 20 weeks, and had seven visits to the clinic. She described an uneventful pregnancy, and reported no medical or psychiatric history of note and denied any illicit substance use. TR grew up in Limpopo with her grandparents and went to school there.

After two unsuccessful attempts at writing her matric exams, she came to live in Pretoria with her mother and her two siblings. She was never employed, and the family's only source of income was the child support grant that her mother and sister received for their children.

TR did not describe herself as religious, but believed in God and wanted to be close to Him, as she believed that He would protect her. Circumstances that occurred at the time of delivery were as follows: The pregnancy had progressed beyond 40 weeks, and at follow-up at the antenatal clinic, she was referred to the secondary hospital for an induction of labour. TR experienced prolonged labour due to cephalo-pelvic disproportion; she then developed complications subsequent to the caesarean section, which began with a septic wound and led to puerperal sepsis that necessitated a total hysterectomy in the days following the caesarean section. TR was soft-spoken, and although a rapport was established, she appeared uncertain and her mood was subdued.

VM

24-year-old mother of two children who was employed at the time of admission to hospital. VM lived with her parents and children in a house with all the amenities. She reported being in a stable relationship for three years and that her boyfriend was employed. She only discovered the pregnancy when she was admitted to hospital for severe abdominal pain (see below). VM reported that although the pregnancy was unplanned, it was wanted, and even though they had not used any contraceptive methods, her partner intended to marry her, and they wanted to have children. VM reported no medical or psychiatric history of note and reported occasional alcohol consumption. She denied any alcohol or illicit drug use during her pregnancy, but eventually admitted at the follow-up interviews to drug use. She described herself as not religious and said she rarely attended church. Her admission to hospital was as a result of her experiencing severe abdominal pain, and she was diagnosed with pancreatitis, secondary to cholecystitis, and subsequently had a cholecystectomy. VM was non-compliant with the proposed treatment plan and did not go to any antenatal clinic. She was readmitted to hospital at 27 weeks of pregnancy with another episode of pancreatitis. During hospitalization, she reported decreased foetal movement and further investigation revealed an intrauterine foetal death. A hysterotomy was thus performed when she was medically stable. Although VM had agreed to be a research participant, she was reluctantly cooperative at first and a superficial rapport was established.

LM

20-year-old mother of one child, who had been in a relationship for about a year. She initially used the depot contraceptive method, but was erratic in her compliance and subsequently fell pregnant. The pregnancy was thus unplanned and initially unwanted. LM described struggling with the thought of having another child and being unable to provide for her children. She admitted to feeling desperate when she discovered that it was a twin pregnancy, and took an overdose of pills in the hope of terminating the pregnancy. She was subsequently admitted to hospital. Although, she denied wanting to end her life, she admitted that she had experienced difficulty accepting her situation and did not know how she would care for three children. After the event, LM reported that she was referred to a social worker to help her deal with her problems. She was not referred to a psychiatrist or psychologist at the time, and had not received any treatment. Apart from the overdose, she denied experiencing any medical problems. She denied illicit drug use, and although she is not partial to alcohol, she nevertheless consumed it as a means of escape. LM lived with her boyfriend in an informal settlement, in a shack with amenities. Her partner was a contractual worker and she was unemployed. LM was rejected by her mother after the death of her father and grew up in a children's home from the age of 3. LM describes yearning for her mother's acceptance and mentioned absconding from the children's home on more than one occasion, only to be repeatedly rejected by her mother and stepsiblings. She reported being physically abused by her stepfather on one occasion. LM attended primary school, but admits that she had learning difficulties and can thus not read. She lived on the streets for some time and eventually found employment as a cleaner. When she met her boyfriend, she started living with him. LM says that religion plays a very important part in her life and believes that despite the difficulties she has experienced in life, God loves her and has helped her throughout, and even saved her after the suicide attempt. LM reported that she only made an appointment at a clinic after seven months and attended the clinic on three occasions. She reported being unaware of any complications during her pregnancy and only discovered something was wrong when she woke up one morning and realized that her feet were swollen and she had difficulty with her vision. Her boyfriend then took her to the clinic and she was subsequently referred to the secondary hospital where an emergency caesarean section was performed due to severe preeclampsia. Twin baby boys were born, and one of them had congenital anomalies. LM developed respiratory problems in the days subsequent to the surgery and developed bilateral pleural effusions secondary to pulmonary emboli, as well as renal dysfunction and cardiac failure.

Although physically weak and oxygen-dependent, LM was cooperative during the interview. She was friendly and at times became quite emotional, especially when discussing her history and her rejection by her mother.

YK

24-year-old, married mother of one daughter, who was five years old at the time of interview. YK lived with her husband in an informal settlement, in a shack with amenities. Her husband was not formally employed but did piece jobs to provide an income, and YK was employed as a domestic helper but stopped working when her pregnancy was confirmed at two months. She reported no previous medical or surgical problems and her previous pregnancy was uncomplicated. She also reported no psychiatric history or illicit drug or alcohol use. YK was born and raised in Zimbabwe. She was unable to complete her secondary schooling due to financial constraints, and started working at a market to provide an income for her family, as she was the eldest child. After her marriage, YK and her husband came to South Africa in search of a better life in 2010. Religion plays a very important role in her life and she reported attending church weekly. YK reported that the pregnancy was planned, and after confirmation of pregnancy at the clinic, she made an appointment at the antenatal clinic at three months and attended subsequent appointments at the required intervals. She reported no problems during the pregnancy and it was only during the clinic visit at 30 weeks that she was told her blood pressure was raised. Two days later, she started experiencing severe headaches and pain in her abdomen. She went to her local clinic and was told that her blood pressure was very high, and after physical examination, she was told that her baby had not survived. She was then transferred to the tertiary hospital for further management. YK was cooperative during the interview, but her mood was objectively low, and she became quite tearful when recalling events prior to admission to hospital.

RN

29-year-old, married mother of one child who lived with her husband in a home with all the amenities. She was previously employed, but had left work approximately two years prior to the interview as they had been planning to have a baby and RN did not want to have any stress when she conceived. She made an appointment at an antenatal clinic after three months and had three appointments prior to being diagnosed with hypertension at 21 weeks of pregnancy. Anti-hypertensive medication was then prescribed.

Upon further special investigations, she was diagnosed with lupus nephritis and prescribed anticlotting medication. RN was then referred to the high-risk pregnancy clinic. On her fourth visit at 27 weeks, her blood pressure was once again very high, and the ultrasound had revealed that the baby had died in utero. She was then admitted to hospital for an induction of labour. RN denied any problems during her first pregnancy and the hypertension was only diagnosed during the second pregnancy. She denied experiencing any other medical problems and reported no previous psychiatric history. She denied any illicit drug or alcohol use prior to or during the pregnancies. RN was born and raised in Limpopo and after failing matric she left school and came to Gauteng to find employment. Her first child, who was six years old at the time of interview, lived with RN's parents in Limpopo. RN described herself as religious and attended church weekly. She was friendly and cooperative and despite experiencing many problems during and subsequent to her pregnancy, including the loss of her child, she appeared positive in spirit. She did become emotional, however, when recalling the events that led to her losing her baby.

PM

16-year-old scholar who was in Grade 11 at the time of interview. She lived with her aunt and sister in a house with all the amenities, and her sister provided financially for the family. PM was born and raised in Malawi, and at the age of 15 came to complete her schooling in South Africa. PM reported an unplanned pregnancy and was not using any contraceptive method. Her boyfriend was also from Malawi and came to South Africa to seek employment, but was unsuccessful and returned home, and was thus unaware of her pregnancy. PM reported being afraid to disclose her pregnancy to her family as she felt that she had behaved irresponsibly. She thus only disclosed her pregnancy at 20 weeks, when she made an appointment at the antenatal clinic and subsequently followed up three times.

She described having no problems during the pregnancy and was told that everything was fine when she attended the clinic. She was admitted to the secondary hospital when she started experiencing abdominal pain, and was told that she was in labour. She experienced prolonged labour and subsequently had a caesarean section for cephalo-pelvic disproportion. The first few days post-surgery were uneventful, and a day prior to discharge she started experiencing abdominal discomfort, and developed a fever and persistent tachycardia. She was told that she had to be treated for an infection, but her condition continued to deteriorate and she was taken back to theatre for another operation. She was later told that the infection had spread and she had to have a hysterectomy.

She described feeling very confused and scared at the time, and apart from her family, she did not have anybody to talk to and discuss her fears with. She mentioned that her aunt and sister were very supportive and helped her get better. PM did not report experiencing any other medical problems and had not received treatment previously. She also did not report any psychiatric history and denied any illicit drug or alcohol use. She described herself as a regular churchgoer and said that attending church was very important to her as she learns not only about God but also about fellowship with friends too. PM appeared as a young girl, somewhat uncertain of herself, but was cooperative during the entire interview.

TDM

42-year-old, married mother of three children. She lived with her husband and children in a house with all amenities. Her husband was employed and she worked as a child-minder. TDM discovered that she was pregnant when she attended the clinic for a cold. The pregnancy was totally unplanned and unexpected, as she reported that she had continued menstruating during this time. She describes that period as a very confusing time for her, and said that she became withdrawn, and isolated herself in the hope of making sense of what was happening in her life. She said that she needed time to come to terms with being a mother again, but she never wished the pregnancy away as she believed that it was a "gift and a blessing from God". She made an appointment at the clinic at three months and was referred to the clinic at the secondary hospital as she was of advanced age and needed close monitoring during the pregnancy. She was counselled about the risks of foetal abnormalities. She reported that she delivered at eight months in her first pregnancy, but had no complications, and the second pregnancy went to term.

She followed up at the clinic for her appointment at 38 weeks and was told that she had to have an induction of labour as she had developed gestational diabetes. She did not report any previous medical problems and was not receiving any chronic treatment. She also denied any previous psychiatric history and did not use illicit drugs or alcohol. After delivery of the baby, TDM was informed that her child had a congenital abnormality and it was reported that she had Down syndrome. TDM was cooperative during the interview. She was quite eloquent in her expression of her problems and became somewhat emotional during the interview. She was open and forthcoming with her information.

NN

20-year-old single female who was still completing secondary schooling when she discovered she was pregnant. She was not in a stable relationship and the pregnancy was unplanned and initially unwanted. She lived with her mother and sister in an informal settlement, in a shack without amenities. NN left school when the pregnancy was confirmed at the clinic. She made an appointment at the antenatal clinic at 18 weeks at that appointment she was informed of her HIV-positive status. Ultrasound examination revealed an extra uterine pregnancy and she was then transferred to the tertiary hospital for further management. An exploratory laparotomy during the pregnancy revealed a bicornuate uterus, and she followed up regularly at the clinic. She was also prescribed antiretroviral medication. NN describes feeling very disappointed when she discovered her status, and was initially sad and very tearful. She was worried about how her baby would be affected and did not cope well initially. She did not receive any psychiatric intervention or counselling during the pregnancy, however. She had no other chronic illness of note and reported alcohol use on occasion but no illicit drug use. NN describes having a supportive family who helped her through the difficult pregnancy and time in her life. She does not think she is particularly religious, but believes in the word of God. She feels comforted when she attends church. NN had an elective caesarean delivery at 38 weeks due to the complicated pregnancy. She reported no problems post-operatively. NN was friendly and cooperative, and readily volunteered information. Her mood fluctuated somewhat during the interview when she spoke about her condition and her need for compliance with treatment

EH

28-year-old female in a casual relationship. She lived with her mother, stepfather and siblings in a house with all the amenities. She was employed and was furthering her tertiary studies. She describes an unplanned pregnancy and was not using any contraceptive methods. A general practitioner confirmed her pregnancy, and she admits that she was late in making an appointment at the antenatal clinic and only had three visits to the clinic. She describes no medical problems during her pregnancy, and it was only on her last visit at 36 weeks that her blood pressure was raised and was not abating despite her receiving anti-hypertensive treatment. She was then transferred to the provincial hospital, where an emergency caesarean section was performed. Subsequent to the surgery, it was discovered that she was severely thrombocytopenic, and she was then transferred to the tertiary hospital in Pretoria. Her baby was fine, and she felt that it would not be good for him to be around her so she left him in the care of her mother.

She admits that she did not realize she was severely ill, as apart from some dizziness; she was able to walk and take care of herself. She underwent extensive tests and was diagnosed with idiopathic thrombocytopenia and commenced corticosteroid treatment. EH describes feeling very alone, afraid and confused during her admission to hospital. She did not receive any psychological intervention during this time. She had no previous psychiatric history, and reported that she only consumed alcohol on special occasions and denied any illicit drug use. EH reported that she didn't have many friends and her only support structures were her family, but she was alone during her admission as the family were far away and weren't able to visit often. Although she did not attend church, EH reported that religion was very important to her and it was prayer that helped her get through the days. EH appeared quite anxious and low in mood during the interview. She was cooperative and a rapport was established and maintained throughout the interview. She also appeared physically unwell and the interview was interrupted at intervals to allow her some rest.

CS

37-year-old mother of three children who had been in a stable relationship for three years. She lived with her boyfriend and children in a house with all the amenities. Her boyfriend was unemployed and she was working with her father.

She describes a planned pregnancy and admits that she was particularly stressed prior to conception. Her pregnancy was confirmed at three months when she visited the clinic, and due to her history of diabetes and advanced maternal age; she was transferred to the secondary hospital for specialist care and followed up at regular intervals. She reported controlled glucose levels during pregnancy and had no problems with her blood pressure. She did not report any psychiatric history and denied any illicit drug or alcohol use. She reported no problems during her previous pregnancies either. She went into spontaneous labour at 38 weeks and delivered her baby vaginally. She collapsed a short time after the delivery due to excessive bleeding. Attempts were made to control the haemorrhage but she continued to bleed. She was then taken into theatre where a primary tear was discovered and sutured. All that she recalls of the events after delivery was that she was told she had given birth to a baby boy. She remembers feeling very weak. She continued to bleed and despite efforts to control the bleeding, it had not abated. She was taken back to theatre where a hysterectomy was performed. She was then admitted to the intensive care unit and experienced a number of complications including cardiac and renal failure.

She was intubated for a considerable period and survived against all odds. CS was cooperative during the interview but appeared extremely weak and was found to be both emotionally and physically fragile. She had difficulty speaking and would tire easily during the interview, and she was found to be confused at times. Examination of her clinical notes revealed that there were episodes of irritability and fluctuating level of consciousness. She also appeared paranoid and suspicious of staff members initially.

JM

25-year-old female who was living with her family in a house with all the amenities. She was employed and was studying part-time towards a degree. She had been in a stable relationship of four years and described an unplanned pregnancy as she was still using the oral contraceptive when she discovered that she was pregnant. The general practitioner confirmed the pregnancy at 18 weeks' gestation. She describes feeling angry initially as the baby would change all her future plans. She had a repeat pregnancy test at 22 weeks and says she eventually came to terms with her pregnancy at 26 weeks, at which time she made an appointment at a clinic. She reported that her blood pressure was mildly raised at the appointment, but she never returned to the clinic to get the results of the tests conducted at the clinic.

She was admitted to the district hospital for a week with complaints of nausea and dyspepsia. She subsequently followed up at the local clinic on one occasion. Subsequent to this, she was readmitted to the hospital for three days due to raised blood pressure. She returned to work the day after she was discharged, only to fall ill in the afternoon. She described symptoms of dyspepsia, dizziness, and she subsequently had seizures. She was taken to the secondary hospital where a caesarean section was performed. JM reported no previous medical history or psychiatric history of note. She reported consuming alcohol over weekends and denied illicit drug use. Although she was not a regular churchgoer, JM reported that religion played an important part in her life. She was friendly, cooperative and forthcoming during the interview, and volunteered information readily.

PG

32-year-old mother of one child who was living with her partner in a flat with all the amenities. She was unemployed during her pregnancy, as she had relocated from the Cape to be with her partner. PG was born and raised in Zimbabwe and came to South Africa in search of a better life in 2005. PG described religion as being the cornerstone of her life and denied any illicit drug or alcohol use. She also did not report any previous psychiatric or medical history.

PG reported that she had not used any contraceptive methods since 2013 as she hoped to conceive. Her pregnancy was confirmed at the district clinic before she relocated to Pretoria. She made an appointment at the antenatal clinic in Pretoria at five months and followed up after a six-week period. At that visit, her blood pressure was found to be raised, but had normalised later that day. She reported a previous history of hypertension during the postpartum period in her previous pregnancy, but that she was administered any hypertensives at the time. She reported that she became progressively tired and dyspnoeic in the month after her follow-up at the clinic. One morning, she felt dizzy and started bleeding, and was admitted to the tertiary hospital. She doesn't recall some of the events after her admission and didn't even know that her baby had died in utero. Perusal of PG's clinical notes revealed severe complications subsequent to the abruptio placenta. She was in renal failure and had received dialysis, and there was evidence of an intracranial basal ganglia haemorrhage.

With the exception of SN and PM who had one follow-up at 6 weeks, and VM who followed up at six weeks and at three months, the rest of the case study participants followed up at six weeks, at three months and at six months post-delivery. There was, however, only telephonic contact with PG at six weeks. The narratives and excerpts from the diary are given verbatim.

5.3 THEMES IDENTIFIED DURING QUALITATIVE ANALYSIS OF DATA

5.3.1 Birth experiences

5.3.1.1 Positive experiences of birth

These were the experiences of participants who experienced life-threatening complications and participants with uncomplicated pregnancies.

The highs and lows of motherhood are aptly described in these excerpts from TSM's diary:

"Giving birth is an overwhelming experience that any mom can never forget. Raising a baby brings so much jo into my face. It was wonderful experience for me to actually hold my angle for the first after birth; with my firstborn I did not get the chance to hold him. It really feeled good to hold him and we had a connect; he made me a proud mom.

"I have mixed emotions am feeling tense they's lot of pressure on my shoulders. Am always tired don't get enough sleep the next minute the baby is asleep the next minute he is awake crying. I don't know what to do I always try my best to get him to sleep best it seem like am doing nothing." (TSM) (55:18)

"Every time when I lay into my baby I get happy I am a proud mom seeing your baby growing just bring a smile into my face every day. My children always bring the best in me. Raising a baby has always been my passion. I am looking forward to see my children grow up in front of me, I am learning to put my children before me, and they will always come first. Looking at my children everyday makes me happy and am proud mom." (TSM) (55:25)

"I think for myself I was happy cause the little one is doing smoothly the joy the happiness that you want you are laughing all the time everybody is happy to see you." (JOS) (18:1)

"I'm feeling happy" (SN)

"I've been doing okay, just looking at my baby all the time makes me strong" (TSM) (48:3)

"At the time I just tell myself if the baby to come is to come into that thing it's a blessing from God there is nothing I can do I just tell myself I will love that baby like it or not it's my child and it's a gift from God.

"I was happy about the baby" (PM)

"They have to accept that the baby they have and thank God to make her alive and the baby self." (TR)

"When I look at my baby I just think some other women don't have baby so God blessed me with this child." (CS) (2:21)

5.3.1.2 Negative experiences of birth

"*I was feeling sad and empty you know, having a lot of stress thinking so many things."* (NN) (26:9)

"*I'm not sure I wanted to know what happened because I already lost the baby it was going to cause me more pain."* (YK) (53:10)

"I felt drained emotional drained, I only slept there one night but I couldn't sleep I just felt suffocated I don't know in the room my emotions were just too bad and then I asked if I can speak to a counsellor or someone who can help me, I was choking on the environment." (PG) (33:3)

"It wasn't really easy like I was put in a ward with women who were waiting to be induced or something every time whenever they give birth they come back into the ward with their children their babies and then I was I have just lost a baby in this very hospital and you put me in a room with pregnant women every time they come back holding their babies and I have just lost my own baby it wasn't easy." (PG) (33:12)

"I went to the doctor, he confirmed it, he took my urine then he checked and said I'm pregnant, then he asked my dates, then he said I'm 18 weeks. So, I was angry that time you know, I was angry so I took a lot of time to get it through my mind to settle that I'm pregnant." (JM) (13:3)

"…So I wasn't that much happy I thought maybe it was going to disturb my life." (JM) (13:5)

There were women who had experienced a life-threatening event and who, despite giving birth to live babies, had negative experiences presenting with an overwhelming sense of loss, feelings of inadequacy and guilt, fear of impending death, frustration and a confusing time overall.

For women who had lost their babies, there was anguish, sadness, loss, and ambivalence about their role as women, fear of conceiving again, as well as fear of rejection and desertion. Feelings of worthlessness, hopelessness and helplessness were identified in both groups of women.

Fear of death

"It's still hard now to view all of this that I would have lost my life yes that still is difficult." (EH) (7:5)

"I'm scared I'm scared I'm scared I'm not going to see my baby grow up" (EH)(6:19)

"*Right now I just feel ok that I'm getting better because I was about to die, because of the inferctional they were just spread over the stomach, ja so I had no option but to take it so that my life is saved and I can be with my little baby girl."* (PM) (34:10)

"She told me that my womb it has been removed and I have to accept that and they were worried about me they thought I would die." (CS)(2:3)

"I'm alive because everyone was telling me that you were nearly died." (CS) (2:27)

'I was so so scared, I was so scared, I was going to die, I couldn't see.'' (JM) (13:15)

Excerpt from YKs diary describing her feelings and fear:

"By the time the doctor say to they can't operate, bcoz my blood presser was so high I can die the same time I said god I want to be there for my girl A and my husband. I cry and pray

"I'm not sure I wanted to know because I already lost the baby it was going to cause me more pain." (YK) (56:15)

"I even do a prayer the day they say u are going to theatre at 7oclock I went to theatre and they bring me back three times the doctor says we can't operate her because bp is too high I cry cry until I have no tears my prayer say God I have another girl who need me pliz don't take my life know I love my husband too I know he was not finish pay lobola but my parent swill become hard on him I know. Pliz god be there for him when I'm not there anymore. I was think that I'm going to die I say when my husband get married to another woman is she going to love my little girl, but I ask god to be there for her for me." (YK) (56:29)

Fear of having another baby

"For now I'm too scared, I'm too scared but if the time goes on maybe I will try but for now I'm still scared.

"If I get pregnant will I give birth normal or wont I lose the baby like before will I be pregnant again how long must I take before I try again to have another baby." (YK) (54:8)

Feelings of loss and disappointment

Loss of childbearing potential

"When I think when I grow up and get married that man need another baby it was not be easy." (TR) (44:2)

"I'm not well, I just explain I just don't know how can I say I'm not well I just think that if I met another man who want to marry me how can I explain that I can't get another baby." (TR) (44:8)

"I think that thing happened to me maybe must happen after having three to four babies/kids it will be ok, but only one without marriage and at this age 23 years I'm still young to this situations

"Actually what 'cos this thing to take out the womb? It's my fauld or hospitals fauld? I did not get an answer.

"It's not easy to accept the situation I'm be on why me all of many people

"Is this a punishment from God what's wrong thing that I have done to God if god forgive me where can I get another baby.

"I'm always feel fear when my baby start to getting ill what if I lose him

"I pray all the time for me and my son to live long life 'cos when god take one another one will suffering to spend life alone.

"That time ne when I'm stay alone I'm saying what happened to me why me why me why I am the one but on the other side my mind say no its not you only the other people the same situation you have you know that's why I'm saying ok one day God helped me, one day you see me now God helped me and I'm going to pray and pray.

"It was not easy to accept that I will never fall pregnant again and this is my first and last baby.

"Early morning still unhappy ask myself why me all of many people have bad luck I was haved to deliver the baby normally unfortunately the cervix was too small must to go to operate after operation the bad luck against me they take out off my wound, starting to wipe my tears deep in my heart say why?why? me !!!" (TR) (58:12)

LM describes the loss she felt when she found out about her pregnancy, and also when she lost her baby:

"I feel like I want to die I don't have anything to kill me it's just like I don't have anyone." (LM) (23:9)

"I was playing with my child feeding so after playing after 7 it was so I was playing with her and then she starting not breathing and then I scream I called another people my child is not breathing can I please help me and then when they called the ambulance my child was dead. Because Thursday I was here at the clinic and then they tell me everything was fine and Friday half past seven she was gone." (LM) (21:9)

"…Especially my family my mother, others for maybe their moms they have but me I don't have that relationship with my mom. I was thinking like when they born they coming how I can go to do that so it's better I can kill me and they can maybe my babies I take the pills" (LM) (22:6)

Disappointment

"I've been going the last time I was going to the clinic before 6 I arrive there I go to my check- up every day but what it comes to that I wasn't expecting and I still ask myself so many questions I don't know how to answer them. I ask myself why me but sometimes maybe everything happens for a reason so I just say so. "

“ I feel better when I say so I think maybe there is a reason maybe one day I will know the reason why or I may never know. I used to ask myself that if I if I have another baby the next time I try again sometimes maybe I think it can go as this way.” (YK) (56:82)

“People try to comfort me but when they left I still think and cry I don’t know when will I forget that I have a baby left it’s not easy she/he was part of my family. I even think when I start to plan to have a baby I was happy always say it’s a baby boy. I wish I can ask god face to face why why me my baby. The one I need. I ask myself questions and answer it myself why me by maybe god knows and everything happened by the time today I lose the next time it will be God on my side.”

“But know I’m still scared to have been pregnant again by the time goes I will try ‘maybe’

“I think when my baby die I have a problem of headache every day when I think too much I always love her she left me on the pain.”

“I discover that I became too harsh and angry I even cry when someone talk to me I’m very angry but I don’t knew to who I just be angry. I even do a prayer the day they say u are going to theatre at 7oclock I went to theatre and they bring me back three times the doctor says we can’t operate her because bp is too high I cry cry until I have no tears my prayer say God I have another girl who need me pliz don’t take my life know I love my husband too I know he was not finish pay lobola but my parent swill become hard on him I know. Pliz god be there for him when I’m not there anymore. I was think that I’m going to die I say when my husband get married to another woman is she going to love my little girl, but I ask god to be there for her for me.it still kills me to say I lose my baby.”

“ I wasn’t thinking that when it was the pain I thought it just some pain as a pregnant sometimes you wake up sick. Tired and so no I shocked when the doctor told me that the baby is gone so they are trying to save me it was terrible but thank god I survive.” (YK) (56:95)

VM was disappointed in herself for her behaviour and drug use:

“Nothing much it’s just that `I did something I’m not proud of but at the moment I was so desperate I needed money and got me into trouble.”

“I took the drugs because it makes me feel better I felt better when I take it I treated the problems that I had.” (VM) (51:1)

"…And like everything stresses me so I like went back it's not something I planned to do it just happened I want to stop but I don't know how

"I feel so guilty every time I do that like I think of my parents my children I think of all the things that I've planned for my future but I can't stop with it." (VM) (51:4)

Disappointment and sadness at being diagnosed with HIV, fear for the child:

"I was worried about the baby that maybe she can also be positive."

I was feeling so sad empty you know having a lot of stress thinking so many thing." (NN)

"Ja it is too difficult because we were just starting a new life together everyone here was expecting, I also had expectations for my own relationship now we have to start again." (PG)

Pain and loss

Excerpts from YK's diary that describe her pain and loss:

"Every day I see all the staff I bought for my baby like clothes I cry coz I'm thinking about that day it went wrong it's so bad."

"I think before this happen I have a dream the things I dreamed about. I thought it's just a dream I dream about me my auntie and my husband going to buy some cloths but when we come back it seem like I was crying shout no no my baby no no the baby I never see why why and I woke up my heart beats very fast and I tell my friend and my husband but they say it's a dream but know is happen as the same." (YK) (56:67)

"Yes it pains me at least sometimes I cry I wipe my tears but I was saying this is not the end of the world you have to cope." (YK) (55:3)

"I don't feel anything because it's not so much my time to be angry for someone or anything it can happen it's a decision I only ask myself why I get pregnant I planned to have my baby there is nothing I can do about that I won't be angry I can't be sad because you lose something in your life." (YK) (54:3)

"I ask myself why me why but I don't know the answer." (YK) (54:10)

Guilt feelings and difficulty adjusting

"To be ill when I just had the baby it was difficult for me, because I felt I was supposed to be strong, to get my baby and stay with him at home and raise my baby from the start. But I was ill I had to come here to stay at the hospital and he was home that wasn't ok for me no." (EH) (7:4)

"Sometime I think it was my part to lost my baby but sometimes I say maybe God planned it sometimes I say maybe I get a baby maybe they will going to have something happen to get that baby then you wish God take him its better so they say what happened you have to move on." (YK) (53:22)

"It's been difficult because I'm worried now that any time anything can happen to me yes." (YK) (54:9)

"Like right now frustrated because I've got a baby and my baby doesn't care right now."

"Can't speak to anybody, can't bond with baby, frustration." (EH) (6:22)

"To be ill when I just had the baby it was difficult" (EH) (7:4)

"I do feel guilty that I wasn't there for him I had to let him go home and I was left here." (EH) (6:12)

"Sometimes I feel like more especially the first time I went to work I felt I was abandoning my child and while I'm at work I'm busy phoning most of the times asking how is she doing." (JOS) (19:3)

Excerpts from TR's diary that describe her difficulty and intense feelings of guilt:

"I think maybe God give me the power when I push the baby then maybe a tear, never no operation and when they went to make the second operation so maybe I will be better by myself without the operation." (TR) (58:14)

"I tell them there is nothing they can't put my womb back so what can I do." (TR) (58:17)

"I was regret for why I accept the second operation maybe I will be ok without take out the wound can have children when `I grow." (TR) (58:21)

"Why god not give me more powerful to push the baby the deliver him normally." (TR) (58:27)

"I just feel it's my fault it take out my womb" (TR) (58:30)

"Trust and acceptance of the situation it's difficult

"Ja it's difficult but there is nothing you can change" (TR) (58:45)

"Asking myself why they did not check my cervix before I~ was push the baby and send me to the theatre before I push or cut me on the opening of the vigina so the baby came out."

"Just ask myself but no answer how I can I cope with it? 'cos its really bad to me.

What if I'm not getting married because I can't be pregnant again?" (TR) (58:55)

"I just blame myself for why I agree to sine to take out the womb maybe fine without taking out of the womb

"Now I feel much better you know just take every day at a time but the only problem is that I haven't gone home and there is still things for my baby the stuff I have to start processing again when I get home." (PG) (33:5)

"I feel like I've put everyone's life on hold because everyone was paying attention to me." (PG) (33:14)

"If I get pregnant will I give birth normal or wont I lose the baby like before will I be pregnant again how long must I take before I try again to have another baby." (YK 54:8)

Confusion and isolation

For women who were severely ill or who were admitted to ICU, it was a confusing time.

"Because some things I don't even understand why it all happened." (EH) (6:7)

"I remember when I was in ICU then some of the doctors came next to me and telling me that I have to go back to the operation they have to do another operation and I was surprised I have to do another operation because I don't even thought that I do have one operation on me." (CS) (2:7)

"Eish, I was so stressed telling myself that what about my hormones and what about if my menstruation came what I'm going to do because I don't have a womb the menstruation won't come even I'm worried about I have to get some medication to recover if my system is running through like menstrual cycle so that I can get something to drink so that I must balance my body." (CS) (4:2)

"The problem is if I'm thinking about those days, what happened to me it's stressing me and sometimes if I'm looking at TV and somebody is in ICU eish that thing come what happened to me like dish I'm also going out so they can't see me crying yes." (CS) (4:4)

"I didn't really know about the baby did I lose the baby how did I, was it a boy or a girl, what did she look like I only find out after some days that I had lost the baby cause I thought I had twins so I thought maybe I had at least one of the babies so I have remained with one I only find out later that the twins one of the sisters told me you don't have any babies at all, you lost your babies." (PG) (33:6)

"I don't know, they said I was fitting, I never saw anything, but my mom was crying, my brother were crying, my father was so scared, my junior brother was screaming outside. So I don't know what happened exactly then, they called my neighbour to come and take me to the hospital." (JM) (13:21)

"I was always locked myself with my son in my bedroom telling myself that I won't even have another baby in my life I will still having those three kids that I have and that thing is stressing me because I was supposed to sign that those thing the agreement" (CS) (2:10)

"That thing is stressing me a lot I end up telling myself that I have to take some of these pills, I should take two I feel better if I take two but always everyday I'm taking at least one every morning, every morning.

"Like what must I say like if I'm hearing my things deeply I can't cry in front of people I have to go somewhere and cry and tell myself things will be fine" (CS) (2:15)

"*Feeling alone feeling down, crying a lot when I cry that thing it comes out it become better."* (CS)(2:16)

"I was busy thinking what happen to me and my child." (CS)

I didn't know I hate and big operation like that. I ask myself what I'm going to do with this problem because in the hospital they didn't tell me I'm going to do the operation they just do." (CS) (2:32)

"Looking at the person they think about physically you are fine, but mentally, but it's not how it is looking at me you think I'm fine but actually I'm not Ok there is a lot of things going through my mind so being there alone there is no one to talk to so there would be a lot of things going through my thoughts." (EH) (6:6)

"No there was no one I can talk to, there some people I hasn't trust them no, that's why I don't have a friend because some they won't give you good advice they give you the wrong advice my friend I'm pregnant or abortion you see something that is not good so I was just alone." (NN)

"I still have more questions in my mind and I need answers." (TR) (45:9)

Lack of bonding

For women who were severely ill and hospitalized for an extended period expressed difficulty bonding with their children.

"I didn't feel it I just thing I said oh my son won't even know me the way they are doing he won't know me." (CS) (2:28)

"Emotionally maybe I can't I feel like I can't connect with my baby you see it's like I've been away from home for so long." (EH) (6:8)

"Yes `I was in the hospital he is used to my mother the people he was with that time they don't because when I hold him now sometimes he cries but when they take him away from me he is ok and that makes me feel not so good at all ja because it's my baby yes." (EH) (6:9)

5.3.2 SOCIO-CULTURAL FACTORS

5.3.2.1 Support

Participants from both groups described positive support from family, friends and religious organizations.

"Just what can I say my family their support and my baby I want to go back to my baby I want to be well this time around because last time I think I want to go home I didn't care what was happening." (EH) (8:7)

"From my mother and God just give me the strength and to support form husband." (YK) (53:20)

"I don't know what to say, if it wasn't for my boyfriend's support, and my mother and the doctors support I don't know what would have happened." (JM) (14:5)

"Ok, firstly I'm staying with my husband, my kids the one ne after that 'I've been happy no stress nothing then after a week I go Limpopo I went to sit with my mom and my little sisters and my brothers, just stay at home to make a traditional healing you know, but 'I'm not finish I have to go back to Limpopo to finish my things and every day I'll be happy I forget it that I lost my child." (RN) (37:1)

"Ja people are always judging so I don't always open up to them so but my family is not going to judge me." (TSM)(42:9)

"Right now I'm actually not feeling down I'm always happy I have my class mates to talk to I actually opened I can talk to my family and my boyfriends family I've got a problem I must talk to them I have someone to talk to at home." (TSM) (49:1)

"No no family here only only friends my family is only my husband and my kids." (PYM) (29:3)

"Now that I am relieve from the stress and problems. It's all thanks to my family and my boyfriend's family's helped, they are really helping me so much with the kids. Opening up to them wasn't easy and they were willing to help me with the kids no matter what. Now that am back to college is go to focus into my school work and forget about everything that am going through." (TSM) (49:5)

"I am happy that I have families that cares about me and the children. Am stress free now." (TSM) (49:7)

Lack of support

There were women, however, who did not experience the support that others did.

"I don't think he was supporting me because somewhere I was feel like he doesn't understand my situation by then." (NN) (26:10)

"They were my father was dead my mother she didn't want me she say in the papers ho children's home she don't want me any more I'm not her child and I grow up in the children home and I run away the children home cause I need my family I don't have and then when I find my family they tell me they don't like me I must go there when I'm pregnant I find that boyfriend in the street because I didn't have a place to sleep and then I found to satay with this boyfriend." (LM) (23:7)

"Because I called my mother she didn't care about everything and once come with my brother to check the baby, call me even the message the please call me nothing." (LM) (23:9)

"Alone with the baby, no support, I have thought myself that my mother is far away and I can't run to her every time, and my in-laws live near but they never come to visit so I've accepted that is part of life." (EM) (11:8)

Fear of disclosure, fear of rejection and abandonment

For participants who had lost their babies or who had hysterectomies, there was an intense fear of rejection and abandonment.

"I'm hurt because like I didn't even tell my boyfriend that I don't have the womb she just like saw that 'I have operation and he said what happened to you I said its and operation, I don't know what happened, he said ok you will be fine." (CS) (2:11)

"Even now I didn't tell him what happened to me I just he just ask me about the operation and you ok I just tell him I'm ok." (CS) (3:3)

"*I afraid he was going to run away because some of the guys if you tell him you don't have the womb in his mind that thing is telling him joh this lady he doesn't have a womb and then it seems that he doesn't have anything inside yes."* (CS) (4:16)

"Why I told my boyfriend that I will never fall pregnant again because of having no womb maybe we will still be together now. Which man will accept me when I told him that I will never fall pregnant again, it will be easy to explain that?" (TR) (45:6)

"I tell him I'm sterilizing, there is a fight inside my house no happiness and also now he tell me that baby does not belong to him it belong to another man, he is not talking to me at all he is not talking to me at all because that baby is a Down syndrome and they treat him here, all the time inside my house he won't talk to me if come back from hospital I must explain to him what's going on about the baby and after that I tell him lets go see the baby, he doesn't want to. He doesn't want to support me with anything and doesn't buy anything for the baby." (TDM) (42:1)

Infidelity, poor support

"Problems with husband, I thought he was cheating and the baby is young, he didn't sleep at home." (NN) (27:1)

"I'm raising my child alone without the old people." (EM) (10:1)

My husband is supportive but during the weekend he drink too much, during the weekend he is not going to help at all he drunk always drunk." (EM) (10:6)

"Relationships are hard I thought that I could really manage but everything seems to be a lie I have been with my boyfriend for 8 years now but I still get the same results, he is still the same H who likes to cheat and it really breaks my heart 'cause I am faithful to him and our relationship. Sometimes I just wish the earth could open up and swallow me so that I don't get to go through the pain that I am in. All the years that we've been together have gone to waste. (TSM) (57:12)

"Am stressed the only person that I relayed on financial has been off work for three weeks. It heart breaking to see my boyfriend at home not working that means they won't be any income this month, am so scared for my children."

" It's a stressing situation, my children are going to suffer for few months. Right now I can't even afford to buy formula for my baby. This should be the happiest year of my life but problems keep coming." (TSM) (57:16)

"The boyfriend doesn't come, no it's just me and the baby he changed the phone." (TR) (44:7)

Stigma and social prejudices

"Because you can stay with your friend talk with your friend everything and she is go to laugh at you and tell everyone." (LM) (21:27)

"No there was no one I can talk to, there some people I hasn't trust them no, that's why I don't have a friend because some they won't give you good advice they give you the wrong advice my friend I'm pregnant or abortion you see something that is not good so I was just alone." (NN) (26:10)

"It is the culture, nothing we have to talk to." (RN) (38:9)

"I went home my mother took me to my baby's grave then everything was ok but then I don't know how to explain I don't know what happened everything was ok at that point but I don't know what changed." (VM) (52:12)

"I was sad but I couldn't talk to anyone not anyone.

"I wanted to talk to somebody I call my cousins I call my friends but no one had the time to come to me and talk to me and in our culture I wasn't allowed to go anywhere." I needed somebody to understand how I feel, I feel like I'm not worth the trouble." (VM) (51:4)

"Can I be honest with you I don't want you to judge me, OK since going home I was like not every day I've used drugs again like just to cope or to keep myself busy because I think a lot and like everything stresses me so I like went back it's not something I planned to do it just happened I want to stop but I don't know how cause I feel like I don't have the support like my family doesn't support me they just fight and argue with me." (VM) (52:20)

"In our culture does not allow some people to come and see the baby after certain months, outside people they can't come and see the baby.

"The eldest people say you have to respect the child." (JOS) (18:1)

"Some of them are afraid that if they express their feelings someone maybe those people will judge them and some are afraid of maybe their boyfriend or husband why are you telling other people our stuff." (EM) (10:8)

"Traditionally my friends there are not around coming to visit until the baby is three months, so like my g=friend when they come I stay with them outside they can't see the baby." (EM) (10:15)

"Right now they have their own problems and they got their own children to look after I have nobody to complain to, but with my problems I like to keep things within myself I don't like talking a lot I don't like telling my problems to other people even friends. It's just the person I am I cannot open up to anyone. No I haven't asked for help because if I ask for help it seems like I'm bothering them, I don't want to bother other people." (TSM) (52:5)

"Yes to the other women just telling them people things like this if you talk you break the silence you be free in your mind." (EM) (13:6)

"Some are too lazy they just want to sit at home talking doing nothing they don't see this as something that can help them maybe they don't have the problems like I did but I know they do have everyone have, everyone have problems in life so I don't know what's going through their mind not wanting to come to this session I don't know maybe but I don't think they have someone to talk to just like we as women we don't take things seriously we take life for granted but we must take life seriously if we don't take care of life, life won't take care of you so we have to put life first before fun and things so I think it's more about being lazy just want to be at home doing nothing and it's not a matter of staying at home not doing anything I know a lot of young kids that just sitting at home not doing anything just chilling, they just see the fun they don't just see life negatively.

"Maybe they are scared to come forward 'cos they also having the problem I was having before, they afraid of being judged." (NN) (26:6)

5.3.3 THE HEALTH SYSTEM

5.3.3.1 Positive experiences of the health system

"The care it was fine I don't want to lie that care was fine" (CS) (4:12)

"I receive care a lot" (SN) (39:1)

"…and special thanks to Steve Biko Hospital and all the doctor who works there" (YK) (56:22)

"I don't know what to say, if it wasn't for my boyfriend's support, and my mother and the doctors support I don't know what would have happened." (JM) (14:6)

"Ay, I don't know, I think with the help of the doctors and God it's where I managed, but I couldn't manage myself." (JM) (14:11)

5.3.3.2 Negative experiences of the health system

For a number of women, especially those who had experienced severe life-threatening stressors, there were a number of negative comments regarding the experience with the health system.

Lack of communication

"…The doctors didn't tell me anything" (CS) (2:7)

"They just give me an appointment to do a blood test for my sugar diabetic if I'm still having a sugar diabetic or what then I came here on Monday then they said that I must come back on Monday next week to get my results and so that they can give them the machine for the test." (CS) (2:9)

"There was a lady who was coming at home because she used to work here at Kalafong, somebody told that lady I think it's those ladies who are working in ICU they told her about what happened to me and then she just come tell me and telling me that I'll be fine so." (CS) (2:12)

"Some they didn't care they didn't tell me anything the first time the first visit they helped me they say how many weeks are you pregnant I say I don't know they say go to the sonar and

do the sonar, I go to the doctor after they came back to the clinic follow up I told them that I was 8 weeks so they sent me to the Mamelodi hospital and they didn't tell me why I sent me to Mamelodi hospital they didn't tell me so Mamelodi hospital take me to Tshwane they tell me the baby is not inside the womb its outside so we will sent you to Steve Biko so then I see realize ok that's why they moved me to hospital because of they didn't see well in that picture of sonar pregnancy but they didn't told me anything advise me if you are pregnant you must do this." (NN) (26:8)

"I also asked my mom after my first operation here in theatre she said I came here the following day he says searching for you they said you were in 26 I didn't see you at 26 they just went to ward 10 I was there they were worried because they said they must come and my baby not the baby the bags and my phones they didn't know where I am then she came back to ward 26 they said no just go theatre maybe they will allow you to enter there and search for your daughter then she said the time she saw me I was so big, the face, my hands my legs they were big and she was then starting worried that what happened to me" (CS) (3:12)

"Ja then the date they give me to come to the clinic they they didn't give me the medication, the doctor said I gave to buy it at a chemist this was happen painful no money to buy.

"Eish sometimes I blame this hospital why did you do this? Can I open a case for them that say no cause some people they will lose their job because of me and what will happen to their baby they will never they can't take care of their baby because they lost their job.

"Why they didn't give me something to treat it." (TR) (44:4)

"They discharged me with the open wound they didn't close it." (TR) (45:2)

"Why they did not give me all medication know it was not easy to get it or buy it after all they have done to me." (TR) (43:12)

"They say to me I must go straight to the operation they bring the papers they said to me sign here I just sign and I go straight to the operation after the operation I go to the ward." (TR) (43:8)

"I came here on the 24th they took my blood and they said they will call me but they never called so I think I'm going to go there and find out what is happening." (EH) (6:3)

"You must speak to someone, maybe someone who can make me understand yes about "maybe my platelets my illness yes." (EH) (6:20)

"Right now maybe if I can speak to someone maybe something someone about something happening to me yes." (EH) (8:1)

"…Also ask my mother what happened to me after giving birth; she said I lost many blood that's why; I also ask he who told her that she said somebody from the ward, not one told me that I don't have the womb, up until I was discharged." (CS) (59:4)

"Nobody said anything about blood pressure just right until now." (PG) (33:9)

Lack of understanding and empathy

"She told me that my womb it has been removed and I have to accept that and they were worried about me they thought I would die." (CS) (2:13)

"Some they think they will never get help because of clinic are not the same some they take care of people and some they don't care with people" (NN) (26:8)

"They took me there, ja I wanted to leave because I was there for so long and I wanted to go home and the doctor said if I go home I was going to have a stroke or I was going to bleed in my brain, but I didn't care at that time because I wanted to go home and be with my baby." (EH) (5:7)

"They just said that they don't know what happened and that I must be strong we don't know what God has planned for us."

"Nobody to talk to."

"Nobody understands nobody to talk to." (TR) (43:8)

"Not feeling happy there was no sister who came to dress my wound, the smell was bad and they did not stich the wound after the next operation. Not feeling well the whole day I have try to speak to another nurse and says that she will come to dress me soon she never came to me again."

"Not well I was sleep without any nurse to dress the wound I try to clean myself early morning by using hibitane pink in colour, ask the sister even that day never came to dress the wound." (TR) (58:42)

"Early morning still unhappy ask myself why me all of many people have bad luck I was have to deliver the baby normally unfortunately the cervix was too small must to go to operate after operation the bad luck against me they take out off my wound, starting to wipe my tears deep in my heart say why?why? me !!!" (TR) (58:47)

"Dr check my wound say it smell they will send me to theatre next days."

"No one came to dress the wound and when I sleep the fluid from the womb was on my baby's clothes, I ask myself "why me all the times?" (TR) (58:54)

Starting to remember when I was kalafong hospital when sometimes bad and sometimes good I was thinking after the first operation the following day I was lost the drip on my hand spend two day not giving me medication because of not having drip." (TR) (58:56)

"I didn't really know about the baby did I lose the baby how did I, was it a boy or a girl, what did she look like I only find out after some days that I had lost the baby cause I thought I had twins so I thought maybe I had at least one of the babies so I have remained with one I only find out later that the twins one of the sisters told me you don't have any babies at all, you lost your babies." (PG) (33:56)

"…They took my blood pressure, and they measured my stomach then they said you are 26 weeks, ok wasn't sure about my dates or the month, but the nurse measured my stomach and he shouted at me, why did you take so long to come to the clinic. Wara wara wara then he gave me, I think it was 8 weeks to go because I think I was supposed to go there when I was turning 32 weeks of which is the week I delivered here." (JM) (16:10)

"….so I was admitted there Monday and Tuesday and Wednesday they discharged they said my BP is now controlled and before they told me that if BP is not controlled, they are going to take out my baby, because this baby cannot give back to me, but I can give birth to another baby, then that thing disturbed my mind a lot." (JM) (16:15)

5.3.4 MENTAL HEALTH AFTERCARE EXPERIENCES

5.3.4.1 Positive experiences of interview

"Like what must I say like if I'm hearing my things deeply I can't cry in front of people I have to go somewhere and cry and tell myself things will be fine for me like now I can also share my things with you telling what happened to me and this and I feel better. Like me I feel better if you are available I can also call you and tell you I need help or I have a problem of this and that and sharing with you I feel better." (CS) (4:13)

"I just too when I came to this hospital, I speak to you, you listen you give me advice so with your advice I be strong." (EH) (7:15)

"I'm doing good ever since I found a person I can tell my story, the person who understand is only you, you are the only one who know my story ever since I'm talking to you telling you what happening I feel very better. I become better and try to move on forget the past to relax because of you are here for me and you are the one who understands I'm telling you I'm getting well." (CS) (2:33)

"The thing that makes help me is because of this someone I can talk to yes someone I can talk to who helped me understanding me." (CS) (4:14)

"They helped me a lot they helped me to see how ill I was because I couldn't see how ill I was before, yes Everyone was talking about my platelets went down I didn't even understand what that mean and what it meant for me yes." (EH) (7:6)

"It helped me in talking about my feelings because I never talked about my feelings before yes." (EH) (7:7)

"Before opening up was difficult because I didn't want people to see what was wrong in my life." (EH) (7:8)

"I don't know just having a lot of strength inside myself back then it wasn't like this I was always down I was not happy but now I 've seen a lot of change inside myself my confidence my self-esteem everything is just ok so I focus on a lot of things." (EH) (7:15)

"I don't like people judging me. I feel like when I talk to people they can judge me and I just don't like to talk about myself, yes." (JM) (14:2)

How to offer it to other women

"I think talking to them understanding their feelings I think that's it because a lot of people don't like to talk about themselves yes." (JM) (14:4)

"I think cultural thin and personal thing, because in our culture we don't talk that much about our feelings we just keep things inside." (JM) (16:4)

"It's not about the stigma I think so because it's about talking in general because when we grow up our parents don't talk to us they think that if they tell you about maybe getting pregnant then you'll go and do those things. They feel like they are the parent and you are the child- you don't supposed to ask them about those kind of things in our culture.

"I think it's best to talk about it because if they don't talk we don't know and you'll do those things you were supposed to tell you don't go there or you don't do that, yes

I was trying to help the best thing is that I've been talking to you most of the days and clear my head I talk to you like when I talk to you I feel so much better when I go home, someone came we talk but I used to avoid this topic when we started talking about the babies all over but when I talk about it now I think I get better." (EH) (7:12)

"Cause now I'm have somebody to explain my situation to and that in the past few months there was nobody that I can explain my situation so that things that was making me depression so I think now I'm getting much better because I can call out then when I come here and you are asking me how is your life now and I can tell you and I think now I'm having somebody who is understanding my situation who can help me so it helps me

"I mean like it was very hard 'cause I was holding so many things in my heart that is bothering me that it hurts me so now since I started to attend my therapy it helped me a lot cause I started to talk out and talking out all those things so it really helped me. "

" It helps me in the way of I started to realise that I must what kind of a person what life I must live because I must live for my children so I must take it all out all those grudges and the anger an move on with my life yes."

"Cause I was having this thing I was shy and like I was scared as I'm saying I was scared to talk to someone cause of I think maybe someone will judge me or think maybe I'm crazy. "I learned that when you talk to other people then the stress come out." (NN) (26:1)

"Because my mind refresh and then I also know everybody love me yes because if things that happen to me no one hates me no one I have to talk to anyone 'I'm going to talk to her it's because of you that thing you want to know I have to talk everything I have I my mind has helped me a lot." (RN) (38:6)

"Cause of that time I want to sit alone thinking thinking thinking alone I don't want to share with somebody maar after I talk to you everything in my mind I talk to you helped me that is why I say that thing conversation me and you has helped me a lot because after that in Rinah what's going on with her I tell you my problems 1, 2, 3." (RN) (38:7)

"I swear my God one day I talk to when I go home I tell my husband that woman I love her he said why because I say because that time I start to talk to her my mind was open, I have to talk everything I my mind I have to talk with her so that's why that thing he helped me survive a problem in my mind you know that pain of my baby is gone now I have to talk ja that's why." (RN) (38:8)

"The way I'm staying I'm being ok my heart is feeling better, cause I have someone to speak I didn't know I have someone else outside, I can speak with her but I don't know who is .I can talk to you I have someone to talk with and then heart opening and then I can relax. It's very difficult to find someone to speak to, so you keep inside, and if I keep it inside it hurts too much because if I'm staying everything is coming back I want to forgot, but to be with you, you've helped me, because sometimes I think I can die but oh my baby I have baby to think about." (LM) (23:8)

"They have to come and talk about things hurting them and they have to be free inside and outside you see because talking helping so much." (LM) (24:7)

"Because they don't have a clue like put how like sometimes maybe someone ne she can't talk about things is happening to her because maybe she is not free you see maybe she will take it.""" What is I can tell her she will tell me what you see and then she is afraid to tell you, you see and she is keeping inside because one day she will do things wrong you see they don't have to do things she have to open and she have to come and open to you." (EM) (12:6)

"It's because of you I'm talking to you and then you make me happy and then you make me open the feelings I have inside I don't want to keep things inside of me so I can open it to you so you helped me so much."

" It's like the people they have to pray to God to help but he won't help you if you don't help yourself so you have to help us yourself and ask to help us too and then he will help us because you see I remember that day I was coming here joh I was thinking I will die because my body my everything was so dead." (JM)(16:4)

"They have like sometimes I sit alone I feel like talking to someone, someone I don't know just to talk to and tell everything how I feel what's happening because I feel like the people I know they judge me they don't know why I do some of the things I do but they judge me so if I can get someone that's objective form outside maybe you tell me what to do you advise me better you won't judge what I say." (TSM) (49:9)

"Ja you know what because I didn't the past pregnancy I didn't have something someone to express how I am feeling asking me what's happening how you know that thing so now I see there is a lot of changes because I know that I'm preparing myself I'm going to see my doctor and tell her everything." (PM) (32:3)

"Some people can't expose whatever they are feeling, you know it's difficult sometimes you can say you need to I mean some people can expose what they are feeling. Tell what is happening what's happening what's wrong some they can't but I think its best maybe you can push harder and just try to talk to them people this is to keep quiet is not right. It helped me even for myself because I can deal with my problems like my husband when he was drunk I can deal with him." (EM) (12:6)

"By talking to me to be more comfortable in my own zone because I wasn't no comfort there because I had low self-esteem the talking really make me see that life has more to offer like focusing on the negative things I have to accept myself." (TSM) (49:4)

"You have to talk with someone and that thing you go in your mind and you refresh your mind nice." (RN)

"I've gained a lot of confidence so I'm no longer shy about open up my problems to my family so I am more changed I'm no longer that sad I'm happy so but the time I came here I wasn't sure I was facing a lot of problems not thinking straight."

" I was thinking who was going to help me maybe I should stay home and not go to school but speaking to you really opened up my mind and set my mind free so I could talk to my family, so it really helped me a lot and I'm thanking you for that."(TSM)

5.3.4.2 Negative aftercare experiences

When PG was contacted telephonically to remind her about her follow-up, her response was that she was trying to rebuild her life and put the unfortunate incident behind her and by attending the appointment and talking about her feelings would just open up a wound that she was trying to heal. She felt that she would deal with her emotions and feelings in her own way and on her own time and terms.

"Ja I think because I was also part of that women and I didn't know I'm having a problem it can be solved so I think there are many women

"According to my experience when you are in that situation you been you are confused and you don't know like who you can go to or who can help you and sometimes you feel like when you are telling somebody your problems maybe they will laugh for laugh after you and then so you keep those things on you and then it's starting to hurt you." (TSM) (50:9)

"And then getting depression its hard doctor to come up front and then you say I'm having this problem it's very hard I think maybe if I wasn't come for delivery here I wasn't going to know how it is going to affect my health this thing." (JM) (13:6)

"Cause I was having this thing I was shy and like I was scared as I'm saying I was scared to talk to someone cause of I think maybe someone will judge me or think maybe I'm crazy. "No, at first there was difficulty, for the past the 2 months they were very difficult, because even myself, I couldn't share my stress with anyone, I was always angry, impatient, crying, I couldn't share with any one." (JM) (13:15)

"I'm not sure, maybe I was confused, and maybe I don't know who to share it with." (JM) (13:9)

"I took the drugs because it makes me feel better I felt better when I taken it I treated the problems that I had." (VM) (51:7)

"Didn't want to write in the diary because I didn't want to think about my problems every time I had to write I had to think about them but I did write I did actually write and it makes me want to deal with my problems. I did know I found out I was pregnant a long time before but I was afraid I was taking drugs so I thought maybe the drugs had killed the baby so there is a lot of things like even the drugs I told you I wasn't honest with you." (VM) (51:9)

"Right now they have their own problems and they got their own children to look after I have nobody to complain to, but with my problems I like to keep things within myself I don't like talking a lot I don't like telling my problems to other people even friends. It's just the person I am I cannot open up to anyone. No I haven't asked for help because if I ask for help it seems like I'm bothering them. I don't want to bother other people" (TSM) (48:7)

"No don't call her I can carry this on by myself the woman sometimes is scared to go to talk to somebody to talk about my problems it's the way I am I just tell myself I don't want to talk it's my problem but now I see myself I kill myself I must talk to take out that thing they said you can't carry this problems you see your situation, I said no I want to talk about this other things to refresh my mind." (RN) (36:4)

"I coped very well but just another but I just tell myself it's my problem I don't know what to give another somebody my problem, but you never cope very well really." (RN) (36:6)

Unanswered questions

"*I still have more questions in my mind and I need answers like*

Last time `I was still sad I wasn't coping I wasn't doing anything crying too much and then think now I'm not crying anymore so I'm better and then I see someone with a baby I won't cry." (YK)

"Am worried about the menstruate if and sexular change I become more stressed it is only a month but you can feel it; *y I play with the child also.";(CS)*

5.3.5 ACCEPTANCE

Women who had both negative and positive experiences in pregnancy there was a strong sense of acceptance in spite of all the challenges they experienced.

"It means I will no longer have babies in my life" (TR) (45:11)

"It's very sad but it was to save my life" (PM) (34:8)

"My future I will have to get a job and take good care of my kids and forget about this operation because it's not me alone that I have this operation." (CS)(2:29)

"Like I'm just telling myself that `I have to counsel myself before because I used to counsel some of the people telling me the things that they do like or they don't like and then why me should I counsel myself and tell myself that those things are past you see even my operation I don't blame myself to do that now I'm ok because of I've got kids and then like I've got kids and that thing now it's fine my operation is fine like it's only the scar its bad but I'm also telling myself that I will be ok yes." (CS) (4:11)

"*I just accept being diagnosed with HIV and continue to live a s a normal person." I feel sad but there is nothing I can do I have to be strong to continue to be a live person it's just that I have to take care of it."* (SN) (39:5)

"I just think what if I lost my baby.

"I just say to myself God loves me that is why I'm still alive He still have a hope for me so what make me happy." (TR) (45:5)

"I think that maybe this one my son grow up then came to adopt another child." (TR) (45:7)

"Right now…I'm coping because last time I was scared I was going to die I was going to bleed on my brain but right now I think I'm coping a little better. I understand what it means to have this ya, this sickness; I think I'm doing better than the last time

baby I want to go back to my baby I want to be well this time around because last time I think I want to go home I didn't care what was happening." (EH) (8:6)

"It helps me, it gives me strength these days yes to cope with being sick yes." (EH) (8:8)

"When I look back I feel like I've grown a lot because in the last six months before I didn't understand my illness and what was happening and what but for now I'm adjusting to it yes." (EH) (7:3)

"Now I'm feel right and then I hope one day one day I will be pregnant again and I will find the baby." (RN) (36:6)

"Eish it's like as a mother I told myself that I have 2 children I have to accept that and move on with life because always if I panic it will affect you and I won't have time to take care of my child." (TSM) (50:1)

"I just accept and continue to live normal as a person." (LM) (23:4)

It affected me at that time but after I come to be strong, I feel sad but there is nothing that I can do I have to be strong to continue to be a live person it's just I have to take care of it." (LM) (23:6)

"I was cry but now I not cry again I just feeling I just think everything will be ok one day because if I just cry I feel that time I was crying too much I have a problem for me, but now I don't want to cry again, yes I see one day everything will be fine." (YK) (53:19)

"Last time I was still sad I wasn't coping I wasn't doing anything crying too much and then think now I'm not crying anymore so I'm better and then I see someone with a baby I won't cry I play with the child also." (YK) (54:3)

"It's not easy but it's no worse than the same if you are a woman you have to be strong so I'm trying to be strong the way my mother told me they always say you have to be strong if you are a woman." (YK) (53:18)

"I'm doing fine and ja I start getting at least better I want to go back to work last time I got doing nothing I've losing hope of myself but for now I think ja and I realise the I have another baby so I can't let down myself." (YK) (54:5)

"At that time I started to I'm pregnant they ask can they book me I tell them wait I talk to my husband first and then after the next months I go to the clinic and they admit me and I see it's not only me that is over age and I just tell myself there is nothing I can do I must carry on with my pregnancy and I start to be happy now life go, just like that and I have to carry on it's a gift from God nothing I can do." (TDM) (41:4)

"Right now I wanted to do maybe some course I want to support my children I don't like it my mom helps me a lot I want many things and people my age have all like have some of those things and I have nothing because sometimes I'm so stressed I can't cope when I think of people I go to school with and I think of my situation right now I'm so behind that I don't know how I'm going to achieve the level where they are now" (VM) (52:5)

5.3.6 THE WILL TO SURVIVE

"I open the business." (LM) (24:1)

"That day I was talking with you here that day I was telling you I want to change my life thinking go back to school and then maybe I can read learn to read, because it is difficult for me if someone else say take this book and read for me an then how I can tell her I can't read. They will go to school come with their homework mama please help me this and then they come to and I have to help, me I have to help

"Because it's difficult I see many people they age like me they go to school reading working proper work but me I'm just only stay I for accept everything its happening to me because sometimes maybe I want to take a book to read but I don't know where I can start." (LM) (24:2)

"I have to do something about it because God want to see me what I'm going to do I need to help myself first before God helps you." (LM) (24:12)

"I want to be fine and then I want to work for my children yes I want to give them the support I don't want them to grow up like me" (CS) (4:18)

"I sit down and then ask God why why this things happening to me but when I must ask him like I must ask something like everything is going to be ok it's not everything will be ok with you everything is not perfect it can go wrong it can be right" (LM) (21:22)

Anything I said its ok its fine because I don't have anywhere I can go so I have to stay there with her. I have to accept things happening to me because I don't have anybody.

Like I say if something's happened to me I can't talk with my mother I can't talk to my family because they doesn't care." (LM) (21:20)

"I'm just thinking if I can get money any support I want to learn something after to learn is better I can learn." (PYM) (29:9)

"Walking into a mall not being able to buy my children clothes just breaks my heart since well my boyfriend who always come through to support the children financial, but I know that one day thing are going to be okay it just for time being. Life has its ups and down am learn it will all pass." (TSM) (50:4)

"God is great, thank him for so much he has done for me and my family I cannot complain much about life, my life has changed so much am back at school which is great cause it been in my blood and heart I love what I am studying for I wanna be proud of myself." (TSM) (57:6)

"I am no longer worried or stressed. I just accept whatever that life throughs at me." (TSM) (57:9)

"I'm doing fine and ja I start getting at least better I want to go back to work last time I got doing nothing I've losing hope of myself but for now I think ja and I realize that I have another baby so I can't let myself down." (YK) (54:7)

Women from both groups who had positive and negative experiences had strong religious conviction in spite of all their tribulations.

5.3.7 FAITH

Another aspect that was prominent during the review of these narratives was the strong religious conviction of the women in spite of everything that happened in their lives.

"When I look at my baby I just think some other women don't have baby so God blessed me with this child.

"They have to accept that the baby they have and thank God to make her alive and the baby self." (TR) (45:5)

"No I don't blame God I never blame God for anything that is happening in my life God is not punishing me it's just an obstacle that we have to meet along the way through life they will pass." (TSM) (48:9)

"I've told myself that you know what I'm alone I said god you are with me always so you have to give me power to move on." (LM) (24:9)

"I told myself God loves me some people lost their lives because of damage womb I am lucky I'm still alive and going to take care of my child." (TR) (44:9)

"It is because I pray God and then I see that he can help many things that I achieve because as long as I pray I see many differences is happening to me." (PYM) (28:9)

"I'll say praying I've learnt to pray. It helps me, it gives me strength these days yes to cope with being sick yes." (EH) (8:10)

"God knows our life (PYM)(28:12)

"Sometimes I'm stressing but I don't have a choice."

"I just thinking my husband is not working and now me I'm also not working whether I will survive I will get the support from somewhere what my family or what that's what I'm thinking but I know one day everything will be all right."

"I believe because I know it's not the first time the first time, the last time my husband he was not working I was not working that we have the one baby but it will be so maybe we survive." (PYM) (32:2)

"Myself inside I'm feeling pain but this pain I can't just show everybody I'm suffering like this that only God knows our life, God is knowing what is going on with my life but I know I believe one day god is going to help me, it is a period that is going to pass.

But the words now is the first thing I can see is God because those people they coming to see me is God that just send them." (PYM) (30:1)

"At the time I just tell myself if the baby to come is to come into the world that thing is a blessing from God there is nothing I can do I just tell myself I will love that baby like it or not it's my child and it's a gift from God." (TDM) (42:10)

"I just pray all the time form the night to the day I just pray all the time, I tell my God all my problems I don't like that life inside my house and sometimes I feel angry.

"I just tell myself everything I give to God and pray its God that knows everything I know nothing and its God that is giving me that heavy thing they want to see me how I am strong

"I just tell myself this thing I just give to God to help me and I'm going to help myself." (TDM) (42:14)

"For now I don't know in future for now everything is fine the happiest thing is that I'll be able to go to church because I was not able to go to church, my three months are over." (JOS) (19:7)

"Myself inside I'm feeling pain but this pain I can't just show everybody I'm suffering like this that only God knows our life, God is knowing what is going on with my life but I know I believe one day god is going to help me, it is a period that is going to pass." (YK) (53:17)

"If I can shout or if I can cry and sometimes I don't want to talk to somebody I said to be angry at the end that thing is gone I can be angry, I want to talk if I can do something wrong I come to you if we can discuss that thing they come outside my mind but if we never talk to each other about that thing is all the time on my mind." (CS) (4:10)

"I'm always praying thank God that I'm alive and I say thanks to him millions and millions." (CS) (2:27)

"The baby with Downs syndrome at the beginning I ask myself at the beginning I said this kind of baby I'm going to live with this at the beginning that time I was sick at the hospital but since I go home I tell myself it's a gift from God yes I just tell myself I love that baby a lot a lot I can stop everything about that baby." (TDM) (42:8)

"Even though I don't have the money I know that one day God is going to help me." (TSM) (48:9)

"When I lose my baby whoo that day I say it's my last last life, but today I know this is God." (RN) (35:6)

"O God is everything I did God I trust my saviour I think I think to be here is Gods making to breathe that's why I did manage to be here but I think its God."

I pray every day to say my God help me I have to find another baby my child, that one was not mine, it was Gods." (RN) (36:7)

"I said what happened to me my husband says no God knows everything you don't know you don't know anything. God know everything I ask are you sure he said I'm sure but then I said ok every day when I sleep I'm wake up I have to pray then after that my God answer me."

"When I sit with my husband every time I sit with they have told me R you have to be patient you that thing is not it's not the first time for you in other people they do the same, it happened also so you have to be patient and one day you going to be, the God will answer you, I know my God will answer me." (RN) (37:1)

During the second stage of recruitment a year later, at the secondary hospital, RN came up to me and shared her happiness.

"You say to that time I told you that I leave it everything to God see today God helped me for a lot of things I know if everything you pray God I pray for you everything is happy everything." (RN) (38:3)

5.3.8 PSYCHIATRIC-RELATED SYMPTOMS

Anger

"If I can shout or if I can cry and sometimes I don't want to talk to somebody I said to be angry at the end that thing is gone I can be angry." (YK) (54:9)

Depressive symptoms

"I also lost my mind I afraid to tell my boyfriend that I don't have womb. I told my family but am weak, I can't do anything I can't wash, I can't clean and I can't hold my little son." (CS) (4:5)

Psychotic symptoms and aggression

"*Am losing weight I can't sleep at night I have to get some pill to sleep*

"my voice is gone I can't call anyone; I f I make noise no one can hear me, I do have some holes in my operation. I remember when I was in ICU the was a lady came next to me, telling me that I'm in ICU, then she wash me, that time I didn't know that I do have a child"

"As time goes on I thought I was kidnaped me and my son, I started fight with the doctors telling them that, they took me somewhere. I want to go home, I started taking out drips on my hands when I realize that I was in ICU;I start telling myself that I must start fighting for my life and get out of ICU because many people are dying there." (CS) (4:13)

"Am not happy with myself I have gained a lot of weight ever since, I have lost confidence in myself, am no longer the person I used to am angry for myself because I have let myself down I always look down on myself I don't appreciate myself can't even look at myself at the mirror. I haven't really come into terms with really accepting myself." (EH) (5:22)

"I really don't care what people really say or think of me 'cause what they say or think of me won't harm and won't stop me from living my life. I want my children to grow up being happy." (TSM)

"And also my mind it was lost. Yes I was lost I thought even I was not in Kalafong, I be somewhere and they steal my baby then somebody came I don't know which who that person was but he she told me that your baby is fine and you have to accept that you are in Kalafong then you had an operation you were in ICU there and that." (CS)(3:2)

5.4 SUMMARY

Prominent themes that were identified included feelings of inadequacy and guilt, fear, uncertainty about the future, and frustration, not only with regard to the participants' physical condition, but also about their psychosocial circumstances. For women who had lost their pregnancies, there were feelings of sadness, loss, anguish, as well as ambivalence about their role as women and their future. Abandonment and rejection by their partners' lack of support, as well as financial and relationship stressors were also identified. The most prominent theme identified in the majority of cases was that of the strong religious convictions about the role of God in their lives and their circumstances. Also very prominent was the absence of feelings of punishment of God and the acceptance of the adversity in their lives.

SECTION 3

"NARRATIVES, PSYCHIATRIC SEQUELAE AND INTERGRATION"

In this section:

Chapter 6: Discussion of findings of the quantitative arm

Chapter 7: Discussion of findings of the qualitative arm

Chapter 8: Integration of findings

6 DISCUSSION OF THE FINDINGS OF THE QUANTITATIVE ARM OF THE STUDY

6.1 INTRODUCTION

Pregnancy and childbirth represent a time when women are vulnerable to developing psychiatric disorders. (Stocky and Lynch 2000) These disorders could present as a significant public health problem as they are not only associated with mortality and morbidity in women, but also with increased morbidity in their children. (Stuart et al 1998) Hormonal fluctuations that occur during the perinatal period are thought to predispose women to the development of psychiatric conditions, whilst psychological, socio-environmental and cultural factors have also been identified as risk factors that can influence disease expression. (Filippi et al 2007) There is growing evidence that high levels of maternal stress as well as psychosocial stress can affect not only maternal and foetal health, but the health of the growing child too.

Research pertaining to the prevalence, risk factors, treatment and complications of psychiatric disorders that develop in the peripartum period increased during the 20th century, but there are limited studies available at present that investigate whether life-threatening or maternal near-miss complications during pregnancy or delivery can predispose women to developing psychiatric complications. This makes it difficult to compare or contrast results. (Filippi et al 2007)

The participants in the present study included women who had experienced life-threatening stressors during pregnancy and women who had uneventful pregnancies. The women with life-threatening stressors were identified and recruited if they met the WHO criteria for a near-miss event, which include a diagnosis of preeclampsia, eclampsia, obstetric haemorrhage or septicaemia. As mentioned previously, these women were interviewed shortly after delivery, then at six weeks, three months and six months post-delivery. Relevant psychiatric scales were completed at each interview to establish whether these participants developed psychiatric sequelae in the postpartum period.

6.2 SOCIO- DEMOGRAPHIC RISK FACTORS THAT COULD PREDISPOSE THE DEVELOPMENT OF POSTPARTUM PSYCHIATRIC CONDITIONS AS IDENTIFIED IN STUDY PARTICIPANTS

A total of 89 women were recruited for the present study, of whom 46 had experienced a life-threatening event in pregnancy and 43 had uneventful pregnancies.

More than two thirds of the participants were between the ages of 21 and 35 years, (Table 1, Age distribution of study participants, page 105) with a third of the participants reporting that they were married. (Table 3, Relationship status, page 106) Almost a third of the participants had matriculated (Table 4, Level of education, page 107) and a similar proportion was employed. (Table 5, Employment status, page 107) Furthermore, a third of the participants lived in informal settlements (Table 6, Living circumstances, page 108) with basic amenities (Table 7, Amenities, page 108).

More than 71% of the pregnancies were unplanned, and more than 15% reported that the pregnancy was unwanted as well. Almost a third of the women who experienced life-threatening complications experienced a foetal demise. (Table 8, Obstetric history, page 109)

Approximately 13% of the participants reported not attending any antenatal care, (Table 9, Antenatal care attendance, page 110) with a fifth of the participants reporting that they were uninformed about the signs of potential pregnancy complications. (Table 11, Information pertaining to potential pregnancy complications, page 111) Furthermore, 71.9% of subjects intended to have a future pregnancy, (Table 12, Future pregnancy intention, page 112) 42% of the participants intended to use the injectable contraceptive. (Table 13, Contraceptive methods, page 112) Approximately a fifth of the participants were HIV-positive at the first interview (Table 14, Medical history, page 113) 12 % of subjects received treatment for a psychiatric illness previously. (Table 15, Psychiatric history, page 114)

Ninety-one percent of participants were from the lower socio-economic strata, and a quarter of the participants were immigrants from other countries in Africa. Almost a fifth were women who experienced life-threatening complications during pregnancy. The present study was conducted during a turbulent time in South African politics when there were xenophobic attacks against non-South Africans. The problems this posed were relayed through telephonic contact with some women, or their partners, who, when informed about the follow-up appointments, explained the difficulties they experienced.

The aforementioned variables have previously been described in the literature as significant risk factors that can predispose women to developing postpartum depression. These include being from low-socio-economic strata, being of an ethnic minority, young age of pregnancy, unplanned pregnancy, unemployment, gestational diabetes, infants with congenital abnormalities, and an existing psychiatric history or a family history of psychiatric conditions. (Warner, Appleby, Whitton and Faragher 1996; Kozhimannil, Pereira and Harlow 2009; Rona, Smeeton, Beech Barnett and Sharland 1998; Brugha, Sharp, Cooper, Weisender, Britto, Shinkwin et al 1998)

Immigration has also been identified in some studies to be a significant risk factor for developing depression depending on the differences between the original and new cultures as well as the circumstances that resulted in the immigration. (Zelkowitz and Milet 1995; Danaci, Dinc, Deveci, Sen and Icelli 2002; Dankner, Goldberg, Fisch and Crum 2000; Glasser, Barell, Shoham and Hart 1998; Dennis, Janssen and Singer 2004) Whilst some studies describe obstetric complications that can precipitate life-threatening complications such as preeclampsia, eclampsia, to be modest but significant risk factors for developing postpartum depression, this was not confirmed in other studies. (Warner 1996; Boyce and Todd 1992; Nielsen Forman, Videbech, Hedegaard, Dalby Salvig, and Secher 2000; McCoy, Beal, Saunders, Hill, Payton and Watson 2008)

6.3 PSYCHIATRIC SEQUELAE IDENTIFIED IN STUDY PARTICIPANTS

6.3.1 Postpartum depression

Despite the presence of the aforementioned risk factors, only a quarter of the total study participants, reported mild to severe depressive symptoms that met the criteria for depressive disorder at delivery (Table 19a, Figure 2, Depressive symptoms, pages 122&123). More than 63.6% (n=14) of the sample who experienced depressive symptoms was women who experienced life-threatening stressors. When the two groups of women namely those with life-threatening stressors and those with uneventful pregnancies were compared then approximately a third (30.4%) of women who had life-threatening complications presented with symptoms of depression, whilst 18.6% of women with uneventful pregnancies presented with mild to severe symptoms at delivery (p=0,196) (OR 1.91 for women with life-threatening complications at 95% CI)

The rate of women experiencing depression almost doubled at six weeks, with 49.1% (n=26) of the women reporting significant depressive symptoms that warranted completion of the Level 2 questionnaire. Seventy-three percent of the sample was women who experienced a life-threatening stressor during pregnancy. When the two groups are compared, then 65.5% of women with life-threatening complications experienced mild to severe symptoms of depression whilst 29.2% with uneventful pregnancies experienced symptoms. (p-value=0.08) (OR of 4.91 for women with life-threatening complications). At three months, the number of women experiencing symptoms decreased to 37.5% (n=12), with the largest proportion of women who experienced symptoms (83.3%) being women who had a life-threatening complication. Within the two groups, 47.6% of women with life-threatening stressors continued to experience symptoms as compared to 18.2% of women with uneventful pregnancies. (p=0.102) (OR of 4.09 for women with life-threatening complications.)

At six months 15% of women presented with residual symptoms of depression with approximately two-thirds being women with life-threatening complications. Within the individual groups, 16.7% of women with complications were symptomatic whilst 12.5% of women with uneventful pregnancies experienced residual symptoms. (p=0.798) (OR of 1.40 for women with life-threatening complications, 95% CI)

As indicated previously, the participants in the present study presented with significant risk factors that could predispose them to developing postpartum depression. It was further hypothesized that the rates of depression in women with life-threatening complications would be higher, depressive symptoms more severe and present for a longer duration than women with uneventful pregnancies. The rates of depression found in the present study were higher than the wide range of rates of postnatal depression in women from developing countries, which are found to be between 16 and 35%. Within the individual groups however, the rates of depression in women with life-threatening complications was double that of women with uneventful pregnancies at delivery and almost four time that at the six-week follow-up. Although bereavement could not be excluded in women who experienced a foetal loss, the symptoms they experienced were not only about mourning the loss of an infant. These women experienced neuro-vegetative symptom changes, cognitive and memory deficits as well as impairments in functioning that were suggestive of a depressive syndrome. Therefore, distinguishing between bereavement and major depressive disorder is rather difficult to elucidate in clinical settings.

The above results confirm the hypothesis that women who experience life-threatening complications experience more depressive symptoms than women with uneventful pregnancies. However, the duration and intensity of symptoms, including the levels of impairment, were not sustained for a significant period. This could indicate that the illness presentation in these participants involves a complex interplay of not only biological processes but also psychological, socio-cultural and religious factors. These factors can therefore not only exacerbate the condition but also attenuate symptom presentation.

An alternative explanation could be that the presentation and resolution of depressive symptoms could have been part of an adjustment disorder with depressed mood that did not cause impairment for a significant portion of time during the postpartum period.

Varying prevalence estimates have been described in different regions of the world and range between 7.6% and 39%. (Sword, Landy, Thabane, Watt, Krueger, Farina et al. 2011; Breese McCoy, Beal, Saunders, Hill, Payton and Watson 2008; Chaaya, Campbell, El Kak, Shaar, Harb and Kaddour 2002; Gonidakis, Rabavilas, Varsou, Kreatsa and Christodoulou. 2008) Furthermore, studies have shown that depressive symptoms decrease steadily over time. (Rahman and Creed 2010) O'Hara et al. (1984) who followed 99 women from the second trimester to six months postpartum, found that less than 12% of the subjects were in the mildly depressed range at nine-week and six-month follow-up visits.

A study by Campbell and Cohn followed 70 women who met the criteria for depression at two months postpartum, and found that at four months, 48% continued to be depressed, whilst at six months, 30% and at 12 months, 24% continued to experience depressive symptoms. (Campbell and Cohn 1997) Furthermore, a study by an Australian cohort that followed women from early pregnancy up to five years after birth suggested that the symptoms did not continue after a few weeks in the majority of women who experienced postpartum depression. (Najman, Andersen, Bor, Callaghan and Williams 2000) However, Beeghy et al. (2002) followed 106 women with high depression scores at two months post-delivery and found that 35 and 31% of the women continued to have high scores at 6 and 12 months respectively, whilst Rubertsson et al. (2005) who followed a national cohort of Swedish women, found that 24% of women continued to have high depressive scores up to one year postpartum.

A large-cohort study in the Netherlands identified that various complications during pregnancy can predict postpartum depression in women two months after delivery.

The researchers found that women who experienced more than two perinatal complications are at high risk for developing postpartum depression. (Blom, Jansen, Verhulst, Hofman A Raat, H., Jaddoe et al. 2010) Another study of 1 095 women conducted in the United States found that women with severe complications of pregnancy were significantly more likely to experience postpartum depression than those without a complication. (Burger, Horwitz, Forsyth, Leventhal and Leaf 1993) Furthermore, an Australian study reported that surgical and instrumental deliveries placed women at risk for developing depression. Another Australian study by Johnstone et al. identified obstetric factors that can predispose life-threatening events like preeclampsia to be associated with developing postpartum depression.

The variables, however, did not remain significant when entered into a hierarchical logistic regression model. (Astbury, Brown, Lumley and Small 1994; Johnstone, Boyce, Hickey, Morris-Yatees and Harris 2001) Furthermore, a study by Benute et al (2010) found an unplanned pregnancy to be an independent risk factor associated with major depression during pregnancy in women with medical disorders. The authors postulated that the concomitant occurrence of a medical disorder and an unplanned pregnancy could cause stress in women, especially those from the lower socio-economic group.

In summary, only a quarter of the study participants presented with symptoms of a depressive disorder at delivery and this figure doubled at the six-week follow-up (49.1%). The depressive symptoms however, were not enduring and resolved during the subsequent three and six-month appointments respectively. An important finding in this study is that the rates of depression in women who experienced life-threatening complications were higher than the prevalence rates described in the literature of women who experience depression during the peri-natal period in developing countries. The rates of depression fell within the prevalence rates described in the literature at the six-month follow-up. The results confirm the hypothesis that women with life-threatening complications experience more depressive symptoms than women with uneventful pregnancies. However, the duration as well as intensity of symptoms including the levels of impairment was not sustained for a significant period in both women with life-threatening complications and those with uneventful pregnancies.

6.3.2 Anxiety disorders

Approximately 19% of the participants in the current study presented with symptoms of anxiety at delivery, with 82% of the sample being women who had experienced life-threatening stressors.

Within the individual groups, approximately a third of the women (30.4%) who had a life-threatening event and 7% of women with uncomplicated pregnancies presented with symptoms of anxiety at delivery. (p=0,005) (Table 19c, Figure 4, Anxiety symptoms, pages 127&128). The total number of women who experienced symptoms at six weeks increased to 39.6% and more than three-quarters of the sample represented women with life-threatening complications.

Significant differences with regard to symptom presentation were found between the two groups of women, with 55.2% of women with complications and 20.8% of women who had uneventful pregnancies presenting with symptoms at six weeks (p= 0,011). The number of women who continued to experience anxiety symptoms decreased to 34.4% at three months and more than 80% of the group were women who had a life-threatening complication. Within the individual groups, 42.9% of the women who experienced life-threatening complications continued to experience symptoms of anxiety as compared to 18.2% of women with uncomplicated pregnancies (p=0.163). At six months, 10% of the participants had residual anxiety symptoms with 8.3% of women within the life-threatening group and 12.5% of women with uncomplicated pregnancies experiencing residual symptoms (p=0.761). Only 2.2% of the subjects reported experiencing some intrusive thoughts at the six-week follow-up. However, these symptoms did not fulfil criteria for an obsessive-compulsive disorder and there were no symptoms elicited in any of the participants who followed up at three and six months.

The women from both groups experienced anxiety symptoms that were present at delivery, reached a peak at six weeks and the symptoms decreased at the three and six months visit. The women with the life-threatening stressors experienced greater distress than the women with uncomplicated pregnancies.

It is possible that they may have experienced acute stress symptoms, which could have resolved in the postpartum period similar to what Souza et al. (2009) described in their sample of women in Brazil who experienced near-miss pregnancies, but who did not fulfil criteria for PTSD.

They suggested that the symptoms could potentially represent an acute stress disorder, which resolved during the postpartum period. The women in the present study who followed up at the six-month period did not present with symptoms of reliving, intrusive thought, nightmares that were suggestive of a post-traumatic stress disorder. It is possible that although participants experienced stressful situations during pregnancy or delivery, including life-threatening stressors that threatened their wellbeing to an extent that they developed significant anxiety symptoms, the symptoms did not reach a threshold that fulfilled the criteria for post-traumatic stress disorder. This diagnosis however, cannot be confirmed in view of the attrition rate of study participants. Another condition that could be considered in view of the severity and duration of symptoms is an adjustment disorder, with both depressed mood and comorbid anxiety symptoms, as both the anxiety and depressive symptoms showed a similar trend in that symptoms were present at the time of delivery, reached a peak at six weeks and subsequently decreased and resolved in the months that followed.

A similar finding was reported by Matthey et al (2003) who found that in a group of 216 postpartum women at six weeks, 25.9% met criteria for depressive or anxiety disorders that included panic, phobia and acute adjustment disorder with anxiety.

The rate of anxiety disorders in women who experienced life-threatening complications in the present study differed significantly from those women who had uneventful pregnancies at six weeks and three months. The rates of anxiety in the women with life-threatening complications were higher than the prevalence rates described in the literature for women with uncomplicated pregnancies. Global prevalence estimates for perinatal anxiety disorders like depressive disorders vary according to region. Prevalence rates in developed countries range between 4 and 39%, and those found in developing countries range between 15 and 39%. (Mota, Cox, Enns, Calhoun, and Sareen 2008) Literature on anxiety disorders describes a chronic course that fluctuates in intensity and degree of impairment over the peri-natal period. Although a major risk factor for perinatal anxiety disorders is a previous history of anxiety disorders, studies on perinatal anxiety disorders are mixed and inconclusive. (Wenzel and Stuart 2011) A large screening study found that 66% of women with major depression in the postpartum period were found to have comorbid anxiety disorders. (Wisner, Sit, McShea, Rizzo, Zoretich, Hughes et al. 2013)

Although pregnancy can be a source of stress and anxiety in women with a normal, low-risk pregnancy, it can be more stressful and anxiety provoking in women who are experiencing difficulties in their pregnancies. (Besser, Priel, Flett and Wiznitzer 2007)

A number of studies have indicated that maternal prenatal anxiety is associated with adverse pregnancy outcomes including miscarriage, preeclampsia, preterm delivery and low birth weight, whilst as mentioned previously, anxiety in pregnancy is found to be a strong predictor for postnatal depression. (Kofman 2002; Mulder, Robles de Medina, Huizink, Van den Bergh, Buitelaar and Visser 2002; Schneider, Moore, Kraemer, Roberts and DeJesus 2002; Wadhwa, Glynn, Hobel, Garite, Porto, Chicz-DeMet A. et al. 2002) There are, however, limited studies to date that have assessed the prevalence of anxiety disorders among women who experience life-threatening medical complications during pregnancy. (Fairbrother, Young, Zhang, Janssen and Atony. 2017) Thiagyson and colleagues reported a prevalence of 12.5% of anxiety disorders during a medically high-risk pregnancy, but their study only included a limited number of anxiety disorders. (2013)

The relative risk for an anxiety disorder in women with a medically moderate- or high-risk pregnancy was found to be five to seven times greater than in women with low-risk pregnancies, as it is considered that the stress of experiencing medical problems increases the risk of developing anxiety disorders in vulnerable women. (Fairbrother, Young, Zhang, Janssen and Atony 2017)

The findings of the present study did not confirm the results of a study by Engelhard (2002) as well as an increasing number of studies in the literature that have recently described post-traumatic stress disorders (PTSD) in women who experience a medically high-risk pregnancy. (Simon 1992) A Brazilian study by Henrique and colleagues (2015) found that 9.4% of women who delivered in a foetal high-risk hospital experienced PTSD at six to eight weeks postpartum. Shlomi Polachek et al (2016) found a prevalence of 7.9% of PTSD at one month postpartum in their sample of women. Baeuquier-Maccotta and colleagues (2016) found the prevalence of PTSD during pregnancy in mothers with specific medical risk to range between 12.5 and 22%. A systematic review of the association between women experiencing severe maternal morbidity during labour, at the time of giving birth or within the first week following birth, and the development of post-traumatic stress disorder was explored by Furuta et al. (2012) They concluded that the available evidence pertaining to the relationship between maternal morbidity and post-traumatic stress disorders (PTSD) or post-traumatic stress symptoms (PTS) was inconsistent and varied between studies, with the relationship possibly mediated by other factors such as foetal and neonatal conditions.

They also reported that no robust evidence existed to indicate if there was a direct relationship between severe maternal morbidity and PTSD/PTS symptoms after controlling for variables like mode of delivery, or pre-existing psychological morbidity.

The authors further found no evidence to determine whether the type of severe maternal morbidity affected the relationship between severe maternal morbidity and PTS/ PTSD symptoms.

In summary, approximately 19% of the total study participants presented with symptoms of a generalized anxiety disorder at delivery. This figure increased to 39.6% of participants who experienced symptoms of anxiety at the six-week follow up. However, the anxiety symptoms that women experienced decreased during the subsequent appointments with only 10% of women having residual symptoms at six months. An important finding in the study is that when the two groups, namely those with life-threatening complications and those with uneventful pregnancies were compared, then approximately a third of the women (30.4%) who had a life-threatening complication and 7% of women with uncomplicated pregnancies presented with symptoms of anxiety at delivery.

The significant differences between the two groups with regard to symptom presentation remained at the six-week follow-up, with 55.2% of women with life-threatening complications and 20.8% of women with uncomplicated pregnancies experiencing symptoms of anxiety.

Both anxiety and depressive symptoms showed a similar trend in that symptoms were present at the time of delivery, reached a peak at six weeks and subsequently decreased and resolved in the months that followed. In view of the severity and duration of symptoms an adjustment disorder with both depressed mood and comorbid anxiety symptoms could be considered.

Furthermore, the women presented with anxiety symptoms that were severe at delivery and at six weeks but decreased at the three and six-month period. The symptoms were more pronounced in women who had life-threatening complications. It is possible that these women presented with acute stress symptoms that improved in the subsequent months during the postpartum period. Also, of the women with life-threatening stressors who followed up at six months did not present with significant symptoms that fulfilled criteria for a post-traumatic stress disorder. It may be, that although the participants experienced stressful situations during pregnancy or delivery, including life-threatening stressors that threatened their wellbeing, the symptoms did not reach a threshold that fulfilled the criteria for post-traumatic stress disorder. This condition could however not be confirmed in view of the attrition of study subjects. However, information obtained during the qualitative analysis could indicate that other factors may have played a role in limiting symptom presentation.

This possibility is explored in the subsequent chapter when integration of the qualitative and quantitative results is explored.

6.3.3 Psychotic and manic symptoms

In the present study, 4.5% (Table 19h, Figure 9, Psychotic symptoms, page137 &138) of the participants presented with psychotic symptoms and 2.2% (Table 19b, Figure 3 Manic symptoms, pages124&125) presented with manic symptoms, which occurred in the immediate postpartum period. With regard to the manic symptoms, 2.2% of women with life-threatening complications and 2.3% of women with uncomplicated pregnancies presented with symptoms at the initial interview. (p=0.962) Approximately 6% of women presented with manic symptoms at the six-week follow-up.

When the two groups are compared then, 3.4% of women with life-threatening complications and 8.3% of women with uneventful pregnancies presented with symptoms respectively. (p=0.444) The women with uneventful pregnancies who presented with manic symptoms were women with known diagnoses of bipolar disorder who had relapsed during the postpartum period. The participant with the life-threatening complication who became manic was a patient with an existing diagnosis of HIV who presented with manic symptoms after delivery. These women were referred for further in-patient psychiatric management and were subsequently lost to follow-up.

Among the women who presented with psychiatric symptoms, 4.5% presented with psychotic symptoms at delivery of whom three quarters were women who had experienced a life-threatening complication. When the two groups are compared, then 6.5% of the women who experienced life-threatening stressors and 2.3% of women with uncomplicated pregnancies experienced psychotic symptoms at delivery respectively. (p=0.340)

A figure of 4.5% appears to be a relatively small percentage of women who became psychotic, especially when considering the fact that more than half of the total study participants were women who experienced life-threatening complications. The life-threatening conditions included not only eclampsia and preeclampsia, but also haemorrhage and septicaemia, amongst other complications. Further, more than a quarter of the total study population were HIV-positive, which could have raised the possibility of participants developing an HIV-induced psychotic disorder or HIV-induced delirium.

It is possible that the psychotic symptoms may have been transient in nature and resolved prior to the first interview, which would indicate that the symptoms could have been part of a delirium, which resolved with prompt treatment of the underlying medical complications.

The incidence of postpartum psychosis is one or two per thousand births. (Munk-Olsen et al 2006; Kendell et al 1987) Postpartum psychosis can occur rapidly after birth and can present with mood fluctuation, confusion, marked cognitive impairment suggestive of delirium, bizarre behaviour, insomnia, and hallucinations, which can include visual, auditory, tactile or olfactory hallucinations. (Heron, McGuinness, Blackmore, Craddock and Jones. 2008) Most postpartum psychotic episodes have an onset within two weeks of delivery, with more than 50% of symptom onset occurring on days one to three postpartum. (Jones, Heron and Robertson Blackmore 2010) Fluctuations in the intensity of symptoms, which can occur suddenly and can result in a rapid decline in the clinical presentation, have been described. Other cerebral or systemic conditions, such as eclampsia, delirium, thyroid disorders or infection, can present with psychotic symptoms.

These conditions have to be excluded as their misidentification as a psychiatric disorder has previously led to several deaths in new mothers. (Cantwell, Clutton-Brock, Cooper, Dawson, Drife J, Garrod et al. 2011)

The findings of the present study showed that 4.5% and 2.2% of the participants presented with psychotic and manic symptoms respectively. Of the participants that presented with psychotic symptoms, more than three quarters were women who experienced life-threatening stressors. A figure of 4.5% was a relatively small percentage, given that almost half of the total number of study participants experienced life-threatening stressors. The psychotic symptoms that occurred in these participants were of transient nature and resolved within a short span of time. The presentation and resolution of psychotic symptoms could therefore indicate the presence of a delirium that occurred secondary to the medical complications.

6.3.4 Symptoms of anger

An interesting finding in the present study was that less than 1% of women presented with mild to moderate symptoms of anger that was expressed at the first interview and was still present at the six-week interview (Table 19d, Figure 5, Anger symptoms, page 129&130).

Within each group, 4.3% were women who experienced life-threatening complications and 2.3% were women with uncomplicated pregnancies. (p=0.597) At the six-week follow-up 11.32% of study participants expressed symptoms and majority (80%) of the sample were women who had life-threatening complications. When the individual groups are compared, then, 17.2% of women with complications and 4.2% with uncomplicated pregnancies expressed symptoms of anger. (p=0.135) Only 9.3% of participants presented with residual symptoms of anger at the three-month follow-up, which resolved at the six-month follow-up. The quantitative results concur with the prominent theme of anger identified in the qualitative arm of the study.

The participants expressed anger about their current medical/physical conditions, the situation they found themselves in, relationship difficulties (including lack of support from their partners and, in some instances, desertion from their partners), social circumstances, as well as isolation that they experienced during the postpartum period. Women were also angry about the care or lack thereof, as well as the lack of information that they received whilst in hospital, and others expressed anger after learning about being diagnosed with HIV. An interesting observation is that participants expressed symptoms of anger but did not volunteer thoughts of self-harm upon completion of the self-reporting Level 1 questionnaire.

6.3.5 Somatic symptoms

Further, less than a fifth of the participants (16.9%) (Table 19e, Figure 6, Somatic symptoms, pages 131&132) presented with mild to moderate somatic symptoms. More than 80% of the sample was women who experienced a life-threatening complication. A significant difference between the two groups with regard to symptom presentation was found with 28.3% of women with complications and 4.7% with uneventful pregnancies presenting with symptoms respectively (p=0.003)

The somatic symptoms persisted at the six-week follow up in 26.4% of participants with more than three quarters of the group being women who had a life-threatening complication. When the two groups are compared, then 37.9% of women with complications and 12.5% with uneventful pregnancies experienced symptoms at six weeks. (p=0.037) Symptom resolution gradually occurred during the three- and six-month appointments, with only 6.3% of women presenting with somatic symptoms.

Within the two groups, 4.8% of women with life-threatening complications and 9.1% with uncomplicated pregnancies experienced symptoms at three months. (p=0.631) None of the women who followed up at six months reported any somatic symptoms.

The presence of somatic symptoms could either have occurred as a result of the physical and physiological symptoms that occur during the perinatal period. The symptoms may also present as part of the adjustment necessary to fulfil the demands of motherhood. It could further be postulated, given the simultaneous symptom duration and presentation of women experiencing anger and somatic symptoms respectively, at delivery and at the six-week follow-up, that these symptoms may be part of atypical symptom presentation of postpartum depression.

Kelly et al. have described a correlation between somatic complaints experienced during pregnancy and anxiety and depression in the literature. (Kelly, Russo and Katon 2001) They postulate that somatic complaints can be found in pregnancy but that they may be confused with somatic symptoms related to depression. Spinelli et al. have recommended that women be screened for the length and seriousness of somatic symptoms to either confirm or exclude the diagnosis of depression. (Spinelli 2001) A study conducted in Brazil reported that

30% of their subjects presented with significant somatic symptoms during pregnancy and the postpartum period and found a similar percentage of women presenting with sleep disturbances. (Faisel-Curry, Menezes, Arayay, and Zugaib M 2009)

Andresson et al. (2006) however, described the two most frequent symptoms found in depressed women to be fatigue with loss of energy and diminished interest in daily activities, and not a depressed mood as would have been expected. They explained that women can present with atypical symptoms of depression as well as unspecified somatic complaints, or only unspecified somatic complaints as symptoms of psychiatric disorder.

Further, a study conducted in Zimbabwe found that women often expressed their difficulties through somatic symptoms. (Abas and Broadhead 1997) In an Ethiopian cohort, there was a moderately high correlation between perinatal total somatic symptoms and depression or anxiety scores. The findings supported the importance of somatisation of mental distress in the perinatal period. (Senturk, Hanlon, Medhin, Dewey, Araya, Alem et al. 2012) It is known that alterations in sleep, weight, appetite, energy and concentration can occur in pregnant and postpartum women, and although they may not be pathological, these symptoms could also be experienced during depressive episodes.

Some authors suggest that some symptoms of depression and those found during pregnancy and the postpartum period may overlap, which can make the diagnosis of depression difficult. (Yonkers, Smith, Gotman and Beelanger. 2009) Similarly, patients may attribute symptoms to pregnancy rather than to a depressive disorder. Furthermore, through the indiscriminate use of standardized questionnaires, an over-diagnosis of depressive disorders in pregnant women can occur if somatic experiences are considered pathological rather than normal.

Zimmerman et al. (2006) and Andrews et al. (2007) have questioned the relevance of somatic symptoms in the criteria for a depressive disorder and explained that these symptoms may confuse diagnosis of major depressive disorder among individuals with medical conditions. However, behavioural and somatic complaints expressed by depressed pregnant women have also been found to relate statistically to the severity of a mood disorder and may alert clinicians to the existence of depressive disorder in pregnancy. It therefore stands to reason that a relationship between depression and somatic complaints does exist, as individuals with a clinical diagnosis of depression are more likely to report various somatic complaints, chronic medical problems, and poorer self-rated health than non-depressed individuals. (Duer, Schwenk and Coyne 1988; Simon, VonKorff, Piccinelli, Fullerton and Ormel 1999; Simon and VonKorff 1991; Wells, Stewart, Hays, Burnam, Rogers, Daniels et al. 1989) Depressed individuals have also been found to have more functional disability and to make more frequent use of the health care system than non-depressed individuals. Thus, as important as it is not to pathologize somatic symptoms, a high index of suspicion should be present when somatic symptoms are identified. Somatic symptoms present in the absence of mood or cognitive changes could indicate a benign physiological course.

However, should the symptoms be present in addition to alterations in mood, neuro-vegetative or cognitive symptoms, or alterations in the levels of functioning, this should raise the suspicion of a diagnosis of depression.

In summary, less than a fifth of the study participants presented with somatic symptoms, which persisted at the six-week follow up and subsequently resolved during the three- and six-month appointments. The presence of these symptoms was accompanied by impairments in social and occupational functioning, as indicated by the results of the disability assessment. It is possible that these symptoms could have been an expression of the initial distress that the participants experienced in hospital and upon return to their respective environments.

The somatic symptoms were not enduring, however, and resolved during the subsequent months. Furthermore, the somatic symptoms could have represented atypical features of depression, as they were accompanied by impairments in the levels of functioning in these participants.

6.3.6 Sleep disturbances

In addition to the above conditions, approximately 18% of participants in this study presented with sleep disturbances at delivery, with women who experienced a life-threatening event representing more than 80% of the sample. (Table 19f, Figure 7, Sleep, disturbances, page 133 & 134). Within each group, 28.3% and 7.0% of women with complications and uneventful pregnancies respectively, experienced disturbances in their sleep pattern. (p= 0.009) Furthermore, 41.5% of women continued to experience sleep disturbances, which caused them distress and limited their ability to function adequately at the six-week follow-up. When the two groups are compared, then, a quarter of women with uneventful pregnancies and 62% of women with complications experienced disturbances of sleep at six weeks. (p=0.007) These symptoms improved during the subsequent months, with approximately 31% of women with complications and 5% of women with uneventful pregnancies experiencing residual sleep disturbances at three and six months respectively. Within each group, 38.1% of women with complications and 18% of women with uneventful pregnancies experienced symptoms at three months (p=0.248) and only 5% of subjects reported sleep disturbances at six months of whom 8.3% were women with life-threatening complications.

Sleep disturbances, like somatic symptoms, can occur in pregnancy and the postpartum period. These changes can occur as a result of physiological processes that occur in the postpartum period that are required to re-establish homeostasis.

Alternatively, these symptoms could be experienced as part of the adjustments that are required during motherhood and are not necessarily pathological. However, sleep disturbances could be a manifestation of an underlying depressive disorder, given the fact that almost a quarter of the study participants at delivery and 30% at the six-week follow-up had depressive disorders. Furthermore, 13.5% of the women who experienced sleep disturbances were those who had experienced a severe, life-threatening stressor.

It is postulated that the presence and meaning of the stressor could have impaired not only the women's ability sleep, but the quality of their sleep as well.

Sleep disorders, including disrupted sleep, reduced total sleep time and decreased sleep quality, are common in pregnant women, especially in the third trimester. (Dorheim, Bjorvatn and Eberhard-Gran 2012; Kizilirmak, Timur and Kartal 2012) The symptoms are thought to occur in 52–61% of women in the last eight weeks of pregnancy. They can also be associated with a recent-onset or pre-existing depression. (Okun, Kiewra, Luther, Wisniewski and Wisner 2011) It is thought that the insomnia may be exacerbated prior to delivery as a result of the oxytocin secretion, which has been found to be a wake-promoting agent that occurs at the time of delivery. (Pires, Andersen, Giovenardi and Tufik 2010) According to the literature, complaints of insomnia may remain prevalent from delivery up to three months postpartum and tend to be more prominent among women who have had surgical deliveries. Maternal sleep disruptions are also thought to occur as a result of co-bedding as well as infant temperament. (Ko, Shin, Kim, Kim, Lee, Kil et al. 2012; Lahr, Rosenberg and Lapidus 2007; Goyal, Gay and Lee 2009) Pre-partum sleep disruption and insomnia have been reported to increase the risk of postpartum depression, whilst sleep loss during pregnancy may be a risk factor for the subsequent development of postpartum depression, which can in turn worsen sleep quality. (Okun, Luther, Prather, Perel, Wisniewski and Wisner 2010)

Gonadotropic and sex hormones are also thought to influence the quality of sleep and the risk for sleep disorders such as insomnia and sleep-disordered breathing, whilst oestrogen and progesterone are known to change the sleep microstructure. (National Sleep Foundation 2007; Carrington and Trinder 2008; Spiegel, Leproult, and Van Cauter 1999) Alterations in respiratory physiology can occur in pregnancy and some of these changes can result in the development of sleep-disordered breathing. Obstructive sleep apnoea can occur as a result of physiological and anatomical changes that occur in peri-partum period. (Abbott, Attman, Zee, Boshes and Boshes 2014) This can result in adverse pregnancy outcomes like intra-uterine growth retardation and other complications including preterm birth, as well as increased risk for caesarean section deliveries and low birth weight. (Chen, Kang, Lin, Wang, Keller and Lin 2012)

Obstructive sleep apnoea may also be a major risk factor for the development of pregnancy-induced hypertension, preeclampsia and eclampsia, and an independent risk factor for preeclampsia and gestational hypertension. (O'Brien, Bullough, Owusu, Tremblay, Brincat, Chames et al 2012; Franklin, Holmgren, Jonsson, Poromaa, Stenlund and Svanborg 2000)

In summary, approximately 18% of the study participants presented with sleep disturbances at delivery and this number increased to almost 40% of the total number of participants who experienced sleep disturbances at the six-week follow-up. Women who experienced life-threatening complications presented with greater impairment than women with uneventful pregnancies. This may indicate that the sleep disturbances could have occurred as a result of the distress that these women experienced around the time of delivery. It may also indicate that the distress continued initially upon return to their respective environments. Another possibility is that the sleep disturbances could have occurred as part of the adjustment required to re-establish homeostasis in the postpartum period.

6.3.7 Cognitive and memory disturbances

Participants in this study also presented with cognitive and memory problems, with 9% of women presenting with symptoms at the initial interview. (Table 19g, Figure 8, Memory disturbances, pages 135&136) More than 85% of the sample was women who had life-threatening complications. There were significant differences with regard to memory disturbances between the two groups with 15.2% of women with complications and 2.3% of women with uneventful pregnancies experiencing symptoms respectively. (p=0.034)

The symptoms of memory impairment were pronounced at the six-week interview, with approximately 22.6% of the participants experiencing significant memory problems. More than 80% of these participants were women who had experienced life-threatening complications in their pregnancy and delivery. When the two groups are compared then 34.5% and 8.3% of women with complications and uneventful pregnancies respectively presented with significant memory difficulties. (p=0,024) A decline in symptoms of memory impairment in the subsequent months was noted, with 18% of participants experiencing residual cognitive symptoms at three months and none of the participants complaining of any cognitive or memory difficulties at the six-month follow-up. More than 23.8% of the women who presented with memory deficits at three months were those who experienced life-threatening stressors, whereas 9% of women with uneventful pregnancies presented with symptoms.

Significant differences with regard to memory deficits were observed between the two groups of women at delivery and six weeks.

The women with life-threatening complications who presented with memory deficits were those who experienced stressors including medical and obstetric complications such as, eclampsia, postpartum haemorrhage and septicaemia. These conditions could have resulted in multi-organ dysfunction and caused a delirium as a result. The complications that occurred often required mechanical ventilation of these women for a period of time during admission. These interventions and complications could have resulted in women experiencing cognitive and memory difficulties. Furthermore, women who had eclampsia and preeclampsia could have had vascular dysfunction and clotting abnormalities, as well as cerebral oedema, which also could have caused memory deficits. A quarter of the participants in the study were HIV-positive, some women were diagnosed during the peripartum period and the infection could result in women experiencing cognitive difficulties.

Results from the qualitative arm showed that the women expressed that the experiences were distressing, and some had no recollection of how they arrived at the hospitals or the interventions that they were exposed to, which indicates that these events could have precipitated memory deficits as well. The distressing experiences could have been repressed and attempts made to forget the events, which could also result in memory difficulties. It is also possible that the cognitive and memory problems could have occurred as part of the symptom complex of depressive, anxiety and psychotic disorders that the participants experienced.

An increasing number of studies in the recent literature have described cognitive deficits in women who were diagnosed with eclampsia, preeclampsia, or gestational hypertension. In a study conducted on women who had been admitted to the Academic Medical Centre in Amsterdam between 1984 and 1996 with problems related to HELLP (haemolysis, elevated liver enzymes and low platelets) syndrome, the women were asked an average of ten years later to complete a questionnaire concerning their general health and any subsequent pregnancies. (Baecke, Spaanderman and Van der Werf 2009) Disturbances in memory and concentration, forgetfulness, fears and symptoms of depression during the first year after delivery were reported. Studies on women who had eclampsia report cognitive difficulties related to memory and concentration, although small studies have not clearly demonstrated these occurrences in women diagnosed with preeclampsia. (Aukes, Wessel, Dubois, Aarnoudse and Zeeman 2007; Andersgaard, Herbst, Johansen, Borgstrom, Bille and Ian 2009; Baecke, Spaanderman and Van der Werf 2009; Brussé, Duvekot, Jongerling, Steegers and De Koning 2008; Postma, Wessel, Aarnoudse and Zeeman 2010; Rana, Lindheimer, Hibbard and Pliskin 2006)

At long-term follow-up, it was found that women with preeclampsia and eclampsia might present with cerebral white matter lesions on MRI. (Aukes, de Groot, Aarnoudse and Zeeman 2009; Aukes, De Groot, Wiegman, Aarnoudse, Sanwikarja and Zeeman 2012) The presence of these lesions and superimposed chronic hypertension has been associated with cognitive decline in later life. (Qiu, Winblad and Fratiglioni 2005; Desmond 2002; Sachdev, Chen and Wen 2008) It was reported that both biological changes as well as psychosocial factors might be responsible for the neurocognitive difficulties reported by women who had been diagnosed with preeclampsia and eclampsia. (Postma, Groen, Eastering, Tsigas and Wilson 2013) It is hypothesized that brain dysfunction that can occur in preeclampsia as a result of vasodilation, vascular dysfunction and platelet aggregation, has been associated with cardiovascular disease and brain white matter lesions. (Porcels, Feigal, Poe, Postma, Zeeman, Olowoyeyn et al. 2013)

Follow-up studies have reported that, years after their pregnancy, women with a history of preeclampsia appear to perceive more cognitive problems, as well as poorer quality of life and social functioning, including psychiatric problems. Possible explanations for the changes that occur in women with preeclampsia and eclampsia are that a pregnancy complicated by preeclampsia may be experienced as a traumatic event and can result in post-traumatic stress disorder (PTSD) or depression, and that the conditions may influence cognitive functioning, quality of life and social functioning. (Gaugler-Senden, Duivenvoorden, Filius, De Groot, Steegers and Passchier 2012) Previous studies evaluating cognitive functioning in women 6 to 24 months after eclampsia found that 18% of the women reported problems with concentrating, whilst 14% presented with symptoms of depression. (Porcels, Feigal, Poe, Postma, Zeeman, Olowoyey et al 2013) Small-scale studies evaluating objective neurocognitive function using a variety of tests have shown inconsistent results, where women who had been diagnosed with eclampsia scored significantly lower than normotensive women in certain domains, whilst no difference was found between preeclamptic women and normotensive women.

In summary, approximately 14% of women presented with symptoms of cognitive impairment in this study. Of these, 11% were women who had experienced life-threatening stressors. The impairments in memory and cognitive functioning could have occurred as a result of life-saving interventions, such as mechanical ventilation that was required at the time of admission. Furthermore, the impairments could be part of the symptom complex of depressive, anxiety or psychotic disorders. These cognitive symptoms were not enduring and resolved during the subsequent appointments, which may indicate that they were part of the symptom complex mentioned above and improved with treatment of the condition.

6.4 IMPAIRMENTS LEVELS OF FUNCTIONING

Finally, levels of functioning, be it personal, social or occupational, are important indicators of the severity of psychiatric disorders. The World Health Organization Disability Assessment was completed to assess functioning in the following domains: understanding and communicating; getting around; self-care; getting along with people; household, school and work activities; and participation in society. (Tables 18a, 18b, 18c & 18d, Results of WHO Disability assessment, pages 116-120). The results of the disability assessments indicated that the participants experienced impairments in their levels of functioning around the time of delivery, and some of the participants continued to experience difficulties in their functioning at six weeks. However, the levels of functioning in all spheres had improved at the subsequent appointments. (Figure 1a, Functional impairment, page 120) Furthermore, although women in both groups namely, those with life-threatening complications and those with uneventful pregnancies experienced impairments in functioning, the women in the former group presented with a greater variation in their levels of functioning as compared to women with uneventful pregnancies. (Figure 1b, Functional Impairment per group page 120)

The improvement in functionality is mirrored in the results of the psychiatric sequelae in that, at delivery and six weeks, women experienced psychiatric symptoms that were accompanied by impairment in functioning. As the psychiatric symptoms improved, so did the levels of functioning. These disturbances occurred in both the women with uneventful pregnancies the women with life-threatening experiences and were found not to be enduring. A possible explanation for this improvement might be the adjustments that take place in the postpartum period that are necessary to re-establish homeostasis. An alternative explanation is that the impairments could have occurred as part of the impairment in activities of social and occupational functioning that occurred in women with psychiatric sequelae.

The results of the study are interpreted with caution due to the high attrition rate. Participants were selected over two cycles, as women with uneventful pregnancies in many instances did not follow up after the six-week appointment. Attempts were made to remind patients of their upcoming appointments through telephonic contact and financial assistance for transportation was provided to the participants at each interview.

It is postulated that the women may not have felt the need to follow up in the absence of psychiatric symptomatology or that the women with life-threatening complications may have lacked the motivation to attend the appointments due to the psychiatric symptoms that they experienced.

Another possibility is the that women may have had difficulty in accessing the hospital to attend their follow-up appointments, as more than a fifth of the participants were non-South Africans and the present study was conducted during a turbulent time in South African politics. Xenophobic attacks against non-South Africans were taking place in the public health sector during this period. The problems posed by this were relayed through telephonic contact with some women, or their partners, who, when informed about the follow–up appointments, explained their difficulties.

Various factors influence the attrition rate in studies and some of the reasons found in the literature are reported on. Fillippi et al (2010) reported that women accessing postnatal services were found to be less than 50%, whilst Spinelli and Endicott (2003) attributed the high attrition rates in their study to several factors, namely child care and work demands which were considered obstacles in single support mothers. They also reported that their sample was predominantly composed of immigrants whose homes were often transient and chaotic, with these women having unstable and unpredictable support systems and many women were lost to follow-up due to disconnected telephone numbers. The duration of the study was also reported as a potential factor. Furthermore, in a systematic review of birth cohort studies in Africa, Campbell and Rudan (2011) reported that longitudinal studies pose methodological challenges to researchers in that two types of sample loss are often reported, namely initial non-enrolment in studies and attrition on follow-up. The authors reported that both these factors could cause systematic bias in collection and interpretation of results. They further reported that failure to trace individuals is reported as the most common cause of attrition, with lack of infrastructure, administrative centres, national databases and patient identifiers also contributing to the high attrition rates. Furthermore, high rates of migration were also considered to be a challenge in longitudinal studies as the more educated, urban section of the cohort being likely to migrate.

6.5 SUMMARY

Psychiatric sequelae occurred in study participants who experienced life-threatening stressors as well as those who had uneventful pregnancies. Psychiatric conditions that were identified in these participants included major depressive disorders, with approximately 25% of the total study participants experiencing symptoms of a depressive disorder, whilst approximately 19% presented with generalized anxiety disorders.

Furthermore, psychotic disorders, namely relapse of a manic episode and delirium, occurred in 2.2% and 4.5% % of participants respectively. Almost a fifth of the participants experienced somatic disturbances, with approximately 10% of the study subjects presenting with cognitive and memory impairments. Sleep disturbances were also reported in 18% of cases.

An important observation in the study was that the women who experienced life-threatening complications were more vulnerable than women with uneventful pregnancies to develop psychiatric sequelae. These women were more prone to develop symptoms in almost every symptom domain as compared to women with uneventful pregnancies. These conditions were diagnosed at the first interview, which was shortly after delivery; an increase in the number of women experiencing psychiatric symptoms reached a peak at six weeks.

The duration and intensity of symptoms were however not sustained and symptom resolution was observed during the ensuing three months with only a limited number of women presenting with residual psychotic symptoms at the six-month appointment.

The participants initially experienced impairments in social and occupational functioning as evidenced by the results of the WHO Disability Assessment scale. The results obtained from the disability assessments mirrored the psychiatric symptom presentation in certain respects. The participants experienced impairments in their levels of functioning at delivery and continued to experience some impairment at the six-week follow-up. The psychiatric symptoms were similarly identified at delivery and reached a peak at the six-week follow-up.

Subsequent to this appointment, improvements in psychiatric symptoms and levels of functioning were observed. The women presented with anxiety symptoms that were severe at delivery and at six weeks but decreased at three and six months and were more pronounced in women who had life-threatening complications.

It is possible that these women presented with acute stress symptoms that improved in the subsequent months during the postpartum period.

Also, of the women with life-threatening stressors who followed up at six months, did not present with significant symptoms that fulfilled criteria for a post-traumatic stress disorder. It may be, that although the participants experienced stressful situations during pregnancy or delivery, including life-threatening stressors that threatened their wellbeing, the symptoms did not reach a threshold that fulfilled the criteria for post-traumatic stress disorder. This condition, however, could not be confirmed in view of the attrition of study subjects. However, information obtained during the qualitative analysis could indicate that other factors may have played a role in limiting symptom presentation.

Furthermore, the participants presented with atypical symptoms, such as sleep and somatic symptoms as well as comorbid depressive and anxiety symptoms. The duration of symptoms accompanied by impairments in the level of functioning during this period could indicate that these women experienced an adjustment disorder with comorbid depressive and anxiety symptoms. An important observation is that the symptoms that women experienced were pronounced at delivery and six weeks but decreased at three and six months postpartum. Women with life-threatening complications experienced greater distress than women with uneventful pregnancies.

7 DISCUSSION OF THE FINDINGS OF THE QUALITATIVE ARM

7.1 INTRODUCTION

Motherhood is often described as a wonderful, fulfilling experience, a bittersweet time, where joy and happiness go hand in hand with the challenges of caring for a newborn. This period requires an adjustment, a shift from the known to the unknown, familiar to unfamiliar, an overwhelming experience that mothers never forget, the pride and joy accompanied by mixed emotions and sacrifice of time, sleep and comfort.

Further to the thematic analysis identified from the data obtained from the study participants, a discussion of the themes is presented in this chapter and subsequent to this discussion references from the literature pertaining to the relevant themes is presented. As mentioned previously maternal health is a complex construct that not only involves biological processes but psychological and sociocultural aspects too. The initial literature review presented in Chapter 2 addressed these issues pertaining to the quantitative arm of the study. However, for the qualitative arm of the study, the grounded theory method for data analysis was considered and this method is a way of generating theory from the data obtained in the field. As the grounded theory method involves an inductive-deductive process, the literature was reviewed only after the themes were identified from the existing data that was obtained in the qualitative arm. References to the literature were made to compare and contrast the themes that had evolved from the data.

7.2 PSYCHOSOCIAL EXPERIENCES OF STUDY PARTICIPANTS WHO HAD LIFE-THREATENING COMPLICATIONS AND THOSE WITH UNCOMPLICATED PREGNANCIES

Information obtained from the quantitative arm and thematic analysis of the interview transcripts and journals provided by the study participants from the qualitative arm allowed for the broad classification of the results into the following categories namely; biomedical, psychosocial, socio-cultural and health system related categories.

The bio-medical category or psychiatric sequelae was discussed in the preceding chapter and in this chapter a discussion of themes in the remaining categories will be discussed.

Within each category, study participants had positive and negative experiences. Among the positive experiences that some of the women expressed upon confirmation of a pregnancy was the joy of impending motherhood. A number of women in both groups namely those with life-threatening complications and those with uncomplicated pregnancies had unplanned pregnancies. For some of these women, the pregnancy was welcome and wanted. Women in both groups who had given birth to a live baby expressed the process as an overwhelming indescribable experience. The baby was viewed as being a blessing from God. Some participants described having a baby as a joyous event not only for the mother but for the families too. For others having a baby and bonding with them filled them with joy and pride.

However, not all of the participants had such positive experiences. The negative experiences for some participants included amongst others, unwanted pregnancies, whilst for others, who had unplanned and unwanted pregnancies, there was great ambivalence about the pregnancy and what it could potentially represent. The women described the fear of rejection of paternity or infidelity by the respective partners. Some young women described rejection by family upon confirmation of pregnancy, whilst others described potential disturbance in schooling or the study participants also described career opportunities, stigma and social prejudices. This was disclosed not only by young women who became pregnant but also by older participants. These women expressed that their pregnancies were ridiculed not only by members of their families, but also members of society and some older women even mentioned that the nursing staff at their local clinics ridiculed them for becoming pregnant at an older age. Other women described the confirmation of the pregnancy as a burden, which would have potential financial implications for them. Despite these negative experiences, the women chose to continue with the pregnancies even though there was the option of terminating the pregnancy as this was legalized in 1996. (Termination of Pregnancy Act 92/1996)

For women who developed eclamptic seizures and those with life-threatening complications described feelings of impending death. For others, it passed by in a haze, with some having either no recollection of the events at all, or confusion about the events that occurred prior to and during hospitalization, as well as the time spent in the ICU. The severely ill women complained of memory deficits and confusion with regard to not only orientation in some cases, but also the extent of their respective illnesses.

Some women described confusion about the need for the life-saving interventions, whilst in other cases women were oblivious to the fact that they were gravely ill, due to the absence of or as a result of non-specific physical symptoms that they experienced. Health professionals and members of their families only made these women aware of the gravity of their health status whilst they were recovering.

For the study participants who experienced the loss of a pregnancy, there were prominent feelings of sadness and disappointment. The immediate postpartum period was described as an emotionally challenging time for them. Women, who had experienced a life-threatening stressor and subsequent loss of a pregnancy, as well as those who lost the ability for future conception, described an overwhelming sense of loss. These women were mourning not only the loss of a child or the ability of having children in future, but also the loss of an identity as to them bearing children is considered the duty of a woman. Apart from the sense of loss there was also a strong sense of frustration and guilt feelings about the losses. A number of women felt personally responsible for the event. These women felt like failures, and also expressed ambivalence about their role as women. This was especially prominent in women who had survived life-threatening stressors and subsequent complications. Feelings of despondency and disappointment were prominent among all the women who experienced life-threatening stressors. For those who had lost their babies, the disappointment about returning to their lives without the anticipated newborn was experienced not only by the women, but their partners and families as well.

Despondency and disappointment were not only present in women with pregnancy loss or those who experienced life-threatening stressors, as other women in the sample, for example, those who became aware of their HIV status during the pregnancy, described similar emotions.

Furthermore, feelings of inadequacy and frustration were also found in young women and primigravida's with uncomplicated pregnancies, who, in the absence of support from family members (especially elders), had difficulty adjusting to the demands of motherhood.

A prominent theme highlighted in both groups of women was a sense of isolation, not only physical but emotional and socio-cultural as well. Women who were severely ill described physical isolation resulting from the fact that they removed themselves from the family and community, to allow themselves time to process the events that occurred during the hospitalization.

For the women who had lost their babies, the isolation provided them an escape from the responsibility of the family and community, thus allowing them an opportunity to grieve. Some women described feeling emotionally removed and withdrawn from their respective spouses and families, and for the very ill women who were hospitalized for extended periods, the lack of bonding with their babies was difficult to accept as they felt isolated from their babies.

Social isolation was also described by the study subjects, because, as reported by them, cultural dictates require that a woman who has recently delivered needs to remain indoors for a period of three months. This period is considered a time of protection from evil for the baby. To the women who had lost their babies, the social isolation was sometimes self-inflicted, as they feared rejection by their respective partners; in some cases, these fears proved to be justified. Women who were rejected and abandoned reported that their partners were either unwilling to take responsibility for the pregnancy or disputed paternity, and in some cases rejected the woman due to her inability to conceive in the future.

Rejection by spouses and family members was also brought to the fore. For some, it was involuntary, as they felt stigmatized and judged because of their inability to have children. In one instance, the participant experienced rejection by her immediate family, whilst others were afraid of disclosing their fertility potential for fear of stigmatization and being judged by family and friends. A number of women reported the peri-partum period to be a very lonely time for them, as they did not have many people in whom they could confide in. These women also felt unable to express what they were feeling, as, according to them, it was deemed culturally inappropriate to disclose their personal problems to others.

Narratives of women who experienced near-miss events in pregnancy by Souza et al (2009) in their sample in Brazil, and a master's dissertation (Nkosi 2011) conducted in a sample of women with near-miss events in the same health complexes where the present study was conducted, described similar results regarding fear of impending death, guilt feelings, feelings of inadequacy and memory deficits. Fottrell et al (2010) highlighted the loss of health and vitality in women who survived life-threatening complications along with feelings of grief in women who are deprived of their reproductive and productive capacity, which may result in marital instability and loss of income.

Although studies describing the experiences of women who have had life-threatening or near-miss complications are limited in the literature, (Filippi et al 2004; Filippi et al 2007) other studies of women who have lost their babies have described similar experiences after their loss.

Layne (1990) explained that many women accepted responsibility and felt like failures after experiencing a pregnancy loss, whereas a study by DeFrain et al. (1996) also described a sense of fear in the mother and families when the thought of a subsequent pregnancy is considered after the death of a baby. The grief response is considered appropriate and may be individualized and varied in women who experience a pregnancy loss. (Brown 1993)

In the 'listening to parents' study conducted in the United Kingdom, 68% of mothers reported four or more negative psychological symptoms at ten days after a stillbirth, which reduced to 35% at nine months post the event. (Redshaw, Rowe and Henderson 2014). Many factors have been identified that influence a woman's responses following a pregnancy loss, and include self-blame, searching for answers, (Harris 1984; Kavanaugh 1997) lost hopes for the future, (Harr and Thistlethwaite 1990; Welch 1991), shattered dreams of parenting (Carroll-Frey 1997), perceived loss of self, (Harrigan, Naber, Jensen, Tse and Perez 1993) silence from others (Lindberg 1992; Mahan and Calica 1997) and lack of appropriate rituals. (Layne 1990; Bansen and Stevens 1992; Lauterbach 1993).

A systematic review of studies that looked at the psychological effect of stillbirths found that negative psychological symptoms were the most frequently described symptoms, with the ability to express grief reactions considered to be an integral part of the psychological response. (Lee 2012; Kavanaugh and Hershberger 2005).

Some participants felt that the family, society or health professionals inadequately acknowledged their grief. (Cote-Arsenaut and Donato 2011; St John, Cooke and Goopy 2006; Gold, Boggs, Mugisha and Palladino 2012) They reported suppressing their grief in public and dealing with their emotions by themselves, in private. (Sun, Rei and Sheu 2014; Cote-Arsenaut and Donato 2011)

For mothers, the loss of a baby affected their approach to life and death, self-esteem and identity, and some described a sense of loss of control during subsequent pregnancies, whilst questioning their ability and confidence in parenthood and raising children. (St John et al; Säflund, Sjögren and Wredling 2004)

These reactions were also described in studies originating from low- and middle-income countries, especially studies originating from Tanzania, Ethiopia and India, where it was reported that despite experiencing feelings of grief and loss, mourning was discouraged and suppressed, and found to be culturally unacceptable. (McCreight 2004; Haws, Mashasi, Mrisho, Schellenberg, Darmstadt and Winch 2010)

Some mothers isolated themselves socially for fear of meeting people who had known they were pregnant, and also avoided contact with babies. (Kavanaugh and Hershberger 2005) Some women, who reported being stigmatized, which made them feel inadequate and less valued as members of society, described involuntary social isolation. Women who had stillbirths were even rejected in their respective cultures as it was thought that evil spirits possessed them. (Roberts, Montgomery, Lee and Anderson 2012; Sisay, Yirgo, Gobezayehu and Sibley 2014; Murphy 2012; Hsu, Tseng, Banks and Kuo 2004, Sun et al 2014)

7.3 THE IMPACT OF SOCIO-CULTURAL FACTORS ON STUDY PARTICIPANTS EXPERIENCES

Socio-cultural factors were prominently identified during the thematic analysis of the present study, and this influenced both women's behaviours and experiences. Among the positive experiences described by some study participants was the support that they received from their partners, families, members of the community, as well as members of the religious organizations that they belonged to. This support was in the form of words of encouragement and moral support during the post-natal period. For others who had experienced a life-threatening event and who were medically unwell, it was the visits by members of the community or the prayer visits by members of the religious organizations that they belonged to that gave them the courage and strength to heal and recover. However, not all case-study participants had these positive experiences. Some women had to contend with rejection of paternity, as described by one of the participants, who mentioned that her husband refused to accept the baby as his, after Down syndrome was confirmed in the new-born. Other study participants described rejection after losing their babies or their loss of reproductive abilities, whilst some women had to contend with infidelity and the lack of a faithful partner causing them much distress.

For women who experienced a pregnancy loss however, the burden was even harder to bear as these women felt that they would be judged as failures. Women who were severely ill and had hysterectomies were reluctant to disclose the interventions carried out on them. The reluctance for disclosure was the fear of being deemed a failure as a woman as well as the fear of being ridiculed and belittled by their families and members of the community.

These women feared the consequences of disclosing the extent of the interventions that they had been exposed to. Disclosure did lead to rejection and abandonment by partners for two participants as a result of the surgical interventions that they were subjected to. Furthermore, the women also expressed difficulties in having to contend with societal norms, social prejudices and stigma. Study participants who had a life-threatening stressor in pregnancy and those with uncomplicated pregnancies described difficulty in discussing or sharing their problems with their friends or families, for fear of being ridiculed or mocked, as well as being deemed unable to cope. Some women mentioned that their difficulties were a private matter and thus inappropriate to discuss outside the family context, and for some, even within the family system. Other factors that were described as sources of distress were adjusting to the demands of life outside the hospital, the lack of support (both emotional and financial), and the responsibilities of motherhood.

Within the literature, the importance of social support in maternal mental health has been described in a number of studies conducted in Europe, North America and African countries, (Cooper et al 1999; Owoeye, Aina and Morakinyo 2006; Ramchandani, Richter, Stein and Norris 2009) and authors have suggested that the cultural context is a significant factor for the women's wellbeing. Stressful life events, cultural values, the extended family system, negative cultural perceptions, as well as adhering to cultural traditions and values, have been shown to play an important role in women's experiences of postnatal distress and postnatal depression. In these studies, four major themes were identified and were considered as risk factors. These were lack of support, relationship problems, unwanted pregnancies and cultural factors. (Hanlon, Whitley, Wonimagegn, Alem and Prince 2009; Sawyer, Ayers and Smith 2010; Oates, Cox, Neema, Asten, Glangeaud-Freudenthal. Figueiredo et al 2004)

Among the cultural risk factors for postnatal distress and depression discussed in the literature that were unique to sub-Saharan countries, were the traditional African value systems and customs, which included, amongst others: polygamy, (Adewuyaand Afolabi 2005; Fatoye, Oladimeji, Adeyemi 2006) rejected paternity, (Bina 2008) negative cultural perception of others, (Sawyer et al 2011) the threat of spirit attack and adhering to African cultural traditions. (Hanlon et al 2009) One of the strongest risk factors for postnatal distress in South African women was exposure to societal stress by either witnessing or being in danger of violence. (Ramchandani et al 2009)

A review examining the impact of cultural factors on postnatal distress found that rituals could have a negative effect on the mood of women, especially in the postpartum period, if the women did not identify these rituals to be of help to them. The authors reported that cultural traditions might either have a protective or an aggravating role in the development of postnatal distress or depression in different cultures. (Cooper and Murray 1998)

Another risk factor for postnatal distress and depression that differed amongst the studies in developed and developing countries was the association between socio-economic disadvantage and postnatal distress. Socio-economic disadvantage was identified as a significant risk factor for postnatal depression in developed countries but may not be so in developing countries such as those in sub-Saharan Africa, where social adversity appears to be endemic and may therefore not be a contributing factor in these populations. (Sawyer et al 2010)

As described earlier in the discussion, participants in the present study (both those with life-threatening stressors and those with uncomplicated pregnancies) described a lack of support, especially from the husband, as a reason for distress in the postnatal period. This was found to be a risk factor for postnatal distress in a number of other studies as well. (Beck 2001; Dressler, Baleiro, Ribeiro and dos Santos 2007)

Relationship problems and subsequent marital conflict were identified as risk factors for postnatal distress and postnatal depression in sub-Saharan African countries. (Ribeiro and dos Santos 2007) Women in Uganda and Ethiopia identified infidelity on the part of the husband as a cause of disappointment and distress in the postnatal period. (Hanlon et al 2009) Conflict and relationship difficulties with family members, as well as unwanted pregnancies, were also identified as risk factors.

Factors that contributed to distress included pregnancies that were unwanted because the woman was young, had too many children, had marital problems or having another child would cause financial strain. Individuals, who felt that they were unable to adhere to cultural values, resulting in distress and predisposing them to developing postnatal depression, described cultural conflict and subsequent distress. (Chapman 2003) Negative cultural perceptions were considered to be risk factors in a number of studies; for example, being a single, unmarried parent was considered socially unacceptable in the study conducted in The Gambia. (Sawyer et al 2011). The stigma associated with being single was not the only cause of distress to women, however, as childless women were also viewed negatively and with suspicion.

The fear of stigma resulted in women concealing their pregnancies, not only from the community, but from their close family as well. (Chapman 2003; Maimbolwa, Yamba, Diwan and Ransjö-Arvidson 2003; Bazzano, Kirkwood, Tawiah-Agyemang, Owusu-Agyei and Adongo 2008) The women feared evoking malice from community members and also believed that community members would not only jeopardize the outcome of their pregnancy but also the onset of labour due to the influence of witchcraft. (Bazzano 2008) Other culturally relevant themes included the belief that obstetric complications occurred as a result of a woman's bad behaviour (Bazzano 2008; Mrisho, Obrist, Schellenberg, Haws, Mushi, Mshinda et al 2009; Telfer, Rowley and Walraven 2002; Orji, Adegbenro, Moses, Amos and Olarenwaju 2007; Seljeskog, Sundby and Chimango 2006) and that the failure of labour to progress was due to paternity or infidelity. (Mrisho et al 2009; Orji et al 2007) The second theme identified was the need for medical intervention during pregnancy, which was considered a failure on the woman's part, as women who gave birth naturally were valued and respected by their communities, and medical interventions such as caesarean deliveries were viewed as a weakness in the women. (Kyomuhendo 2003; Odimegwu, Adewuyi, Odebiyi, Aina, Adesina, Olatubara et al 2005; Mathole, Lindmark, Majoko and Ahlberg 2004)

Another risk factor contributing to postnatal distress described in the reviews was the women's inability to adhere to postnatal traditions, as was evident with Ethiopian women, where the tradition of a postnatal period of confinement appeared to exacerbate their pre-existing difficulties. (Hanlon et al 2009) These women felt unable to leave the house for fear of being shamed. Their distress during this period appeared to be as a result of their inability to share their problems with their friends or neighbours, their fear of not adhering to postnatal rituals and traditions, which they believed could result in postnatal ill health and misfortune, (Hanlon et al 2009) as well as the fear that postnatal women and new-born babies were at risk of spirit attack and bewitchment, as they believed that supernatural agents caused disturbance in the woman's thinking and behaviour in the postnatal period. (Jansen 2006; Telfer et al 2002; Bazzano et al 2008; Salako 2006; Rasch 2007)

The women also identified the role of the community as a contributory factor to postnatal distress. They reported that women without financial freedom were unable to make independent decisions about their health and relied on their husbands or other family members to make financial contributions toward their healthcare (Telfer et al 2002; Rasch 2007; Mubyazi 2007; Brown and Harris 1978).

An important theme identified in a number of studies described the influence of the husband and the elder members of the community in making important decisions about pregnancy matters, and the women reported that they were more likely to trust and remember the advice of elder family members than the advice given by health care workers. (Kyomuhendo 2003; Mathole et al 2004; Rasch V 2007; Mubyazi 2007; Brown and Harris 1978; Edge and Roberts 1978) They also expressed their concerns about causing themselves problems within their community if they did not adhere to the wishes and advice of the elders in the community. (Mathole 2004)

7.4 COPING MECHANISMS EMPLOYED BY STUDY PARTICIPANTS

7.4.1 Acceptance and the will to survive

Within the present study, women had both negative and positive experiences during pregnancy and the postpartum period. Negative experiences included some women losing their children, and others even the ability to conceive in future due to the life-saving interventions that were conducted on them. Women who experienced life-threatening stressors were gravely ill and some were intubated for varying periods of time. This resulted in women experiencing memory deficits and cognitive difficulties.

Some women from both groups experienced rejection not only of paternity but rejection by their family members. These women also had to contend with not only personal stressors but financial stressors as well. Some of the participants were unmarried, had unwanted pregnancies, were unemployed, or were displaced as a result of immigration and asylum-seeking. These immigrants were also exposed to violence in the communities they resided in as a result of xenophobic attacks that occurred during the period when the study was conducted. As rapport and trust developed with the study participants during the subsequent interviews the women were forthcoming with information. These women described the need to cope and this was evident during subsequent follow-up appointments at three and six months respectively, when the study participants reported that they were more accepting of the events that occurred during pregnancy and the postpartum period.

For the women who had life-threatening complications and were physically ill, there was an initial fear of impending death and during subsequent appointments there was an acceptance of their ill health and a determination to recover.

A number of women from both groups became aware of their HIV status during the peri-natal period and although they expressed anger about their condition during the initial interviews, they appeared to be more accepting of the condition during the subsequent appointments. Two participants who had severe life-threatening complications expressed the desire to plan for their futures, the need to be employed and provide financially for their respective families and to accept what had happened to them and move on. Another participant described that her illness had resulted in her growth as a person, as she did not understand her illness before but as she started understanding the nature of her illness she was able to adjust to it and became more accepting of her condition. One participant who experienced a life-threatening complication and subsequently lost her baby described that she initially had difficulty coping but as she is a woman there is an expectation to be strong and accept the situation. The women in the study appeared to accept both the negative and positive aspects as their fate and chose to find solutions to deal with their problems.

These women from both groups presented with a strong sense of acceptance of their situations, irrespective of the magnitude and nature of the problems, be it their physical health, psychological well-being relationship status, loss of a child, rejection by a partner, family, society, infidelity, isolation, or financial and employment stressors.

The bio psychosocial approach is often used in the understanding of psychiatric illness, where along with biological factors, psychosocial stressors also contribute to or exacerbate illness. As described in the literature, women's vulnerability to social stressors such as deprivation, the role of major adverse life events, on-going socio-economic difficulties, as well as the burdens associated with pregnancy, childbirth and early motherhood, may predispose them to developing psychiatric conditions. (Van P 2001)

However, a mixed design study conducted on black Caribbean women in the United Kingdom (Siegel and Scrimshaw 2000) found that these women chose to deal with the adversity they were faced with, irrespective of its nature or extent. The quantitative component of the study indicated that black Caribbean women were significantly more likely than white British women to report social risks for depression because they were found to be socio-economically more vulnerable, with fewer and less-stable sources of social support. Despite these findings, the study indicated that black Caribbean women were not more likely than white British women to report symptoms of perinatal depression. This indicated that black Caribbean women were not more likely than white British women to report above-threshold depressive symptoms, despite the adversity they experienced.

The study also found that the psychological factors only contributed to perinatal depression if the feelings associated with the stressful life experiences were suppressed or denied. The women's accounts in that study explained that events which triggered psychological distress were the result of dealing with multiple layers of adversity and on-going social stressors, which included financial problems and difficulties in close relationships. To the women in that study, a diagnosis of depression was considered a sign of weakness and a threat not only to their ability to cope, but to their notion of self as well. Thus, their ability to address and deal with adversity emphasized their strength and resilience. They also described the need to be in control in all aspects of their lives, especially their difficulties.

Two other studies, one in the United States on women who had experienced a pregnancy loss, and the second in Africa on HIV-positive pregnant women, revealed similar results. (Tennen and Affleck 1999; Abboud and Liamputtong 2005) In these studies, individuals described the ability to experience positive changes of growth despite adversity such as the stress of living with HIV/AIDS and the negative sequelae associated with this situation, including stigma, disability and psychological distress. (Abboud and Liamputtong 2005)

Most of the women believed that the illness also contributed something positive to their lives and thus did not need to deny the adversity in their situation to perceive positive consequences. The women described that the need to cope with the negative consequences provided them with the opportunity to experience positive change. (Abboud and Liamputtong 2005) There are a number of ways to understand reports of benefit finding in the face of adversity. (Mengel 2008) One is that these reports are accurate accounts of real change, where most of the women appeared to believe the change to be real. Another understanding of benefit finding is that it represents an emotion-focused coping strategy to find positive meaning in stressful situations and thus reappraise their plight more favourably. It is explained that benefit finding helps individuals reinstate valued beliefs about themselves as worthy and relatively invulnerable, and their world as orderly, predictable, meaningful and benevolent or benign. (Mengel 2008)

Stress-related growth manifested itself in different forms, including health-behaviour changes, spiritual changes, changes in relationships, changes in view of the self, changes in value of life and changes in goals. Many of the forms of growth were observed within the multi-ethnic sample of women with HIV/AIDS. The findings suggest that the stress-related growth is generalizable to populations other than the primarily educated, white, middle-class samples previously examined.

Some have raised the concern that this optimistic view of severe stress and illness might be characteristic of only an educated elite; these findings support the notion that stress-related growth exists in women with lower incomes and education, and from diverse ethnic backgrounds. (Abboud and Liamputtong 2005)

7.4.2 The role of spirituality and religion in study participants' experiences

Along with the strong sense of acceptance, another theme that was frequently expressed by the participants in the present study was the prominent spiritual and religious convictions. Their belief and faith allowed these women to accept all situations, both positive and negative, regardless of the challenges life presented them with. Among the positive experiences expressed by the women was the gratitude of being blessed with a baby and for others who had life-threatening complications was the gratitude of life.

For women who experienced the loss of a child or the ability for future conception, did not believe that they were being punished but accepted their situations as being the will of God. One participant who was rejected by her family believed that she was not alone in her struggle and that God was there to guide her. For an asylum-seeking immigrant who had to care not only for an ill husband and baby but also for the rest of her family, had no means of an income but continued to believe that God would help her and that she would achieve things through her prayers that would be answered by God. Another patient described that she learnt to pray as a result of her illness and that through prayer she got the necessary strength which helped her cope. Study participants believed that God is aware of their lives and it is only God who would help them during their periods of distress. Women from both groups presented with a strong sense of faith and belief in God, irrespective of the magnitude and nature of their problems, be it their physical health, psychological well-being, marital problems, the loss of a child or ability to have children in future, rejection by a partner, family, society, infidelity, isolation, or financial and employment stressors.

The one driving force was the will of God in everything that they had experienced, be it during times of joy and happiness or grief and trauma. From the literature, a coping mechanism commonly described in adversity was that of spirituality, faith and religion. DeFrain et al (1996) reported that 73% of their sample found religious beliefs valuable after their loss.

A significant finding in the study on black Caribbean women found that they were more likely than their white British counterparts to access spiritual sources for emotional support. (Siegel and Scrimshaw 2000) The findings were validated by narratives of women, which indicated that spirituality was a way of dealing with adversity. Spirituality was also found to be a means of making sense of adversity, and to provide a source of strength for dealing with it.

Similar themes with regard to drawing on spiritual resources as a means of coping were explored by Souza et al (2009) in the narratives of women who experienced near miss pregnancies. The healing strategies used by the participants reflected their inherent and instinctive processes, resources, and remedies, with limited use of outside resources. Although only 40% of women in the sample attended church, or practised an organized religion or spiritual practice, religion and spirituality were extremely valuable to them.

The theme of life after death was prevalent, and many of the women expressed the view that the babies were in a good and safe place, and, in some cases, being taken care of by loved ancestors. Similar to previous studies, (Lichtenthal, Cuuier, Neimeyer and Keesee 2010)

Murphy et al. (2003) found that the most common sense-making themes involved reliance on spirituality and religious beliefs about God's plan or the continuity of life beyond death.

Another study showed that African American women accessed religion as a coping mechanism more frequently than European American women. African American women used religious practices as a means of gaining strength, stamina and insight to manage the challenges of daily life. (Roberson 1985; Wilson-Ford 1992; Killion 1995; McIntosh 1993) They also used these practices as a means of finding answers to unexpected adverse events, such as the loss of a baby. Furthermore, the religious beliefs included the view that God has a reason for everything that happens to them and that healing would be achieved if they turned to their beliefs for assistance in finding acceptable answers. DeFrain et al (1996) reported that 73% of their sample found religious beliefs valuable after their loss, with most of the participants reporting that religious and spiritual beliefs and practices were important in their lives, especially when they had to deal with traumatic events such as pregnancy loss. Connectedness to spiritual or religious beliefs and activities as a source of strength and guidance was found to be important to many African American women. (Oates et al 2004) Even those who reported a lack of formal religious affiliation used spiritual beliefs and practices to cope with pregnancy loss.

The strong religious conviction and faith was a prominent theme in both groups of women, and whilst discussing the themes with my supervisor, the question arose whether my role as a female interviewer in Islamic attire, namely the hijab, could have influenced the responses of the participants.

A hijab is a headscarf without a face veil and is the most recognizable symbol of Islam worldwide. (Benstead 2014) However, to some critics it is seen as a symbol of oppression. Hijab has been given many social and political meanings amongst others; it allows women to maintain traditionalism while accessing public space. (Hessini 1994) According Essers and Benschop, (2007) a hijab is understood as a symbol of religiosity and adherence to fundamentalist Islam.

As a researcher, my approach to the hijab is that it is a symbol of religiosity and adherence to Islam, and not "fundamentalist Islam" as defined by Essers and Benschop. (2007) Researchers predominantly working in Western countries have examined how observable interviewer traits affect data quality. Most studies focus on significant characteristics such as race, class, age, language, ethnicity and gender.

Although interviewer effects research is limited outside the Western countries, research has expanded and increasingly informs debate in transitional countries. (Benstead 2014; Scheaffer 1980; Schuman and Converse 1971; Katz 1942; Ehrlich and Riesman 1961; (Fellegi 1964; Webster 1996; Benstead 2013b; Flores-Macias 2008; Kane and Macaulay 1993; Dionne 2014; Koker 2014) Although studies show that interviewer dress systematically affects responses to items about religion, researchers usually do not report or analyse the impact of interviewer traits. (Benstead 2014) Respondents have been found to stereotype interviewers and based on interviewer dress as well as gender and class-based cues, respondents may falsify or exaggerate responses, or refuse to divulge them altogether to avoid embarrassment, social sanction, or the appearance of disloyalty to their in-group. Although actual consequences are unlikely, fear of potential sanction in the form of loss of opportunities or reputational costs may be enough to induce the respondent to edit their responses. (Blaydes and Gillum 2013)

Two theoretical frameworks, namely social desirability and power relations, potentially explain response effects. Social desirability theory posits that respondents engage in self-preservation and impression management by avoiding socially unacceptable views or conforming to socially stereotyped views of the interviewer, (Benstead 2014; Katz 1942; DeMaio 1984; Sudman and Bradburn 1974) whilst power relations theory takes into account the inequality between groups.

They argue that incentives to avoid socially undesirable views are more pronounced among members of vulnerable or less dominant groups. (Kane and Macaulay 1993) In an attempt to mitigate potential bias, Benstead (2014) recommends that interviewer dress should be recorded, reported and controlled for in order to allow readers to better assess results.

Although the interviewer effect has to be borne in mind in terms of the participant responses in this study, a constant finding throughout the process of data analysis was the strong sense of religious conviction in the participants. This was not only evident from the direct interviews with the participants, but also present in the journals that the participants kept.

As the grounded theory principle was the approach to data analysis in this study, a deductive, inductive interplay centred on data offered by the participants is important. (Mc Gee et al 2007) Grounded theory stipulates that themes be grounded in the data rather than being derived from a preconceived conceptual framework. This requires awareness of self and a consciously reflective process called reflexivity. (Patton 1990) Robson states that reflexivity is "an awareness in which the researcher as an individual with a particular social identity and background has an impact on the research process." (Robson 2002).

Furthermore, Neil (2006) argues that the potential impact of the researcher on the data needs to become part of the research record in order to be explored through constant comparative analysis. Although researcher creativity is an integral part of the emergence of categories, these categories must be inductively derived from the data in the field and not forced into the shape of preconceived notions held by the researcher. (McGee et al 2007)

Interviewer dress is thus acknowledged in this study, but the extent to which this may have influenced participant responses is unknown, as findings from the literature, which were discussed, show that women in adversity use religious resources as coping mechanisms.

7.5 AFTERCARE EXPERIENCES OF PARTICIPANTS DESCRIBING BOTH HEALTH AND MENTAL HEALTHCARE AS WELL AS BARRIERS TO SEEKING CARE

Fourteen of the 16 women who participated in the case studies of the present study attended all four interviews. The interviews provided an opportunity to establish a rapport and develop a relationship.

As the interviews progressed, the women gradually became more trusting and forthcoming with their feelings and emotions, whilst voluntarily describing their difficulties. However, it was not an easy task to gain the women's confidence and trust from the outset.

The participants expressed that the regular appointments afforded them an opportunity to discuss many of their challenges, hardships and difficulties, and it was not only the negative perceptions that were shared, but their dreams, hopes and plans for the future too.

The two participants who did not follow up, both of whom were severely ill at the time of delivery, reported when telephonic contact was made that returning to the hospital environment and the interaction with me would remind them of the time of their loss and they did not wish to revisit that traumatic time in their lives.

These women felt that discussing the past wouldn't change their circumstances, nor would it return what they had lost, and thus saw no benefit in attending the follow-up appointments. Other participants, however, considered the follow-up appointments as an opportunity to discuss things without the fear of being ridiculed or judged, and thus a time to express their problems with somebody whom they felt would listen to and understand their experiences. The women had differing views with regard to the overall treatment and care that they received during the peri-natal period. For some, the care was satisfactory and they felt that their needs were met at the antenatal clinic, during their hospitalization and at the time of delivery, with some women reporting that they were informed of the procedures to follow in the event of any complications.

However, there were a number of women in both groups who felt that the nursing staff were not understanding or empathetic. They found some of the staff to be hostile at the time of booking at the antenatal clinic and described that some staff as being rude and discriminating. This behaviour was not only described by young women with teenage pregnancies, but also by women of advanced maternal age. Women who were severely ill felt that there was a lack of communication between them and the health professionals with regard to their physical condition, and also perceived a lack of nursing care during their illness. The women also felt that the extent of their complications, as well as progress regarding their physical conditions, was not explained to them. They described doctors discussing their respective conditions with other health professionals, without really taking the time to explain the situation or extent thereof to them. (It has to be borne in mind, though, that both complexes where the study was conducted are teaching hospitals affiliated with the medical school, and these women may thus have been exposed to teaching ward rounds.)

Women found that they were asked to consent to surgical interventions, be it a caesarean section or a hysterectomy, without being informed of the indications. It may also be possible though that the women may have been informed about the indications for surgical interventions but the language in which the doctors conveyed it may have included medical terminology which the women may not have understood. Women who had lost their babies described a lack of empathy and understanding from the nursing staff and felt that their loss wasn't dealt with in a caring and sympathetic manner by the staff or the environment, as they were often kept in the labour ward or the same environment as other recently delivered mothers. Women who were referred to social workers, and two who saw psychologists, described disappointment as they were not given adequate information regarding the cause of the loss, nor did they feel they were counselled appropriately. These women were merely told that it was the Will of God's and that they could try to conceive at a later stage.

Women's perceptions of the care they received were also described in the literature, with mothers reluctant to disclose emotional and personal problems or seek professional assistance in the postpartum period. In a large, multicultural study spanning 15 centres and 11 countries, British Asian women considered professional or medical assistance as inappropriate for treating postpartum conditions, especially depression. (Parvin, Jones and Hull 2004) Icelandic mothers thought that health centres were inappropriate to treat emotional problems. (Templeton, Velleman, Persaud and Milner 2003) whilst British Bangladeshi mothers perceived emotional distress to be separate from physical symptoms, and to them the health professionals' role was to provide physical care. (Edge, Baker and Rogers 2004) A lack of knowledge about postpartum conditions, especially depression, was also identified as a barrier to seeking care. (Nahas, Hillege and Amasheh 1999; Rodrigues, Patel, Jaswal, Castilla and de Souza 2003; Chan, Levy, Chung and Levy 2004; Chan and Lexy 2004) Many women had difficulty understanding the problems they experienced, and presumed their struggles to be a normal part of motherhood, whilst others were either unaware, (Javanovic 2000; Nahas et al 1999; Chan and Levy 2003; Ugaririzza 2004; Mauthner 1997; Mauthner 1999; Nicholson and Woollett 1998; Tammentie, Paavilainen, Astedt-Kurki and Tarkka 2004) denied or reluctant to admit that they were experiencing depression. (Whitton, Warner and Appleby 1996; Holopainen 2002; Kim and Buist 2005; Kim and Buist 2005 Amankwaa 2003)

Korean mothers in the multicultural study believed that being a mother meant the end of carefree days and the beginning of responsibility and work. Other women were concerned that discussing their emotions would bring their families into disrepute, or that they would be responsible for problems within the family (Edge 2004).

The fear, shame and stigma of being labelled mentally ill were important factors in women's decision to seek or accept help. (Thome 2003; Nahas et al 2004; Holopainen 2002; Mauthner 1999; Mauthner 1997; Tammentie et al 2004; Shakespeare et al 2003)

Different researchers portrayed culture and the various conceptualizations of the maternal role as barriers to seeking help, and as mentioned previously, in some African American communities, depression was seen as a sign of internal weakness and not a legitimate illness. (Shakespeare et al 2003) Similar findings of a mother not wanting to disclose her depression due to implied weakness or perceived failure were found among Caribbean, Finnish, Jordanian, Scottish and Swedish women. (Nahas et al 199; Rodriguies et al 2003; Amankwaa 2003; Chan 2002; Tammentie 2004)

Studies have also described that socio-economically disadvantaged women faced numerous barriers to care at the system, provider and patient levels. (Committee of Health Care in America 2001) System barriers (medical and mental health settings) included a culturally insensitive or stigmatizing environment, high staffing ratios, and long waiting times. (Diamond and Factor 1984) whilst potential patient barriers included practical ones such as financial barriers, inaccessible clinic locations. (Maynard, Ehreth, Cox, Peterson and McGann 1997; Mickelson, Kessler and Shaver 1997; Bifulco, Kwon, Jacobs, Moran and Bunn 2006), cultural barriers, psychological barriers, stigma, and avoidant or fearful attachment styles. (Hobfoll, Ritter, Hulszier and Cameron; Nahas and Amasheh 1999). With regard to the perception of the hospital environment, some women felt that they had to adapt their behaviour within the hospital environment. (Berwick 2001; Diamond and Factor 1994; Okano, Nagata, Hasegawa, Nomura and Kumar 1998) For example, they felt that they and their new-borns needed to wear new clothes, which caused feelings of shame and inadequacy if they were too poor to do so and they were therefore unlikely to attend hospital. (Berwick 2001; Okano et al 1998) Other studies reported that women felt restricted if they were unable to express pain communicate effectively during labour, and therefore felt that the experience of childbirth was devalued in the hospital environment. (Diamond and Factor 1994)

Also, with regard to the hospital environment, research suggests that families and communities may act as barriers as they may be unable to provide assistance or may discourage help-seeking due to a lack of understanding as well as cultural perceptions about admitting depressive symptoms and discussing them with outsiders. (Lichtenthal et al 2010; Nahas et al 1999; Chan and Levy 2004; Matthey, Barnett and Elliot 1997; Thaddeus and Maine 1994; Amooti-Kaguna and Nuwaha 2000)

Bangladeshi women living in the UK who indicated that they talked freely in the hospital about emotional problems demonstrated this, but few discussed their difficulties at home for fear of censorship by family members. (Edge et al 2004)

Distance, cost and quality of service provision are known barriers that influence the uptake of health care in low-income countries. (Umeoa, Ejikeme, Sunday-Adeoye and Ogu 2008) Although these are significant factors, a number of additional barriers specifically related to accessing prenatal care and medical services in the event of an obstetric emergency were also identified. It was reported that patients and communities may have limited knowledge regarding obstetric complications, but there were misinterpretations about the causes of the complications. (Mrisho et al 2009; Telfer 2002; Odimegwu et al 2005) These misinterpretations were probably due to staunch spiritual and cultural beliefs. Women were doubtful of the ability of modern health care workers to deal with obstetric emergencies, mainly because they believed these were caused by "spiritual powers" being used against the pregnancy. (Grossmann-Kendall et al 2001) The women were likely to visit traditional birth attendants or healers, as they perceived them to be more capable of assisting them with their problems. (Mrisho et al 2009) Some studies reported the belief that traditional birth attendants had near-supernatural powers, which could protect a woman and her pregnancy from harm. (Bazzano et al 2008)

As mentioned previously, significant treatment barriers were found in the literature relating to health professionals. The barriers identified were inappropriate assessments, lack of knowledge about postpartum conditions, and the nature of the relationship between the mother and the professional. (Templeton et al 2003; Mauthnet 1999; Nicholson and Woollett 1998)

The review by Brighton (2013) reported that women expressed negative attitudes towards health care workers (D'Ambruoso Abbey and Hussein; Maimbolwa et al 2003; Mrisho 2009; Bazzano 2008; Umeora et al 2009; Seljeskog et al 2006; Lawoyin et al; Ogujuygbe 2007; Brighton et al 2013; Grossman-Kendall et al 2001; D'Ambruoso L; Mubyazi 2007; Ozochukwu 2004; Kowalewski et al), whom they described as being abusive and rude. The women felt that they were not attended to in a caring or empathetic way and described the perceived attitude of health care workers as having a significant influence on their decisions in seeking prenatal and obstetric care. (Owoeye et al 2006; Amooti-Kaguna and Nuwaha 2000; Grosman-Kendall et al 2001; D'Ambruoso et al 2001; Uzochukwu et al 2004)

In the previously mentioned study by Souza et al (2009) on women who experienced near miss pregnancies, the women complained about the way in which health care practitioners, including doctors, treated them. They described the practitioners as being excessively abrupt, displaying a lack of attention as well as distant and non-humanized behaviour. A study in the United States found that women felt disappointment, humiliation, frustration and anger due to their interactions with health professionals, (Beck 1993) whereas an Australian study reported that the women believed their physicians displayed disinterest and patronizing attitudes, which exacerbated their inability to cope. (Ugarriza 2004)

Paton et al. (1999) showed in their study that the majority of women were satisfied with their hospital care, but described areas that needed to be improved, including the way the bad news was given to them, and the explanation of the cause of the pregnancy loss. What women valued most, however, was quality of care in terms of attentiveness, kindliness and sensitivity and many women wanted an opportunity to talk about their feelings with a sympathetic and empathetic listener

In a qualitative sub-study using data taken from the UK National Women's Health Study, Simmons and colleagues (2006) analysed essays related to the aetiology of the loss collected from 172 women who had experienced "miscarriage" A major theme that emerged from the analyses was the "disconnect" between women and their providers over the magnitude of the loss as reflected in ward assignment (including them with women who were still pregnant or having elective terminations), delivery of news that a loss was occurring, and explanations for the loss. The experiences left women feeling that their providers handled their loss as a matter of "routine" care, when it was not at all routine for the women experiencing the loss.

7.6 SUMMARY

The participants in the present study comprised not only women who experienced medical or life-threatening complications, but those who experienced uneventful pregnancies as well. In spite of these differences, women from both groups had positive and negative experiences, be it psychological sequelae, socio-cultural stressors or health system-related factors.

These experiences presented the women with the challenge of having to find ways of accepting and coping with their problems, such as accessing religious or spiritual resources.

Furthermore, with regard to their experiences with the health system, participants described their interactions with nursing staff as unsatisfactory, with staff not having empathy or understanding, which the study participants expected. They also felt that critical information pertaining to their health was not discussed with them directly by the health professionals.

As is evident from the results of the current study and those made reference to from the literature in this discussion, maternal health, and especially maternal mental health, are not constructs that can be considered in isolation. Illness is not only the result of biological causes. Other factors come into play in the illness process and in the maintenance of homeostasis in women's lives. These factors include psychosocial, socio-cultural and health system related factors. In the process, some women learn to cope and accept adversity. Furthermore, care seeking behaviours are influenced not only by culture and religion but can be influenced by the health system too.

8 INTEGRATION OF FINDINGS

8.1 INTRODUCTION

Chapters 6 and 7 focused on the discussion of the quantitative and qualitative results respectively. The study design, as discussed in Chapter 3, was a mixed methods study conducted using the parallel convergent design. This chapter focuses on the discussion pertaining to the mixing of the results of the study. Prior to the discussion, a case vignette is presented which highlights the combination of findings of the two arms of the results, namely the qualitative and quantitative arms.

8.2 CASE VIGNETTE

LM is a 20-year-old P3G2, with a three-year-old daughter and newborn twin boys. At the time of the first interview she had been in a relationship with the father of her twin boys for a year. She lived with her boyfriend in an informal settlement with amenities. LM described the latest pregnancy as unplanned and initially unwanted and mentioned that she had been using the injectable contraceptive when the pregnancy was confirmed. When she discovered that she was pregnant with twin children she felt unable to cope, as she did not know how she would provide for two children because her relationship was in its infancy and she had no other income or form of support. LM felt alone, unwanted and unloved as she was rejected by her mother after the death of her father and grew up in a children's home. After one of her antenatal appointments she attempted suicide by overdosing on folic acid supplements that she was given at the antenatal clinic. After a short admission, she was discharged into the care of her boyfriend. LM reported no previous medical or psychiatric history and denied illicit drug use but admitted that she consumed alcohol on occasion to help her forget about her difficulties. Although she attended school, she did not progress far due to learning difficulties. She ran away from the children's home on more than one occasion, wanting to live with her mother, whose acceptance she yearned for. Her mother and her stepsiblings rejected her, and on one occasion she was almost raped by her mother's boyfriend. She began living on the streets, during which time she fell pregnant, then returned to live with her mother, but after the birth of her daughter, she was once again rejected and her mother refused her access to her child. She returned to living on the streets and did piece jobs such as cleaning to survive, and then moved in with her boyfriend. LM admitted that religion was important to her and that she believed God loves her.

She attended the antenatal clinic on three occasions and was subsequently referred to the hospital for further management of her twin pregnancy. Prior to her scheduled appointment she had abdominal pain and noticed that her legs were swollen and that she had difficulty with her vision. An emergency caesarean section was performed as she was diagnosed with severe preeclampsia with HELLP (Haemolysis, elevated liver enzymes and low platelets) syndrome. Twin boys were delivered at 33 weeks, one of whom was born with congenital abnormalities, and both were admitted to the neonatal ICU. Her condition deteriorated postoperatively, and further investigations revealed that she had a pulmonary embolus and had developed bilateral pleural effusions and multi-organ failure.

At the first interview, she did not present with significant symptoms of depression or anxiety. She remained in hospital for a period of three weeks and was subsequently discharged with her children. Prior to the scheduled six-week appointment, the twin with the congenital malformations passed away, and at her appointment she presented with moderate to severe symptoms of depression and comorbid anxiety symptoms. She was referred for further treatment of her depressive and anxiety disorders. At the three-month follow-up, she reported being rejected by her boyfriend's family after the death of her baby, and that her boyfriend was unfaithful. She was tearful during the interview, but symptoms of depression were not as severe as at the six-week interview, and she reported that the medication had helped her. Her baby was also thriving, and she reported that she was coping. At the six-month follow-up LM presented with no residual depressive symptoms; she was happy and positive about her life. She revealed that after the three-month appointment she used the money given to her for her travel expenses to buy food items, which she resold, leading to her starting a little business. She was thus able to provide for her baby. The prominent themes that were identified during the interactions with LM were her unwavering belief in God, acceptance of her trials as the will of God, her motivation to improve her life and that of her child, a desire to educate herself, and the unmistakable will to survive despite the adversity.

This vignette highlights the strengths of the mixed methods used in this study. The quantitative arm provided the clinical information pertaining to the psychiatric sequelae whilst the qualitative arm, through the in-depth interviews, provided another dimension and deeper insights into the worlds of the participants. When combined, a true reflection of the situation emerged and the sequelae could aptly be explained according to the biological, psychological, socio-cultural and religious process. The methodology decided upon in this study, as discussed in Chapter 3, was that of a mixed methods study consisting of both qualitative and quantitative arms conducted using the parallel convergent design.

The two arms of the study were conducted concurrently, and integration of the two arms occurred at the level of interpretation. Please refer to Chapter 3 for an explanation of the parallel convergent design.

The mixed methods design was chosen as it was deemed the most appropriate way to achieve the following:

1. Determine if women who experience severe, life-threatening stressors would be predisposed to developing psychiatric sequelae.
2. Gain an understanding of the lived experiences of women who experience life-threatening stressors subsequent to discharge from hospitals.
3. Gain insight into the mental health aftercare experiences of women who have experienced life-threatening stressors, as well as those who have had uneventful pregnancies.

Although a quantitative method would have been sufficient to answer the first point, a comprehensive understanding of the lived experiences and aftercare experiences would only be adequately described through the use of a qualitative method. Therefore, a mixed methods study was a suitable choice to answer the research questions.

8.3 FINDINGS OF THE QUANTITATIVE COMPONENT OF THE STUDY

The results of the socio-demographic variables revealed that the study participants – both the women with life threatening stressors and those with uncomplicated pregnancies – presented with a number of risk factors that could predispose them to developing postpartum psychiatric complications. These risk factors included unplanned, unwanted pregnancies, young age, low socio-economic status and being an immigrant. A quarter of the women with life-threatening stressors presented with pre-existing medical conditions. Furthermore, the participants from both groups reported some social support and expressed their religious involvement. Results of the quantitative arm revealed that women from both groups (those who experienced life-threatening complications and those with uneventful pregnancies) developed psychiatric complications.

An important observation, which confirmed the hypothesis of the study, was that the women who experienced life-threatening complications were more vulnerable than women with uneventful pregnancies to develop psychiatric sequelae.

These women experienced greater distress and were more prone to develop symptoms in almost every symptom domain as compared to women with uneventful pregnancies. These conditions were diagnosed at the first interview, which was shortly after delivery; an increase in the number of women experiencing psychiatric symptoms reached a peak at six weeks. The duration and intensity of symptoms were however not sustained and symptom resolution was observed during the ensuing three months with only a limited number of women presenting with residual psychotic symptoms at the six-month appointment.

The rates of psychiatric sequelae in the women who experienced life-threatening stressors experienced were higher than the prevalence rates for psychiatric conditions described in the literature in women with uneventful pregnancies. The number of participants from both groups who experienced psychiatric sequelae increased at six weeks. Symptom distribution and intensity was not sustained and decreased in the subsequent months, as was evident at the three-month follow-up. Furthermore, only 3.3% of women continued to experience residual psychiatric symptoms at the six-month follow-up. When symptom distribution and intensity is considered, it is apparent that these women experienced distress in the first six weeks of the postpartum period. This is normally the time required for physiological processes to re-establish homeostasis. The psychiatric complications that the study participants from both groups experienced included major depressive disorder, generalized anxiety disorder, sleep and somatic disturbances, symptoms of anger, symptoms of cognitive and memory impairment, and psychotic and manic symptoms. The women who experienced psychotic disorders included both women who had experienced life-threatening stressors as well as women with uneventful pregnancies, with women who experienced life-threatening stressors experiencing greater distress than women with uncomplicated pregnancies. The transient nature and rapid resolution of the psychotic symptoms experienced by women with life-threatening stressors could indicate the presence of a delirium. The resolution of symptoms could also have occurred as a result of life-saving interventions and aggressive management of the underlying medical conditions.

Furthermore, the psychotic symptoms evident in the women with uneventful pregnancy occurred as a result of a relapse of a pre-existing psychiatric condition. The women in the study presented with anxiety symptoms that were severe at delivery and at six weeks but decreased at the three and six-month period. The symptoms were more pronounced in women who had life-threatening complications. It is possible that these women presented with acute stress symptoms that improved in the subsequent months during the postpartum period.

Also, of the women with life-threatening stressors who followed up at six months did not present with significant symptoms that fulfilled criteria for a post-traumatic stress disorder.

It may be, that although the participants experienced stressful situations during pregnancy or delivery, including life-threatening stressors that threatened their wellbeing, the symptoms did not reach a threshold that fulfilled the criteria for post-traumatic stress disorder. This condition could however not be confirmed in view of the attrition of study subjects.

As a result of the short duration of symptom presentation and resolution of symptoms, as well as the comorbid presentation of depressive and anxiety symptoms, it was postulated that an adjustment disorder with mood and anxiety symptoms could be considered. Another finding of this study was the presence of somatic symptoms; sleep abnormalities and symptoms of anger that participants from both groups presented with. The presence of somatic symptoms in the perinatal period has been an area of debate in the literature. It has been argued that somatic symptoms may be present in normal pregnancies and occurs as part of the adjustment process that women experience during the perinatal period and is not necessarily pathologic in nature. In the participants in the present study, these symptoms were accompanied by impairment in functioning, as concurred by the results of the disability scale. This could therefore indicate the presence of an underlying distress that the women experienced. These somatic symptoms could also indicate atypical symptoms that were present in the study participants.

Furthermore, participants from both groups also experienced memory impairments that were not sustained and had resolved by the time of the six-month follow-up.

If the quantitative arm of the study were considered in isolation, it would appear that women experienced distress around the intrapartum period, which reached a peak and then subsequently resolved.

This pattern was mirrored in the results from the WHO Disability Assessment, where women from both groups experienced impairment in functioning during the intrapartum period, with dysfunction most pronounced around the time of delivery. A gradual improvement in social and occupational functioning became evident during the subsequent appointments at six weeks, three months and six months. The psychiatric presentation could then be considered to be part of an adjustment disorder that impairs functioning initially, but as time progresses, women adjust to the specific demands expected of them, and symptom duration and intensity thus wane over time.

This appears to be a rather simplistic and one-dimensional explanation, but the additional information provided by the qualitative arm completes and complements the explanation.

8.4 FINDINGS OF THE QUALITATIVE COMPONENT OF THE STUDY

Twenty participants selected for the case studies in the qualitative arm were purposefully sampled, and included women from both groups, namely those who experienced life-threatening stressors and those with uncomplicated pregnancies. Of the women who experienced life-threatening complications, some experienced foetal losses as well. Four in-depth interviews were held with each participant from both groups. Prominent themes were identified from the interviews using the grounded theory method. Themes as discussed in the previous chapter were broadly categorized into positive, negative, socio-cultural, religious, health system and interviewer-related categories. Themes of the will to survive adversity and acceptance were also identified.

The positive experiences included the joy of having a baby, as well as the happiness and fulfilment that the growing child presented the mother and family with. For the women who experienced life-threatening events, there was gratitude for life.

The negative themes included fear of death for women who were severely ill; themes of loss, not only the loss of a child, but for some women the loss of child-bearing potential; fear of future pregnancies and further complications; feelings of disappointment; guilt feelings; and difficulty adjusting to the demands of motherhood. For the participants with life-threatening stressors who had a foetal loss, there was the adjustment of not returning home with a baby.

A theme of isolation was also present in both groups of participants and was exacerbated by the three-month isolation that cultural dictates require of new mothers. The isolation experienced by the women who had life-threatening stressors included the physical isolation required during recuperation. For the women who had foetal losses as well as losses of future fertility, the isolation was described as both voluntary and involuntary. The voluntary isolation these women described was a time to grieve their losses in private, whereas the involuntary isolation was the social isolation that the women with foetal losses experienced. Women who experienced life-threatening stressors described themes of confusion and memory impairment.

Furthermore, a prominent theme experienced by women who were severely ill and hospitalized for a significant period was the lack of bonding with their babies. Health system-related themes included both positive and negative themes about the care and information that the study participants received. Among the positive themes described was the satisfaction of care that some of the study participants received.

The negative themes pertained to a lack of care, empathy and understanding from staff, as well as a lack of information and communication by nursing staff and doctors alike. Socio cultural factors included infidelity of partners, fear of rejection, fear of disclosure of medical conditions and extent of illness, and intervention. Poor support, stigma, social prejudices and cultural practices were themes expressed by women from both groups.

As the interviews progressed, a prominent theme that emerged was a strong sense of faith and unwavering belief in God, despite some of the participants describing themselves as not being particularly religious at the initial interviews. Acceptance of their situations was present in all participants, regardless of whether they had experienced life-threatening complications or uneventful pregnancies.

8.5 DISCUSSION OF THE INTEGRATION OF THE QUALITATIVE AND QUANTITATIVE FINDINGS OF THE STUDY

When the two arms are considered independently, a one-dimensional or simplistic understanding of the study is obtained in that women who experience life-threatening complications developed psychiatric complications, but not more than women with uneventful pregnancies. When the qualitative arm is considered, the lived experiences become evident.

Through combining the two components, a multi-dimensional and deeper understanding and meaning of the circumstances and situations that the participants experienced became evident. Maternal health, and especially maternal mental health, is constructs that cannot be considered in isolation. The socio-demographic variables identified in this study provided an insight into the risks that predisposed the study participants, namely the women with life-threatening stressors and those with uneventful pregnancies, to developing psychiatric sequelae.

Furthermore, the presence or absence of illness does not only occur as a result of biological factors, but consists of a complex interaction of biological, psychological, and socio-cultural factors. Religious and health system-related factors could also influence the presentation of illness. These complex interactions became evident when the two arms of the study were combined, and a comprehensive picture emerged as depicted in figure 11, page 246 where the integration of the findings of the quantitative and qualitative arms are presented and discussed hereafter.

The study participants experienced psychiatric sequelae, which were identified at delivery. An increase in the number of participants who experienced psychiatric complications was identified at six weeks. These women returned to their environments after discharge from hospital and had to readjust to the life and demands outside the hospital in their respective communities. The distress that these women felt could be explained by the presence of atypical symptoms, including the sleep disturbances, somatic symptoms, as well as the mood and anxiety symptoms, which was confirmed by the quantitative results. The duration of the symptoms and impairment in social functioning was also evident at the initial interview and the six-week follow up. Of the participants who experienced life-threatening stressors who were severely ill and ventilated for periods of time, the memory impairments were confirmed in the quantitative results, as were the impairments in various levels of functioning upon return to their homes.

The anger that the women expressed in the qualitative arm was confirmed in the quantitative results and could be explained in a number of ways. Firstly, the anger could occur as part of the grieving process for their respective losses, not only in participants with life-threatening stressors who had foetal losses, but also in women who were severely ill with life-threatening stressors who lost their ability for future conception as a result of life-saving interventions like hysterectomies. Secondly, the infidelity and rejection that some of the women experienced could explain some of the symptoms. Furthermore, the lack of care, empathy, information and understanding that they received from staff in the hospital could explain some of the feelings of anger expressed by the study participants. These feelings were pronounced at the six-week follow-up.

A shift in presentation of psychiatric symptoms was, however, observed during the subsequent appointments, namely at three and six months, as indicated in the results of the quantitative study. During the subsequent appointments, themes of acceptance and the will to survive were evident from the narratives of the study participants.

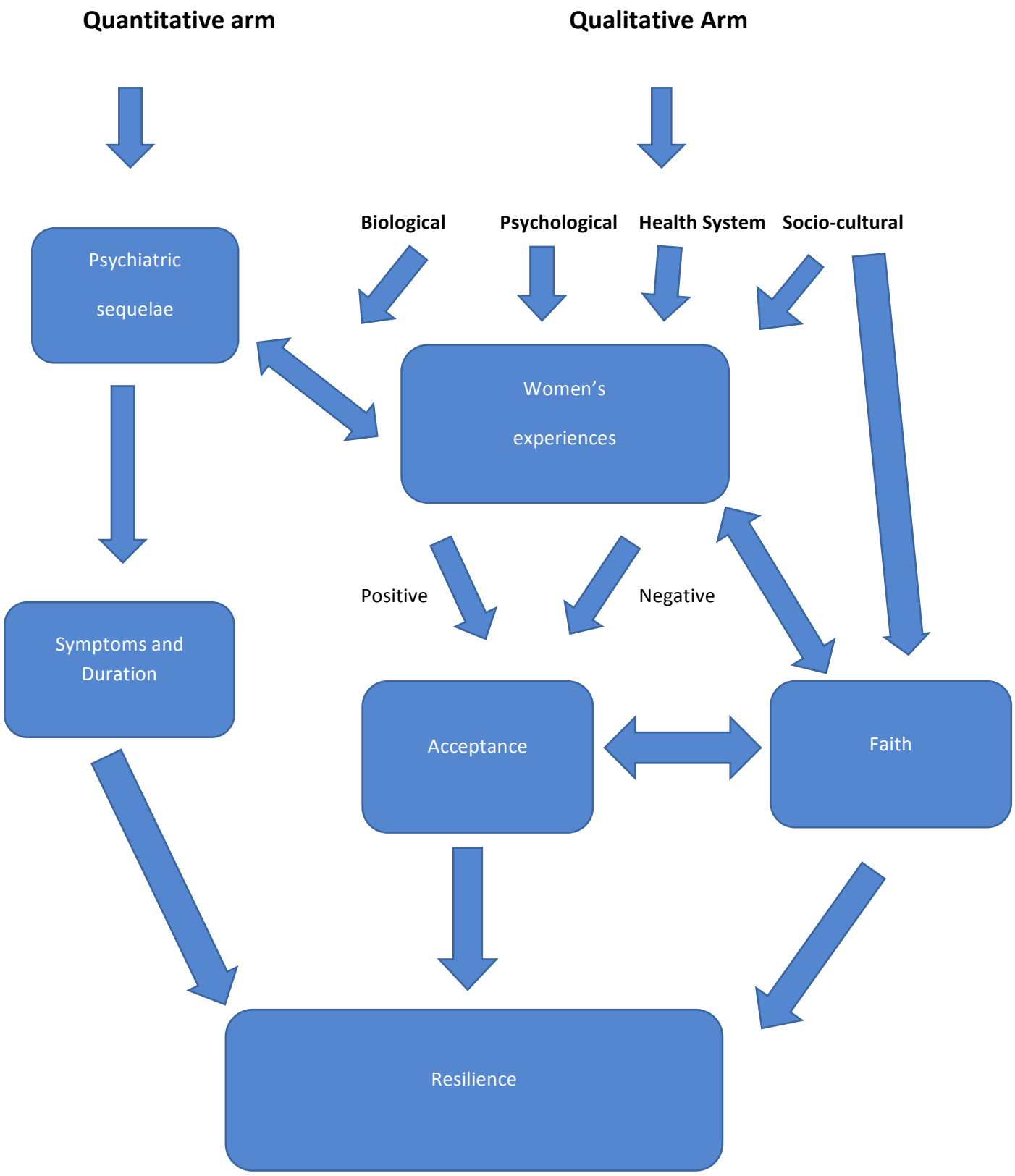
Also, the strong feelings of anger and disappointment had dissipated, and the unwavering belief in God and belief that everything that happened was the will of God was also identified during the three-month follow-up, when the themes of acceptance and religious beliefs were pronounced. Furthermore, the interviews with the participants presented an opportunity to establish a rapport. Although the women had consented to participate in the study, the initial interviews were characterized by a hesitance to be forthcoming on their part. There was thus a superficial rapport established initially, but as the interviews progressed a relationship of trust and understanding developed.

The participants were more forthcoming with their feelings and this provided an opportunity to gain an insight into their worlds. They also found it easier to discuss their problems and felt that somebody understood them. They described that it was easier to discuss their problems with a stranger and mentioned that they didn't feel as if they would be judged if they disclosed their fears and problems. This was not the case for all the participants though. For women who experienced life-threatening stressors and subsequent losses, interaction with the interviewer represented and was associated with an unpleasant and painful time in their lives that they needed to forget. This experience may have influenced these women's decisions not to attend any further appointments.

The study participants from both groups, namely the women with life-threatening stressors and those with uneventful pregnancies, were exposed to adversities. For some of the participants with uneventful pregnancies, this included lack of support from a partner, infidelity, financial stressors, socio-cultural stressors including exposure to violence, and unemployment. Women with life-threatening stressors experienced additional adversity, namely physical ill health that could have resulted in death. The life-threatening experiences evoked feelings about the meaning of life, feelings of inadequacy, and guilt feelings. Some of these participants also had to contend with infidelity or the lack of a supportive partner.

A quarter of the participants were immigrants from other countries in Africa, and of these women almost a fifth were women who experienced life-threatening complications during pregnancy. The present study was conducted during a turbulent time in South African politics when there were xenophobic attacks against non-South Africans. The problems this posed were relayed through telephonic contact with some women, or their partners, who, when informed about the follow-up appointments, explained the difficulties they experienced. Immigration status has been identified as a risk factor for developing psychiatric complications, and pregnant immigrant women may be at particularly high risk. (Zelkowitz et al 2004; Franks and Faux 1990)

Figure 11. Integration of qualitative and quantitative arms



Studies have reported that stresses connected with the immigration process may affect physical and emotional wellbeing, financial worries, social isolation and separation from extended family. These women have lower levels of support, which, rather than the immigration status, was reported to cause the stress and risk for psychiatric disturbance during pregnancy and the postpartum period. (Landale and Oropesa 2001; Brugha et al 1998; Engle, Scrimshaw, Zambrana and Dunkel-Schetter 1990; Zelkowitz 1996) However, despite experiencing these stressors, the women chose to deal with their problems and rise above them.

The stress diathesis model posits that stressful circumstances can predispose vulnerable individuals to developing psychopathology. However, not all individuals exposed to severe stressors or adversity develops psychiatric symptoms. Of the participants in this study, not only those who experienced life-threatening stressors, but also those who had uneventful pregnancies, were predisposed to significant risks for developing postpartum psychiatric complications, as identified by the socio-demographic variables. The women from both groups experienced psychiatric symptom, such as adjustment disorders with mood and anxiety symptoms that were not enduring and were present only for a short period of time.

The women in the study presented with anxiety symptoms that were severe at delivery and at six weeks but decreased at the three and six-month period. The symptoms were more pronounced in women who had life-threatening complications. It is possible that these women presented with acute stress symptoms that improved in the subsequent months during the postpartum period. Of the women with life-threatening stressors who followed up at six months did not present with significant symptoms that fulfilled criteria for a post-traumatic stress disorder. It may be, that although the participants experienced stressful situations during pregnancy or delivery, including life-threatening stressors that threatened their wellbeing, the symptoms did not reach a threshold that fulfilled the criteria for post-traumatic stress disorder. This condition could however not be confirmed in view of the attrition of study subjects. The lived experiences of the participants in this study provided an insight into the way they coped with these stressors. The ability to cope despite the adversity experienced could possibly indicate that these women employed mechanisms that helped them survive and may point to the presence of resilience.

8.5.1 The concept of resilience

8.5.1.1 Definition of Resilience

The word resilience originates form the Latin verb *resilire*, meaning, “to leap back”. It is defined as the ability to withstand or recover quickly from difficult conditions. In the field of psychiatry, resilience refers to the ability to adapt, maintain or regain mental health. (Hu, Zhang and Wang 2015)

Research on resilience is on the increase in a number of disciplines including psychology, psychopathology, sociology, biology and cognitive neuroscience. The relationship between resilience and mental health has been a topic of interest across disciplines.

Initial studies of resilience focused on childhood maltreatment, adversity and subsequent development of psychopathology. (Haskett, Nears, Sabourin Ward and McPherson A.V. 2006)

While its study has increased across all disciplines in recent times, the research and application of resilience has been hampered due to the lack of a uniform definition and corresponding methodology for studying it. (Davydov, Stewart, Ritchie and Chaudieu, 2010)

Definitions of resilience, as reported by a number of authors, include:

- the protective factors and processes or mechanisms that contribute to a good outcome despite experiences with stressors shown to carry significant risk for developing psychopathology
- an interactive concept that refers to relative resistance to environmental risks or overcoming stress or adversity
- a dynamic process of positive adaptation in the context of significant adversity or
- a multi-dimensional characteristic that varies with context (i.e., age gender and cultural origin) as well as within an individual subject to different life circumstances. (Davydov, Stewart, Ritchie and Chaudieu, 2010)

Current definitions of resilience include three orientations, namely:

- Trait oriented: which suggests that resilience is a personal trait that helps individuals cope with adversity and achieve good adjustment
- Outcome oriented: which regards resilience as a functional or behavioural outcome that can help individuals recover from adversity.

- Process oriented: which views resilience as a dynamic process in which individuals actively adapt and recover form adversities. (Hu, Zhang and Wang 2015)

Over the past three decades, the adversity that individuals experienced were broadened to include negative life events across the lifespan that is associated with adjustment difficulties or mental disorders. (Bonanno 2004; Cicchetti 2010; Herman, Stewart, Diaz-Granados, Berger, Jackson and Yuen 2011) The studies of resilience focused on variations in response to risky conditions such as; stressful life events such as; traumatic events, wars, natural disasters, violence including exposure to community violence, maltreatment or poverty. Other conditions such as divorce, maternal mental illness, physical illness and deficient parenting were also considered.

Further studies focused on the contribution of systems, namely families, services and communities, in assisting people to cope with adversity.

The definition of resilience and resilience intervention expanded to become “protective and vulnerability forces at multiple levels of influence including; culture, the community, family and the individual.”

It is thus evident that various factors and systems contribute in an interactive and dynamic manner that influences resilience relative to adversity.

Furthermore, resilience may be considered to be context- and time-specific and may not be present across all life domains. There may therefore be a number of sources and pathways to achieve resilience. These pathways can interact at various levels including biological, psychological (including dispositional attributes), social support, and other attributes of social supports, namely family and community. (Bonanno 2004; Cicchetti 2010; Herman, Stewart, Diaz-Granados, Berger, Jackson and Yuen 2011)

8.5.2 Sources of resilience

A number of sources have been identified that can promote or aid the development of resilience in individuals. These include:

- Personal Factors

These include intellectual functioning, cognitive flexibility, social attachment positive self-concepts, emotional regulation, positive emotions, spirituality, active coping, hardiness, optimism, hope, resourcefulness and adaptability, all of which are associated with resilience. Herman, Stewart, Diaz-Granados, Berger, Jackson and Yuen 2011; Joseph and Linley 2006)

- Demographic factors

Demographic factors that can contribute to resilience include age, sex, gender, race and ethnicity.

- Social relationships

Social relationships such as population characteristics have been found to relate variably with resilience.

- Biological Factors

Research has found that harsh early environments can affect developing brain structure, function and neurobiological systems, which can cause changes in brain size, neural networks, receptor sensitivity, synthesis and reuptake of neurotransmitters. The changes that occur can exacerbate or reduce vulnerability to future psychopathology. (Luthar and Brown 2007; Cicchetti and Curtis 2006; Curtis and Nelson 2003)

- Systemic factors

Factors such as social support, relationship with peers and family can be correlated with resilience. Furthermore, community factors, cultural factors, spirituality, religion and lack of exposure to violence have also been found to contribute to resilience. (Luthar and Cicchetti 2000; Luthar, Cicchetti and Becker 2000)

- Genetic environmental factors

Interaction between personal, genetic and environmental factors have been described in literature on resilience. Genetic studies on resilience have provided insights into the interaction of genes with the environment.

> The development of mental disorders has been known to be related to genetic predisposition in combination with the person's past and current life experiences and environment. There is also evidence that social experiences can lead to substantial and enduring changes in gene expression that can affect behaviour in a person and be transmitted to the next generation. (Herman et al 2011; Parent, Zhang, Caldji, Bagot, Champagne, Preussner et al 2005)

Davydov et al (2010) proposed that resilience arises from a complex interaction of forces at various levels incorporating the person's genetic heritage, gene environment interactions, the effect of negative and positive experiences through life, the impact of social settings, and cultural settings.

Resilience can thus be considered as an interactive and dynamic process, in that various factors and systems interact on a number of levels to increase resilience to adversity. Furthermore, studies on resilience have indicated that resilience may be context- and time-specific.

8.5.3 Resilience and perinatal mental health

Many studies have focused on the effect of mental health disorders and stress on perinatal outcomes. (Premji 2014; Borders, Grobman, Amsden and Holl 2007; Rini, Dunkel-Scetter, Wadhwa and Sandman 1999) Limited attention has, however, been paid to protective factors such as resilience in the perinatal period. Research on resilience has evolved as a research topic that attempts to understand the association between perinatal mental health disorders, maternal stress and adverse perinatal outcomes. Limited studies and data on resilience in the perinatal period are available and the influence of psychosocial factors, including mental health, social support systems, and history of trauma on resilience during pregnancy, have not been explored. (Windle 2011; Dunkel Schetter 2011)

A recent study by Johnson et al. conducted on Black and Hispanic women found that a lowered resilience score was associated with a history of depression and with prior medication used to treat depression, anxiety or insomnia. (Johnson, Plaey, Modest, Hacker, Shaughnessy and Ricciotti 2018) They found a higher resilience score was associated with having religious affiliations and adequate financial resources.

Furthermore, the authors in the study did not find an association between resilience and prior obstetric complications, substance use or history of intimate partner violence. Johnson et al. did not find an association between resilience and anxiety. However, another study by Roos et al. (2013) conducted among low-risk obstetric women in South Africa did find an association between resilience and anxiety. The authors also reported that community norms could influence how distress manifests – either in the form of anxiety or in the form of depression.

The women in the present study were exposed to significant stressors including adverse life circumstances that predisposed them to developing psychiatric complications. Factors that are considered to contribute to resilience in individuals include the presence of family or community support, culture and religion. The narratives of the study participants from both groups, namely the women with uneventful pregnancies and those with life-threatening stressors, provided an insight not only into the negative experiences and severe stressors that they were exposed to, but also into their coping mechanisms. The participants in the study described religion, their belief and conviction in God as strong motivators to cope in adversity.

Several studies show that many people cope with traumatic events on the basis of their religious beliefs, and other studies have shown that many victims of stressful situations seek support from professionals, literature and friends, but most importantly from religion.

Other individuals who were victims of traumatic events, however, coped through silence, isolation, collapse or victimization. (Bonanno 2004; Spouse 1999; Peres, Moreira-Almeida, Nasello and Koenig 2007; Moreira-Almeida and Koenig 2006)

It has been reported that when people become traumatized they often look for a new sense of meaning and purpose in their life. Spiritual and religious beliefs and practices were described as important components of almost all cultures and have been found to have an important influence on how people interpret and cope with traumatic events. Many studies have investigated the relationship between religious involvement and mental health. In most of these studies, it was found that higher levels of religious involvement are associated with greater wellbeing and mental health. (Peres et al 2007; Moreira-Almeida and Koenig 2006) Positive religious coping has been associated with better psychical and mental outcomes. (Moreira-Almeida, Neto and Koenig 2006) [A] meta-analysis of 49 studies investigated the association between religious coping and psychological outcomes. The authors concluded that different types of situations might have different implications for coping and psychological adjustments to stress. (Ano and Vasconcelles 2005)

However, a review by Shaw and colleagues of 11 empirical studies that looked at the association between religion, spirituality and post-traumatic growth, reported that religion and spirituality are usually, but not always, beneficial in dealing with the aftermath of trauma. They reported that traumatic experiences may lead to deepening of religiousness and spirituality, and that positive religious coping was associated with post-traumatic growth. (Shaw, Joseph and Linley 2005) It was also found that religious beliefs and practices might reduce loss of control and helplessness, provide cognitive frameworks that can decrease suffering, and strengthen purpose and meaning in the face of trauma and adversity. There is increasing recognition that resilience factors and the potential effects of spiritual and religious belief on coping behaviour in trauma survivors may advance undertaking of human adaptation to trauma. (Bonanno 2004; Scher and Resick 2005)

8.6 SUMMARY

The participants in the present study were not only susceptible to risk that predisposed them to developing postpartum psychiatric complications, but also experienced life-threatening complications that further increased their propensity to development of complications. However, the study participants from both groups experienced psychiatric complications that were of short duration.

An important observation in the study was that the women who experienced life-threatening complications were more vulnerable than women with uneventful pregnancies to develop psychiatric sequelae. These women were more prone to develop symptoms in almost every symptom domain as compared to women with uneventful pregnancies. While these conditions were diagnosed at the first interview, which was shortly after delivery, an increase in the number of women experiencing psychiatric symptoms reached a peak at six weeks. The duration and intensity of symptoms were however not sustained and symptom resolution was observed during the ensuing three months with only a limited number of women presenting with residual psychiatric symptoms at the six-month appointment.

The women in the study presented with anxiety symptoms that were severe at delivery and at six weeks but decreased at the three and six-month period. The symptoms were more pronounced in women who had life-threatening complications. It is possible that these women presented with acute stress symptoms that improved in the subsequent months during the postpartum period.

Also, of the women with life-threatening stressors who followed up at six months did not present with significant symptoms that fulfilled criteria for a post-traumatic stress disorder.

It may be, that although the participants experienced stressful situations during pregnancy or delivery, including life-threatening stressors that threatened their wellbeing, the symptoms did not reach a threshold that fulfilled the criteria for post-traumatic stress disorder. This condition could however not be confirmed in view of the attrition of study subjects.

Furthermore, these women experienced atypical symptoms such as somatic symptoms, sleep and memory disturbances. These were the findings of the quantitative arm, but a comprehensive understanding of the processes that the study participants experienced was obtained when the two components, namely the qualitative and quantitative arms, were combined in this study. The lived experiences of the women provided some insights into lives and coping mechanisms that these participants employed. The study participants described negative and positive experiences during the interviews.

Among the positive experiences were the joy of giving birth and the joy it brought in the family, whilst the negative experiences included feelings of inadequacy, guilt feelings, loss and disappointment. Fear of rejection, abandonment, and in some cases, infidelity was also described. The study participants also expressed feelings of anger at their respective situations, about the lack of support from their respective partners and families, and about the care that they received.

There was also some unhappiness about cultural practices and customs in that participants felt isolated from the rest of the community during their period of confinement after delivery. As the interviews progressed, there was a gradual acceptance of their situations, a will to survive and cope in spite of adversity, as well as strong belief in God and an unwavering faith. When the qualitative and quantitative arms were combined, it became evident that these women were able to cope and adapt despite their negative experiences and adversity. These women displayed resilience in that they were able to adapt despite experiencing such stressors. Various factors could have contributed to this resilience, including individual traits and the role of the community and culture, but a resounding factor was the religious practice and belief expressed by the study participants.

SECTION 4

"CONCLUDING NOTES"

In this section:

Chapter 9: Summary

Chapter 10: Personal reflections

9 SUMMARY

9.1 INTRODUCTION

Women's health is increasingly recognized as a global health priority with attention focused on sexual and reproductive health. (Ribeiro et al 2008) According to the World Health Organization Global Burden of Diseases study of 2005, neuropsychiatric disorders were estimated to be responsible for 2.5% of all deaths in women aged 15 years and older worldwide. (WHO 2006) Pregnancy-related complications are the leading cause of death and disability globally among women aged 15–44 years and account for 18% of the disease burden in developed countries. (Geller et al 2006) Approximately 8 million women suffer pregnancy-related complications per year, and 1 in 16 women may die due to these complications in developing countries compared to 1 in 2 800 women in developed countries. (WHO Department of Reproductive Health 2004)

Maternal mental health and maternal mortality are multifaceted conditions with a number of factors influencing the outcome. The presence of psychiatric pathology cannot be viewed solely from a biological perspective as the psychosocial elements form an integral part of the disease process. The complex interaction of biological and psychosocial elements not only influences the disease process but also complications of the disease, as well as its prognosis. The link between women's reproductive health and mental health is an evolving area of research and thus familiarity with psychobiological factors unique to women is essential, as the stress of specific life events, such as the postpartum period, can affect female mental health from both a biological and psychosocial perspective. (Chandra and Ranjan 2007)

The perinatal period is a time when women are at increased vulnerability to developing psychiatric complications and epidemiological studies have shown that women are more likely to be admitted to psychiatric units after delivery than at any other time in their lives. Reducing maternal mortality and morbidity is an essential component of safer childbirth in the 21st century. Despite increased awareness, policies, information, education and interventions, maternal mortality continues to increase in developing countries.

The stress diathesis model posits that vulnerable individuals can develop psychopathology under adverse or stressful conditions. (Shen and Williamson 1999.) Stressful life experiences such as exposure to violence and poor physical health, which are known risk factors, can predispose women to developing mental disorders. (Miranda and Patel 2005)

Much attention has been paid to the physical complications that occur during the perinatal period, with limited attention paid to the psychiatric complications that women develop.

The research questions evolved in light of the above:

- What happens to women who experience life-threatening stressors during pregnancy?
- Are they more vulnerable to developing psychiatric complications than women who have uneventful pregnancies?
- Furthermore, is there a difference in intensity and duration of psychiatric symptoms between women who experience life-threatening stressors and those with uneventful pregnancies?
- What are the lived experiences of these women who have experienced life-threatening stressors after discharge from hospital?

9.2 SUMMARY OF THE DISSERATION

This dissertation is divided into three sections. Section 1 focused on the introduction to the study, the literature review and methodology (Chapters 1, 2 & 3). Section 2 looked at the results of the two arms of the study, namely the quantitative and qualitative arms (Chapters 4 & 5). Section 3 discussed the findings of the quantitative and qualitative arms of the study, as well as the integration of the two components (Chapters 6, 7 & 8). Section 4 (Chapter 9&10) consists of the summary of the dissertation and personal reflections. The summary of the dissertation includes research validity, ethical considerations, strengths and limitations, summary of the findings of the study, as well as the study implications and contributions.

Section 1 "The study, existing knowledge and methodology."

Chapter 1 introduced the study, which focuses on the maternal health, including maternal mental health, and the South African perspective.

A brief introduction into postpartum mental health was given. A keen interest as a researcher in women's health, especially women's mental health, was a key motivating factor to conduct the study.

The fact that I had previously worked as an obstetric registrar provided insight into the biological aspects of the perinatal period, which paved the way for exploring the psychosocial aspects in this study.

The study of women's reproductive health and mental health is an area of evolving research. As is evident from the studies cited, women are vulnerable to developing psychiatric complications in the postpartum period and there is growing recognition that severe obstetric complications can lead to long-term adverse consequences, not only for women's health, but for that of their children as well. Furthermore, women's health is a relatively neglected area in the public health sector, with limited attention paid to psychiatric comorbidity in the postpartum period.

There are limited studies from developing countries on the mental health and degree of disability of recently delivered women, especially survivors of complications, and in particular on their mental health and degree of impairment. It is evident from the studies reviewed that there is a relative gap in the field of postpartum mental health in developing countries, as most of our understanding of perinatal psychiatric conditions is based on research conducted in developed countries.

In Chapter 2, the literature review was presented. The chapter focused on the various factors that influence maternal morbidity and mortality, with special attention paid to the woman, who forms the nucleus around which interventions are targeted. Furthermore, the Millennium Development Goals were also included as these were the goals, which highlighted not only the extent of maternal mortality but also various other factors, amongst others, infant mortality, and poverty, which are closely linked to maternal mortality. The health systems were addressed, with particular attention paid to the South African health system and the various policies aimed at promoting maternal wellbeing. Women's health was also reviewed with specific reference to psychiatric complications in women who had experienced a life-threatening stressor in pregnancy. As mentioned previously, there are currently a limited number of studies in the literature that focus on psychiatric complications in women who experience life-threatening stressors.

Severe obstetric complications are common in low-income countries, (Filippi et al 2010) with the risk of maternal death remaining high up to 6 months after delivery. (Hurt et al 2008) Women who experienced severe life-threatening complications (near-miss) especially those who had perinatal deaths were at a greater risk of developing mental disorders and of reporting poor health compared to women with uncomplicated childbirth.

These women reported an increased use of postnatal services compared to women with uncomplicated childbirth, although access of services remained below 50%. (Filippi et al 2010)

The women who survive severe obstetric complications are vulnerable and can suffer physical, social, financial and psychological consequences of the life-threatening event (near-miss event) for up to one year postpartum. (Filippi et al 2007) Yet, the health and subsequent experiences of women who survive these severe complications are underexplored in all countries. Studies that describe the diverse range of postpartum experiences in detail and over a sufficiently long follow-up period are rare. (Saurel-Cubizolles et al; Waterstone, Bewley and Wolfe 2001) A study conducted in Benin (Filippi et al 2000) found women with life-threatening complications (near-miss) and subsequent foetal loss suffered in a number of spheres and to a greater extent than those who had a live baby.

Women who had experienced a life-threatening complication (near-miss) were troubled by the childbirth experience and described their postpartum period as emotionally challenging, and attributed feelings of sadness, worry and discouragement to their near miss event, especially when interviewed soon after birth. Women with severe life-threatening complications (near-miss) who experienced sustained sadness struggled with the effects of life events that occurred following the near-miss event compared to women with uncomplicated deliveries, whose symptoms decreased over time. These life events included, financial debt relating to the cost of birth, inability to resume employment, emotional and physical fatigue, marital uncertainty, and strained relations with family and in-laws. (Filippi et al 2006) Quantitative analysis showed that life-threatening complications (near miss) was not associated with greater psychological distress at 6 and 12 months postpartum when women give birth to live infants compared with uncomplicated deliveries.

The study conducted in Benin provided evidence that a near-miss complication associated with perinatal loss increases the risk of abuse and indicated an increased vulnerability of women with adverse pregnancy outcomes. (Grossman-Kendall et al 2001)

Women with life-threatening complications (near-miss) and perinatal death were at higher risk of psychological distress and were likely to be in need of further mental health care. (Fotrell et al 2010) Evidence for prevention of postpartum mood disorders in low- and middle-income countries is increasing, and strategies such as support groups have been shown to be acceptable to mothers and can lead to reduced morbidity and psychological distress. (Nhiwatiwa Patel and Acuda 1998)

Two previous longitudinal studies described the health effects of women with severe life-threatening complications (near-miss). Waterstone et al. (2001) showed that women who experienced severe morbidity in the United Kingdom were more likely to report sexual health problems and made increased use of health services up to 12 months postpartum compared to controls with uncomplicated childbirth. The authors attributed the sexual health problems reported by some of the severe life-threatening (near-miss) women to their fear of falling pregnant again, given the traumatic event they had experienced.

A study conducted in Burkina Faso found that women in the severe life-threatening (near miss) perinatal group were more likely to experience mental health problems. (Filippi et al 2000) The women expressed more suicidal ideation and babies born to mothers who had a severe life-threatening complication (near miss) were more likely to die post discharge. There was also an increased rate of mortality in the postpartum period among the women who experienced a severe life-threatening complication (near-miss).

The study further reported that women with severe life-threatening complications (near-miss group) expressed more negative feelings and lack of self-esteem up to a year postpartum, used services more than the uncomplicated group, and were under pressure to have another pregnancy quickly. The psychological distress found in the perinatal death group has been documented in developed countries and is often associated with physical symptoms. The majority of deaths and complications and their sequelae may be avoidable through skilled birth attendance and emergency obstetric care, (Sichel et al 1993) although it would be impossible to eliminate severe life-threatening complications (near-miss) even in developed settings. Studies show that some of the women are more likely to be diagnosed with or report health problems at 6 and 12 months postpartum.

There appears to be limited recognition of the difficulties experienced by women who have suffered severe obstetric complications or perinatal death. This is probably because the content of postnatal care in developing countries is focused on reducing child mortality and less emphasis is placed on the need to improve maternal health and survival. (Warren et al 2006) Research shows that some of the problems experienced by women and their babies persist beyond the traditional period of 42 days postpartum; as these problems were either not identified during routine visits or were too difficult to resolve.

Filippi et al. (2007) highlighted in their study that it is important to reach women who have lost their babies as they were neglected by traditional postnatal services, where the focus is primarily on the child.

The authors concluded that women with severe life-threatening (near-miss) complications might benefit from active screening for symptoms or signs of adverse emotional and physical wellbeing during the postnatal visits or other contacts with health professionals in the postpartum period. (Filippi et al 2007; Ransjo-Arvidson et al 1998)

Finally, there is a need to gain an understanding of the reasons for the relatively low usage of postnatal psychiatric services after a complication. It is also important to determine whether outreach services, such as those rendered by community health workers would be beneficial to women who have had a complication. Women in developing countries face a high risk of severe complications during pregnancy and delivery, which can adversely affect their own health and that of their children. Resources are needed to ensure that pregnant women receive adequate routine and emergency care before, during and after discharge from hospital. Women who had a severe life-threatening stressor (near-miss) and a perinatal death appear to be a particularly high-risk group, and the long-term outcome for women who experience mortality as a result of a life-threatening (near-miss) complication in pregnancy has received very little attention to date.

A significant degree of physical and psychological morbidity is experienced, especially among young women who lose their fertility potential as a result of life-saving obstetrical care. In contrast, there is a high likelihood of successful pregnancy outcome among women who retain their fertility potential and choose to have a further pregnancy. (Murphy and Charlett 2002)

As the study at hand is a mixed method study, the afore-mentioned was a review of the literature pertaining to the quantitative arm of the study. Relevant aspects of the literature review pertaining to the findings in the qualitative arm will be incorporated in Chapter 7 that focuses on the discussion of the findings of the qualitative arm.

In Chapter 3, the research methodology was presented. The study was conducted at two hospitals, in Pretoria, South Africa, namely Steve Biko Academic Hospital, a tertiary hospital, and Kalafong Hospital, which at the time of data collection was a secondary hospital but has subsequently become a tertiary hospital. A mixed methods study that consisted of two arms, namely a qualitative and a quantitative arm, was chosen as the study design. The study was conducted in a parallel convergent manner. Data collection for the two arms occurred concurrently and merging of the data occurred at the level of interpretation.

Participants in the study consisted of two groups of women, namely those who experienced a life-threatening complication in pregnancy and those with uncomplicated pregnancies.

Prospective participants were approached soon after delivery, and in the case of participants with life-threatening stressors who were severely ill at the time of delivery, when, they were medically stable.

The purpose of the study was discussed with the prospective participants, and patient information leaflets were distributed. Written informed consent was obtained from women if they agreed to participate, and a copy of the consent was given to the participants. In the event where women had difficulty understanding the informed consent information leaflet due to language difficulties, nursing staff who spoke the participants' language were asked to serve as interpreters during the informed consent process. The women with life-threatening complications were selected if they met the WHO criteria for a "near-miss" pregnancy, and the women in the uncomplicated group were randomly selected from the birth registers kept in the respective labour wards of both hospitals.

Eighty-nine participants were selected, and these included 46 participants who experienced a life-threatening stressor and 43 who had uneventful pregnancies. Participants were interviewed four-time intervals: shortly after delivery when they were able to participate in an interview, at six weeks, at three months and at six months postpartum.

At the initial contact, a comprehensive psychiatric interview was conducted, and obstetric and medical histories were obtained. Socio-demographic information collected included age, race, level of education, employment status, current living circumstances. Pregnancy outcome, services accessed, and future fertility intention were also obtained. Furthermore, enquiries were made regarding the women's social support structure and religious status.

The quantitative arm consisted of the completion of validated Level 1 and Level 2 crosscutting symptom measures. The participants completed the Level 1 crosscutting symptom measure. The symptom domains identifiable from the Level 1 questionnaire included: depression, anxiety, sleep and cognitive disturbances, dissociative symptoms, thoughts of self-harm, anger, psychotic and manic symptoms, post-traumatic and obsessive symptoms, as well as substance abuse. The Level 1 crosscutting symptom measure was used to broadly identify psychiatric symptoms and was scored and interpreted for the presence of psychiatric symptoms. In the presence of symptoms, a Level 2 crosscutting symptom measure, consisting of Patient-Reported Outcomes Measurement Information System (PROMIS) scales, was then completed to obtain information on significant symptoms of psychiatric illness. The PROMIS scales utilised in the study included those for depression, anxiety, mania, substance abuse, repetitive thoughts and behaviours, anger, cognitive disturbances, somatic symptoms and sleep disturbances.

Subsequent to completing the Level 1 and 2 measures, appropriate validated rating scales as identified according to the symptomatology were completed, for example, the Beck Depression Inventory was used to assess the intensity of depression and this scale has been validated for use in obstetric population. (Holcomb et al 1996) The Edinburgh Postnatal Depression Scale in postpartum women was not included in this study, as, although it is a validated screening measure during the peri-natal period, the Level 1 and Level 2 crosscutting symptom measures were already used as adjuncts for symptom identification. Another scale that was used to determine the intensity of anxiety symptoms was the Hamilton Anxiety Scale. The WHO Disability Assessment was completed and impairments in personal, social and occupational functioning identified.

The qualitative arm consisted of in-depth, semi-structured interviews with research participants. Sixteen participants were purposefully sampled to provide a rich description and fully representative sample. The participants selected for the case studies included seven women who had uneventful pregnancies and nine women who experienced life-threatening stressors. Included in those who had life-threatening stressors, were women from different age groups, women who had live babies and some who had experienced foetal losses as well as those women who had lost the ability for future conception. Thus, a range of women with life-threatening complications was purposefully selected. Intermittent analysis of data occurred during the data collection phase, which provided some insights that helped in the subsequent phases of the study. The field notes and observations made at the time of the interviews and the transcripts of the interviews aided in reflexivity. As explained previously, reflexivity is the process whereby the researcher reflects and is aware of their impact on the research process.

A large amount of data was generated through the interviews and the journals kept by the participants, as well as the field notes and the reflective journal. Reading and re-reading the transcripts provided an opportunity to become familiar with the data, to become immersed in the data, and also provided an opportunity for analysis of data to occur. Initially, open coding occurred. Using the constant comparative method, line-by-line coding occurred. After coding the transcripts, the codes were aligned and checked for replication. The codes were then grouped together and families of codes, or themes were created. The creation of categories, which were integrated and refined, using this process is also referred to as axial coding.

Both manual coding and the qualitative data analysis software programme Atlas.ti were used to manage and organize the data. Complete analyses of the cases occurred, which included the process of a within-case analysis where issues within each case were identified. Subsequent to this process, the analyses of themes of each case took place and this was followed by a cross-case analysis when thematic analysis across the cases occurred. The analysis of themes, according to Cresswell (2013) is not to generalize beyond the case, but to understand the complexity of the case. Data were analysed using grounded theory principle where the themes were grounded in the data obtained from the case studies.

Section 2: "The findings of the study."

In Chapter 4, the results of the quantitative arm of the study were presented. These include the socio-demographic results, and results of functional impairments as elicited by the WHO Disability Assessment. The psychiatric sequelae identified from the Level 1 and Level 2 questionnaires were presented. The results of the individual psychiatric scales such as the Beck Depression Inventory, the Hamilton Anxiety Scale and the Brief Psychiatric Rating Scale are also presented. Eighty-nine women signed informed consent to participate in the study. Of these, 46 were women who experienced life-threatening stressors and 43 were women who had uneventful pregnancies. More than two thirds of the participants were between the ages of 21 and 35 years, with a third of the participants reporting that they were married. Almost a third of the participants had matriculated and a similar proportion was employed. Furthermore, a third of the participants lived in informal settlements with basic amenities. More than 71% of the participants reported that the latest pregnancy was unplanned, and more than 15% reported that the pregnancy was unwanted as well. Approximately 13% of the participants reported not attending any antenatal care, with a fifth of the participants reporting that they were uninformed about the signs of potential pregnancy complications. Almost a third of the women who experienced life-threatening complications experienced foetal demise. Furthermore, 42% of the participants used the injectable contraceptive. Approximately 12% of women had received treatment for a psychiatric illness in the past, and a fifth of the participants were HIV-positive at the first interview.

The psychiatric conditions that were identified in these participants included major depressive disorders, which occurred in approximately a quarter of the total participants. Of those diagnosed with major depressive disorders, 63.6% were women who experienced severe life-threatening stressors. The symptoms and number of participants experiencing depression increased at the six-week appointment. Approximately fifty percent of participants experienced depressive symptoms, 73% of the sample were women who had life-threatening stressors. The symptoms were not enduring and decreased during the subsequent appointments. Furthermore, approximately 19% of women had generalized anxiety disorder at delivery. This figure increased to 39.6% at the six-week follow up and of these, more than three quarters were women who had experienced a life-threatening stressor.

The anxiety symptoms improved during the subsequent appointments, with only 10% of women presenting with residual symptoms at the six-month appointment. Furthermore, 4.5% of participants experienced psychotic symptoms and the same number experienced manic symptoms. Less than a fifth of participants experienced somatic symptoms and 9% presented with cognitive and memory impairments. Sleep disturbances were found in 18% of participants. Furthermore, the participants experienced impairment in social and occupational functioning. They experienced impairments in functioning at delivery and continued to experience symptoms at the six-week follow-up. These symptoms improved over the course of the subsequent appointments.

Chapter 5 presented the results of the qualitative component of the study. In this chapter, 16 participants were purposefully sampled for the case studies. The participants selected included nine women who experienced life-threatening obstetric complications. Among the nine who had life-threatening complications were both women who had experienced foetal losses and women who lost the ability for future conceptions. Seven participants selected for the case studies were women who had uneventful pregnancies. \The common themes identified from the case studies included: feelings of joy, pain, loss, feelings of guilt, disappointment, feelings of inadequacy, ambivalence, anger, feelings of impending death, fear of having another baby. Other themes included; feelings of confusion and isolation, lack of bonding, lack of support, fear of disclosure and rejection. There were also themes of infidelity, rejection, stigma, lack of communication, understanding and empathy identified. Themes of acceptance, the will to survive and religious themes including faith were also present.

The themes identified from the case studies could broadly be classified into positive and negative aspects pertaining to the following categories: birth experiences, psychological and socio-cultural experiences, and health system-related factors. Positive and negative experiences regarding interactions with the interviewer were also described.

Section 3: "Psychiatric sequelae, narratives and integration"

A discussion of the quantitative results is presented in Chapter 6. Psychiatric sequelae occurred in study participants who experienced life-threatening stressors as well as those who had uneventful pregnancies. Psychiatric conditions that were identified in these participants included major depressive disorders, with approximately a quarter of the total study participants experiencing symptoms of a depressive disorder. The symptoms and number of participants experiencing depression increased at the six-week appointment.

These symptoms were however not enduring and decreased during the subsequent appointments in the subjects who followed up at the three and six-month intervals. A fifth of the women presented with symptoms of a generalized anxiety disorder. The women presented with anxiety symptoms that were severe at delivery and at six weeks but decreased at three and six months and were more pronounced in women who had life-threatening complications. It is possible that these women presented with acute stress symptoms that improved in the subsequent months during the postpartum period. Also, of the women with life-threatening stressors who followed up at six months, did not present with significant symptoms that fulfilled criteria for a post-traumatic stress disorder. It may be, that although the participants experienced stressful situations during pregnancy or delivery, including life-threatening stressors that threatened their wellbeing, the symptoms did not reach a threshold that fulfilled the criteria for post-traumatic stress disorder. This condition, however, could not be confirmed in view of the attrition of study subjects. However, information obtained during the qualitative analysis could indicate that other factors may have played a role in limiting symptom presentation. Furthermore, other psychiatric symptoms those participants presented with included, psychotic and manic symptoms, as well as cognitive and memory impairments. Women also presented with atypical symptoms, such as sleep and somatic symptoms.

The presence of these atypical symptoms, accompanied by impairments in the level of functioning and the short symptom duration, could indicate that these women experienced an adjustment disorder with comorbid depressive and anxiety symptoms.

The participants in the present study were not only susceptible to risk that predisposed them to developing postpartum psychiatric complications, but also experienced life-threatening complications that further increased the propensity to development of complications.

An important observation in the study was that the women with life-threatening complications experienced greater distress than women with uneventful pregnancies to develop psychiatric sequelae. These women were more prone to develop symptoms in almost every symptom domain as compared to women with uneventful pregnancies. These conditions were diagnosed at the first interview, which was shortly after delivery with an increase in the number of women experiencing psychiatric symptoms reaching a peak at six weeks.

The duration and intensity of symptoms were however not sustained and symptom resolution was observed during the ensuing three months with only a limited number of women presenting with residual psychotic symptoms at the six-month appointment. The results are however interpreted with caution due to the attrition rate of study subjects that occurred.

The participants initially experienced impairments in social and occupational functioning as evidenced by the results of the WHO Disability Assessment scale. The results obtained from the disability assessments mirrored the psychiatric symptom presentation in certain respects. The participants experienced impairments in their levels of functioning at delivery and continued to experience some impairment at the six-week follow-up. The psychiatric symptoms were similarly identified at delivery and reached a peak at the six-week follow-up. Subsequent to this appointment, improvements in psychiatric symptoms and levels of functioning were observed.

A discussion of the qualitative arm was presented in Chapter 7. The participants from both groups, namely the women with life-threatening complications and those with uneventful pregnancies, had positive and negative experiences of the following: birth, psychological and socio-cultural experiences, religious experiences, experiences of the interview process and the health system.

A number of participants in both groups had unplanned pregnancies. Upon confirmation, some saw the unplanned pregnancies as welcomed and wanted, whilst for others they were unwanted. For those who had unwanted and unplanned pregnancies, there was ambivalence about the pregnancy and what it could represent.

They feared rejection of paternity, infidelity by their partners, rejection by their families, disturbance in schooling or career opportunities, stigma, as well as financial implications. Participants in both groups who had live births described the joy and pleasure of having a baby. Among the participants who were severely ill with life-threatening complications during the perinatal period, some had feelings of impending death, whilst some had no recollection of the events, some experienced confusion about the extent of their illness, and others presented with memory deficits.

The women who had life-threatening complications and subsequent pregnancy losses not only presented with sadness and disappointment, but also described an emotionally challenging time and a sense of loss, guilt, frustration and failure.

Women from both groups described feeling isolated, as they described a period of confinement after the birth of the child. For the women who had life-threatening complications and subsequent losses, the isolation was both voluntary, in that it allowed them an opportunity to grieve and process their losses, and involuntary. As the interviews progressed during the three- and six-month follow-ups, a gradual sense of acceptance of their situations became evident. There was also a will to survive and continue despite the adversities they experienced. Furthermore, there was a strong sense of faith and spirituality in that they believed everything that happened to them was the will of God.

Participants had both positive and negative opinions of the interview process and the interactions with the interviewer. To the women who had life-threatening complications and subsequent losses, returning to the hospital environment reminded them of the time of their loss. They felt that talking about their experiences was not going to return what they had lost and thus chose not to follow up. Of the positive experiences described regarding the interaction with the interviewer, the women felt it provided them an opportunity to discuss their problems without fear of censure, or of being judged or stigmatized. They also felt that their problems and experiences were understood and not belittled or minimized.

The participants also had positive and negative views about the health system. The positive experiences were regarding the care that they had received from the staff. The negative experiences described were lack of empathy and understanding from the nursing staff and the lack of information they received from the doctors. Some older participants described being ridiculed by nursing staff when they presented for antenatal care or delivery.

With regard to the aftercare experiences, 14 of the 16 women who participated in the case studies of the present study followed up during the four-time intervals. The women described the sessions as an opportunity to share their experiences; difficulties, dreams and hopes with an interviewer whom they thought would understand their problems. However, two of the participants felt the subsequent interviews would be a time of revisiting the trauma and loss they had experienced whilst in hospital and thus chose not to follow up. The remaining participants appeared to be more forthcoming with information during subsequent interviews as they personally felt less threatened, less judged and stigmatized. Some study participants described satisfaction with the care they received; whilst others described a lack of nursing care and dissatisfaction with the care they received.

Participants described a lack of empathy, understanding, information and communication from the staff, as well as a sense of hostility from staff. Participants who experienced a pregnancy loss found the referral to social workers and psychologists dissatisfying because of the perceived lack of understanding and knowledge pertaining to their condition by these professionals.

Subsequent to the discussion of the themes identified, a literature review of the identified themes and experiences described by the participants in this study was presented. As discussed previously, the grounded theory principle was used during data analysis. This method involves an inductive-deductive process and the literature was reviewed only after the themes were identified from the data obtained in the qualitative arm. References to the literature were then made to link, compare and contrast the concepts obtained from the new data to that of the existing research.

References from the literature included coping strategies used by women who experienced pregnancy losses, the role of adversity in women's lives and the role of religion in adversity. Women's perceptions of the care they received was also described in the literature, with mothers reluctant to obtain professional assistance in the postpartum period or to disclose emotional and personal problems. Studies have also described that socio-economically disadvantaged women faced numerous barriers to care at the system, provider and at the patient levels. System barriers (medical and mental health settings) included a culturally insensitive or stigmatizing environment, limited strategies for maintaining evidence-based practices, technological and financial failures, high staffing ratios and long waiting times. (Lou et al 1994; Kendell et al 1987; Shoeb and Hassan 1990; Ranzini et al 1996; Brockington et al 1981)

Potential patient barriers included practical ones such as financial barriers, inaccessible clinic locations, cultural barriers, psychological barriers, stigma, and avoidant or fearful attachment style which occurred as a result of exposure to previous trauma and was characterized by self-reliance and distrust of others. (Kumar 1994; Marks et al 1992; Davies. Mc Ivor and Kumar 1995; Fatoye and Fasubaa 2002; Videbach and Gouliaev 1995; Gazmararian et al 1995)

Chapter 8 discussed the combination of the two arms of the study. As mentioned previously, data collection for the two arms occurred concurrently and data analysis occurred independently. Merging of the results of the two arms occurred at the level of interpretation. Participants in the study consisted of two groups of women, namely those who experienced a life-threatening complication in pregnancy and those with uncomplicated pregnancies.

When the two arms of the study are considered in isolation, the quantitative arm provides insight into the psychiatric sequelae that the women developed, and the qualitative arm describes the lived experiences – both positive and negative – in various spheres of their lives, namely the biological, psychological, socio-cultural and religious spheres.

The lived experiences of the women provided some insight into the lives and coping mechanisms that the participants employed. As the interviews progressed, there was a gradual acceptance of their situations, a will to survive and cope in spite of adversity, as well as a strong belief and unwavering faith in God. However, a comprehensive understanding of the processes that the study participants experienced was obtained when the two arms of the study were combined. It became evident that these women were able to cope and adapt despite experiencing adversity. Various factors could have contributed to them coping in the face of adversity, including individual traits and the role of the community and culture, but a resounding factor was the religious practice and belief expressed by the study participants. The ability to cope and adapt in in the presence of severe stressors could possibly point to the presence of resilience in these women.

9.3 RESEARCH VALIDITY

9.3.1 Mixed methods research

The researcher's ability to draw appropriate inferences and generalizations is dependent upon decisions made in both the qualitative and quantitative phases of the study.

Various frameworks and models describe strategies to ensure validity of findings. Validity differs in quantitative and qualitative research, but in both approaches it serves the purpose of checking the quality of the data, the results and the interpretation.

Onwuegbuzie and Johnson (2006) describe a legitimation model, and Dellinger and Leech (2007) a validation framework that provides the researcher with two alternatives to evaluate inferences on the basis of study findings, namely data validation and legitimation.

Data validation refers to the implementation of appropriate steps or procedures to assure legitimation by establishing a process of examining inference quality in terms of design quality and interpretive rigor of the study's outcomes. (Onwuegbuzie and Johnson 2006)

This process is known as "inference transferability" (Teddlie and Tashakkori 2003) and allows the researcher to formulate appropriate generalizations. Legitimation has been defined as a recursive process in which the researcher evaluates the quality of the inferences drawn from the quantitative and qualitative phases at each stage of the study and across the research programme.

9.3.2 Quantitative arm

Internal validity, external validity or representativeness, reliability and objectivity are important criteria that have to be adhered to in order to ensure quality of data. The following strategies were employed in this study to ensure quality of the study:

- The design of the study was a prospective study and included a control arm.

- The criteria of reliability and content validity were addressed in that the scales that were used to determine psychiatric complications were validated scales. The Level 1 and Level 2 crosscutting symptom measures was field tested in the DSM-5 field trials and demonstrated mostly good to excellent test-retest reliabilities.
- The measures also showed strong clinical utility from patient and clinician perspectives. Furthermore, the clinical scales used to diagnose psychiatric conditions are valid scales that have been used in pregnant populations previously and also show good test-retest reliability.

- The criteria of internal validity entail the extent to which the investigator is able to conclude a cause and effect relationship among the variables. The cause and effect inferences can only be made if threats such as selection bias and participant attrition are accounted for in the design. The participants in the present study included a group of women who had met the specific criteria for a life-threatening event.

The control group were women with uneventful pregnancies who were randomly selected from the birth registers available in the obstetric wards. The purpose of the quantitative arm in the present study was not to prove causality but to identify psychiatric symptoms in a specific sample of women. The results of the study are however interpreted with caution and are not generalizable due to the attrition rate of study subjects.

9.3.3 Qualitative arm

With the aforementioned in mind, the challenge confronting a qualitative researcher is that of how to assure the readers of the ***quality*** or ***trustworthiness*** of the research. (Schurink 2009) This has led to a contentious debate, which has in turn given rise to the development of various checklists and frameworks to assess qualitative research. (Flick 2006)

Strategies employed to ensure quality or trustworthiness in the present study included:

i. Prolonged engagement with study participants in that they were interviewed four times over a period of six months. Fourteen of the sixteen participants that were sampled for the qualitative arm attended all four appointments. This was one of the steps employed toward ensuring credibility of data.

ii. Field notes and theoretical notes were compiled during the interview process, which provided an insight into the thought process that occurred during phase of data analysis. The field notes and personal diary allowed for reflection on different aspects of interaction with the participants. Theoretical notes and diaries provided by patients assisted with reflection and provided insights about participants' lived experiences and lives.
iii. Audit trail: An auditing trail, according to Schurink, is "a systematically maintained documentation process of the researcher's continuous critical analysis of all decisions and actions taken during the entire research process"

and includes records of how things were discovered. (Schurink, Fouche and de Vos 2011) Important aspects of the audit trail in this study include:

- All the transcriptions of the interviews are available for perusal.
- Theoretical and field notes, as well as the coding process and thematic analysis of the codes, are available.

iv. Triangulation occurred at the level of the research design in that a mixed methods design, which consisted of a qualitative and a quantitative arm, was chosen to answer the research questions. In qualitative research, triangulation refers to searching for convergence amongst multiple and different sources of information. Apart from the interviews with the participants, medical files were also perused for collateral information.

Another aspect of triangulation was included the themes identified during data analysis of the qualitative arm were inductively derived and these findings were confirmed in a deductive manner from the information obtained from the literature.

v. Peer debriefing occurred during the research process, and the data gathered, as well as various issues pertaining to the study, were discussed with my supervisor, Prof JL Roos, at regular intervals. Furthermore, during the process of data analysis and interpretation, Dr E Archer, who presented the workshop on qualitative data analysis using the Atlas.ti programme, was consulted on two occasions to discuss the thematic analysis.
vi. Thick descriptions were utilized in the study, in that the settings, participants and the emerging themes were discussed in detail. The narratives were also quoted verbatim to provide an understanding of the patients' lived experiences.
vii. Member validation: During follow-up interviews, the previous interview was reflected upon with the participants and the discussions during the interview were clarified with them.

The aforementioned strategies employed to ensure trustworthiness and quality in the present study align with some of Lincoln and Guba's (1985) methods to ensure quality of research, which are as follows:

- **Credibility** requires that the research be carried out in a responsible way and in line with what is considered to be good practice. Steps to increase credibility include prolonged engagement and persistent observation in the

field, triangulation of different methods, and formalized qualitative methods such as grounded theory. The following strategies are ways of increasing the credibility of qualitative research:

- **Peer debriefing** entails researchers discussing their views of the findings with peers, namely the supervisor, co-supervisor and colleagues who are knowledgeable, to critique and discuss the interpretations.
- **Triangulation** refers to the use of a combination of methods to explore one set of research questions. For example, a strategy to avoid recall bias would be to obtain information from clinical record in hospital files.
- **Member checks** include returning the life history accounts of the research participants for their approval to ensure that the way the information was understood and interpreted is a representative reflection of the data/information.

- **Transferability** depends on the degree to which the findings can be generalized. The aim with this research is to produce qualitative data that is rich in detail, collected in a transparent process. This transparency will enable others to judge whether or not the results of this study have more general application.
- **Dependability** is determined by the "auditing" process. The researcher will keep a comprehensive record of the complete research process – including field notes, transcripts of interviews, decisions on data analysis and other records such as peer audits.
- **Confirmability** requires that the researcher acknowledges that scientific objectivity is not absolute and that the researcher will act in good faith without allowing personal values and convictions to influence the participants.

Although Creswell and Miller recommend that qualitative researchers use at least two strategies to ensure the quality of data in any given study. Six of the eight strategies they described were utilised in this study and include: prolonged engagement, triangulation, peer review, researcher reflexivity, member checks and descriptions. (Cresswell 2013)

The strategies they refer to are:

- **Prolonged engagement and persistent observation** includes building trust with the participants, learning the culture and checking for misinformation that stems from distortions introduced by the researcher or informants.
- **Triangulation** occurs where researchers make use of multiple and different sources, methods, investigators and theories to provide corroborating evidence.
- **Peer review** or debriefing provides an external check of the research process.
- **Negative case analysis** refers to the researcher refining working hypotheses as the inquiry advances
- **Researcher reflexivity** refers to the researcher reporting on personal beliefs, values or biases that may shape their enquiry.
- **Member checking** is a process whereby the researcher seeks participant's views of the credibility of the findings.
- **Rich, thick descriptions** allow readers to make decisions regarding transferability.
- **External audit** allows an external consultant or auditor to examine the process and the product of the account, assessing for accuracy.

An additional aspect that requires a mention in strategies employed to ensure the quality and reliability of data in this study is the interviewer dress and effect According to Benstead (2014) this effect should be recorded, reported and controlled for in order to mitigate potential bias and allow the readers an opportunity to assess the results.

A prominent finding in the study is the religious conviction and faith of the study participants. The question arose as to whether my role as a female interviewer in Islamic attire, namely hijab could have influenced the responses of the participants. Although the interviewer effect has to be borne in mind in terms of participant responses, a constant finding throughout the process of data analysis was the strong sense of religious conviction in the participants. This was not only evident from the direct interviews with the participants but was also present in the journals that the participants kept.

Furthermore, a literature search revealed that women in adversity use spiritual and religious resources as coping mechanisms. (Edge and Rogers 2005; Van P 2001; Souza et al 2009) This aspect was explored in detail in Chapter 7 of the dissertation.

A master's study conducted by a male researcher on a similar group of women at the same complexes where the present study was conducted reported that women who experienced life-threatening (near-miss) complications in their pregnancies also sought religious means as coping mechanisms. (Nkosi 2011) Interviewer dress is thus acknowledged in this study, but the extent to which this may have influenced participant responses is unknown.

9.4 ETHICAL CONSIDERATIONS

Ethical approval to conduct the study was obtained from the Faculty of Health Sciences Research Ethics Committee of the University of Pretoria (353/2013).

A recommendation of the Ethics Committee was that the phrase "near-miss" be replaced with "severe, life-threatening events" in the study.

The principles of medical ethics, namely beneficence, non-maleficence, respect for autonomy and justice, were acknowledged in the study and adhered to. Participation in the study was totally voluntary and participants were not coerced in any manner to consent to participate. Furthermore, participants had the autonomy to withdraw consent to participate in the study at any time. Study participants who were identified as having psychiatric pathology during interviews were referred to mental health care services for psychiatric intervention.

- **Informed consent:** The study was explained to prospective participants and a patient information leaflet pertaining to the aims of the study was provided to them. Upon agreeing to participate in the study, written informed consent was obtained from the participants, each of whom were given a copy of the informed consent document. Each participant was given an opportunity to ask questions about the study. In the event where women had difficulty understanding the informed consent information leaflet due to language difficulties, nursing staff who spoke the participants' language were asked to serve as interpreters during the informed consent process. (Please refer to addendum 3 for patient information leaflet.)

- **Confidentiality:** Research participants were informed that the researcher would strive to ensure confidentiality and anonymity. The names and file numbers of the patients were handled with utmost confidentiality. A study number was assigned to each participant to maintain confidentiality, but the names and file numbers of patients were documented separately for future reference, follow-up and verification of information. Telephonic communication was initiated prior to the follow-up appointment to ensure compliance with appointments. A budget was allocated for transport costs incurred by the study participants for each interview. A confidentiality agreement was signed with the transcriber to ensure confidentiality of research participants was maintained during the process of transcription.

9.4 STRENGTHS OF THE STUDY

- The study is a mixed methods study consisting of a qualitative and a quantitative arm. This method provided information not only about the lived experiences of women, but the psychiatric sequelae those participants from both groups experienced. The mixed methods allowed for triangulation of results found in each arm. For example, almost a quarter of the women presented with symptoms of anger. The symptoms of anger were also prominent in the narratives of women when they described the difficulties they experienced, including the lack of care and information they received from the health system. They also expressed anger about the situations they found themselves in. The mixing of methods provided for stronger inferences to be made as the data were viewed from multiple perspectives, thereby providing greater breadth and depth to the study.
- The fact that there was a follow-up period after discharge from hospital can also be seen as strength of the study. It is evident from the literature that the perinatal period is a time of increased vulnerability to developing psychiatric complications for women. The participants in the present study were followed up with for a period of six months after delivery, thereby providing a period of time to identify the presence of psychiatric sequelae.
- The study adds to an understanding of the psychiatric sequelae, lived experiences and mental health aftercare experiences of women with complicated pregnancies in the developing world.

- Existing information in the field is limited in the African context and the developing world with regard to research that focuses on the psychiatric complications that occur in women who experience life-threatening complications.
- Through a study of this nature, opportunities for collaboration and liaison can be established, not only at the level of service delivery but also at research level, between the various disciplines like obstetrics, paediatrics, psychiatry, and public health.
- Postnatal care in South Africa, as confirmed in the literature, is still developing, and information of this nature needs to be relayed to the relevant care-providers to create an awareness of the psychiatric aspects of maternal health.

9.6 LIMITATIONS OF THE STUDY

- The sample size is a limiting factor. This limits the generalizability of study results. Participants were selected over two rounds to include a large sample of participants. It proved extremely difficult to retain patients with uneventful pregnancies despite various attempts to remind them of their follow-up appointments.
- A second limitation is the loss to follow-up rate. Participants were selected over two cycles, as women with uneventful pregnancies in many instances did not follow up after the six-week appointment. Attempts were made to remind patients of their upcoming appointments through telephonic contact and financial assistance for transportation was provided to the participants at each interview. It is postulated that the women may not have felt the need to follow up in the absence of psychiatric symptomatology. Another possibility is the that women may have had difficulty in accessing the hospital to attend their follow-up appointments, as more than a fifth of the participants were non-South Africans and the present study was conducted during a turbulent time in South African politics. Xenophobic attacks against non-South Africans were taking place in the public health sector during this period.

  The problems posed by this were relayed through telephonic contact with some women, or their partners, who, when informed about the follow–up appointments, explained their difficulties. Furthermore, results from other studies have indicated that accessing postnatal services was found to be less than 50%.

- Study setting

  The study was conducted at two hospitals in Pretoria – one was initially a secondary hospital at the time of data collection, and one tertiary hospital. Participants were predominantly from urban areas. This participant selection provided limited information pertaining to the rural population.

- Recall bias

  As with most questionnaires, participants may not be able to remember every detail about their illness and therefore recall bias would be a limitation in this study. In order to avoid recall bias, information from clinical records in hospital files was obtained.

- Cultural and linguistic barriers

  Exploring the lived experiences of study participants and gaining an insight into their lives was initially difficult. There was difficulty in establishing a rapport, as some of the participants were initially guarded and not entirely forthcoming with information, probably due the differences in culture between them and the interviewer. However, as the interviews progressed, a relationship of trust and understanding developed. Furthermore, although the participants were able to speak English during the interviews, there were instances when they found it easier to express themselves in their native language and this required the use of a nursing sister as a translator. This could have influenced and impacted on some of the expressions of experiences. In an effort to limit the linguistic barriers, it would be important to train health workers to conduct psychiatric interviews, to prevent loss of valuable information through the process of translation in future studies of this nature.

9.7 SUMMARY OF THE FINDINGS OF THE STUDY

Studies in the literature have revealed that the perinatal period is a time of increased vulnerability for women to development of psychiatric complications. This study set out to determine (i) whether women who experience life-threatening stressors are more vulnerable to developing psychiatric complications compared to those who had uneventful pregnancies (ii) to what extent the presence of psychiatric complications affects the functioning of women who experience life-threatening stressors and (iii) what lived experiences are of women who

had a life-threatening stressor in pregnancy and those with uneventful pregnancies upon discharge from hospital. It was anticipated that these experiences could provide an insight into the lives of the participants and how these experiences would affect their management further.

Within the present study, the negative feelings and distress described during the initial interviews decreased over time. This was evident during subsequent follow-ups at three and six months, when the study participants reported that they were more accepting of the events that occurred during pregnancy and the postpartum period.

The participants in the present study were not only susceptible to risk that predisposed them to developing postpartum psychiatric complications, but also experienced life-threatening complications that further increased their propensity to development of complications.

Study participants from both groups, namely those with life-threatening complications and those with uneventful pregnancies, experienced psychiatric complications that were of short duration. The participants with life-threatening stressors however, experienced greater distress and psychiatric complications than women with uneventful pregnancies.

The women in the study presented with anxiety symptoms that were severe at delivery and at six weeks but decreased at the three and six-month period. The symptoms were more pronounced in women who had life-threatening complications. It is possible that these women presented with acute stress symptoms that improved in the subsequent months during the postpartum period. Also, of the women with life-threatening stressors who followed up at six months did not present with significant symptoms that fulfilled criteria for a post-traumatic disorder. It may be, that although the participants experienced stressful situations during pregnancy or delivery, including life-threatening stressors that threatened their wellbeing, the symptoms did not reach a threshold that fulfilled the criteria for post-traumatic disorder. This condition could however not be confirmed in view of the attrition of study subjects. These women also experienced atypical symptoms such as somatic symptoms, as well as sleep and memory disturbances. These were the findings of the quantitative arm, but a comprehensive understanding of the processes that the study participants experienced was obtained when the two components, namely the qualitative arm and the quantitative arm, were combined.

The lived experiences of the women provided some insights into their lives and the coping mechanisms they employed. The study participants described negative and positive experiences during the interviews.

Among the positive experiences were the joy of giving birth and the joy it brought the family, whilst the negative experiences included feelings of inadequacy, guilt, loss and disappointment. Fear of rejection, abandonment, and in some cases, infidelity was also described.

The study participants also expressed feelings of anger at their respective situations, about the lack of support from their respective partners and families, and about the care that they received. Participants did not always agree with the enforced cultural practices and customs. These aspects made them feel isolated from the rest of the community during their period of confinement after delivery. As the interviews progressed, however, there was a gradual acceptance of their situations, a will to survive and cope in spite of adversity, as well as strong belief and unwavering faith in God.

When the quantitative and qualitative arms were combined, it became evident that despite their negative experiences and adversity, these women were able to cope and adapt. These women displayed resilience in that they were able to adapt despite experiencing such stressors. Various factors could have contributed to this resilience, including individual traits, the role of the community and culture. However, a resounding factor was the religious practice and belief expressed by the study participants.

With regard to their after-care experiences, the participants described the sessions as an opportunity to share their experiences; difficulties, dreams and hopes with an interviewer whom they thought would understand their problems. Although most of the participants felt that the interviewer shared their problems, two of the participants felt the subsequent interviews to be a time of revisiting the trauma and loss that they experienced whilst in hospital and thus chose not to follow up. The remaining participants appeared to be more forthcoming with information during subsequent interviews as they personally felt less threatened, less judged and stigmatized. Some study participants described satisfaction with the care they received; whilst others described a lack of nursing care and dissatisfaction with the care they received. Participants described a lack of empathy, understanding, information and communication from the staff, as well as a sense of hostility from staff. Participants who experienced a pregnancy loss found the referral to social workers and psychologists dissatisfying because of the perceived lack of understanding and knowledge pertaining to their condition by these professionals.

Results of the study have shown that maternal health, and especially maternal mental health, requires a comprehensive approach that addresses not only the biological components of health, but also the psychological, socio-cultural and religious aspects that

can influence maternal mental health, both in terms of the presentation of psychiatric complications and the attenuation of symptoms. Addressing these components may aid in developing programmes that target not only the risk factors that women are predisposed to, but also protective and strengthening factors that could contribute to maternal wellbeing and subsequently reduce the rates of maternal morbidity and mortality.

9.8 IMPLICATIONS AND CONTRIBUTIONS

- Maternal health is often approached in terms of the biomedical model. All efforts and treatment programmes during the perinatal period focus on the biological aspects of pregnancy, and after the birth, on the health of the baby. Limited attention, however, is paid to the psychosocial aspects of the mother's life. Maternal health, and especially maternal mental health, requires a comprehensive approach that addresses not only the biological components of health, but also the psychological, socio-cultural and religious aspects that can influence maternal mental health, both in terms of the presentation of psychiatric complications and the attenuation of symptoms.

- Attention is focused on the physical health of the mother and information is made available at the various points of service, such as the clinics, about pregnancy and related conditions, as well as potential complications in pregnancy. Limited information is, however, provided to the women about possible psychiatric sequelae. Attempts can be made to provide this information when women attend the antenatal clinics in the form of reading material, visual material, and talks by care-workers. In this manner, not only is awareness is created, but mental illness is destigmatized too.

- It is important to educate the health workers who have access to women during the perinatal period, including the health professionals such as the professional nurses and doctors, obstetricians and paediatricians, about psychiatric conditions that can occur during the perinatal period. Prompt detection, referral and treatment of psychiatric conditions can prevent adverse consequences in the long run.

- One of the common experiences that the participants expressed during the interviews was the fear of being judged and deemed unable to cope if they sought help for their difficulties during the perinatal period.

  Efforts need to be made to destigmatize mental illness, including perinatal mental illness, not only among the women, their families, the community and religious organizations, but among health professionals as well. The abovementioned components can all serve either as barriers or facilitators to women in terms of being amenable to accessing psychiatric services or seeking help for psychological distress.

- The participants in the present study were not only susceptible to risk that predisposed them to developing postpartum psychiatric complications, but also experienced life-threatening complications that further increased their propensity to development of complications. Participants with life-threatening stressors experienced greater distress and psychiatric complications than women with uneventful pregnancies.
- The lived experiences of the women provided insight into the lives and coping mechanisms of the participants.

Various factors could have contributed to them coping in the face of adversity, including individual traits and the role of the community and culture, but a resounding factor was the religious practice and belief expressed by the study participants. The ability to cope and adapt in in the presence of severe stressors could possibly point to the presence of resilience in these women. The concept of resilience in women with life-threatening complications could be an area of future research through the use of appropriate resilience scales in a larger study sample of women with such complications.

10 PERSONAL REFLECTIONS

When the thought of undertaking the PhD was in its infancy, the challenge was the subject matter of the study. Having been an obstetric registrar prior to changing career paths to become a psychiatrist, the concept of women's health and especially women's mental health took root. The idea was to combine these two special areas of interest. This subject matter was further cemented after attending a women's mental health conference when this evolving area of research became more evident and so the journey began.

The highlights of the study included returning to the obstetric ward after many years and meeting some of the senior nursing staff whom I had worked with previously. Returning to the wards, but in a different capacity was also a revelation as being an obstetric registrar, the focus was often on the medical and obstetric conditions and as a result of service delivery demands very little attention was paid to the psychiatric and psychosocial complications that these women experience. So, it was the change in mindset that was enlightening. The interaction with the study participants and gaining a peek into their lives was a privilege as well as a revelation. The first interview was just an introduction and the reality of their lives only became evident during the subsequent appointments. Establishing trust and rapport was initially difficult, but during the follow-up appointments it became evident that these women were more forthcoming and trusting.

Undertaking this PhD was indeed a journey not only as a professional but on a personal level too. Interacting with these women and gaining insight into their lives was an eye-opener. The lack of care and ridicule that some of the women experienced at the hospitals was disturbing. The lack of information and lack of empathy displayed by some of the professionals was also a revelation.

There were also initial stumbling blocks and returning to the PhD committee to have the protocol approved was an example of such an initial hurdle. Undertaking two rounds of participant recruitment was time-consuming, physically and emotionally challenging. Making contact with the patients to confirm their follow-up appointments and then waiting in vain for them to attend after they had confirmed was disheartening and disappointing.

Sacrifices in my personal life, many of them self-imposed as a result of the demands dictated by this dissertation were all encompassing, all consuming and emotionally challenging. Persevering when the morale was low and having many a meltdown and writers block were also stumbling blocks. My supervisor will bear testament to that.

Despite these challenges, this journey was a learning and an enriching experience. The lived experiences of the women and the hardships that they endured made some of my personal experiences seem trivial. Some of these women did not only have to contend with physical complications, but also psychosocial challenges. These included loss, in some case loss of a pregnancy, loss of future pregnancies, lack of support, isolation, stigma, cultural dictates and restrictions, financial challenges, infidelity and abandonment. However, their courage in adversity and determination to overcome challenges became evident in their acceptance of situations, the will to survive and their unwavering faith, which left much food for thought and an avenue for learning.

The conclusion of an intriguing and challenging experience can best be described by these words:

"It is good to have an end to journey toward; but it is the journey that matters in the end." (Ernest Hemmingway)

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APPENDIX A

Letters of Approval

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.
- FWA 00002567, Approved dd 22 May 2002 and Expires 20 Oct 2016.
- IRB 0000 2235 IORG0001762 Approved dd 13/04/2011 and Expires 13/04/2014.

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

2/10/2013

Approval Certificate
New Application

Ethics Reference No.: 353/2013

Title: Psychiatric sequelae and mental health aftercare experiences of women who have had a severe life-threatening event during pregnancy and those who have uncomplicated pregnancies: "An explorative-descriptive study

Dear Dr Nadira Khamker

The **New Application** as supported by documents specified in your cover letter for your research received on the 29/08/2013, was approved by the Faculty of Health Sciences Research Ethics Committee on the 1/10/2013.

Please note the following about your ethics approval:
- Ethics Approval is valid for 1 year.
- Please remember to use your protocol number (353/2013) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:
- The ethics approval is conditional on the receipt of 6 monthly written Progress Reports, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

Professor Werdie (CW) Van Staden
MBChB MMed(Psych) MD FCPsych FTCL UPLM
Chairperson: Faculty of Health Sciences Research Ethics Committee

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

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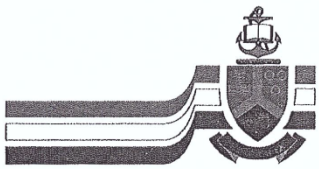

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Fakulteit Gesondheidswetenskappe

16 August 2013

Prof JL Roos
Department of Psychiatry
Weskoppies Hosptial
UNIVERSITY OF PRETORIA

Prof

STUDENT: N KHAMKER (PhD PSYCHIATRY)
"Psychiatric sequelae and mental health aftercare experiences of women who have had a near-miss event during pregnancy and those who have uncomplicated pregnancies: An explorative-descriptive study."

Mentioned student's protocol has been approved by the committee at the meeting held on the 13th of August 2013.

Kind regards

PROF BG LINDEQUE
VOORSITTER: PhD KOMITEE

c.c. Me A Strauss

APPENDIX B: **The World Health Organisation maternal near miss criteria**

Clinical criteria

Acute cyanosis

Gasping

Respiratory rate >40 or < 6/minute

Shock (persistent severe hypotension, defined as a systolic blood pressure <90mmHg for > 60 minutes with a pulse rate of at least 120 despite aggressive fluid replacement)

Oliguria non- responsive to fluids or diuretics

Clotting failure

Loss of consciousness lasting > 12 hours

Loss of consciousness and absence of pulse/heart beat

Stroke

Uncontrollable fit/total paralysis

Jaundice in the presence of pre-eclampsia

Laboratory-based criteria

Oxygen saturation <90% for > 60 minutes	PaO_2 / FiO_2 < 200mmHg
Creatinine > 300umol/l	Bilirubin > 100umol/l
pH < 7.1	Lactate > 5

Acute thrombocytopenia (< 50 000 platelets)

Loss of consciousness and the presence of glucose and keto-acids in urine

Management-based criteria

Use of continuous vasoactive drugs

Hysterectomy following infection or haemorrhage

Transfusion of > 5 units red cell transfusion

Intubation and ventilation for > 60 minutes not related to anaesthesia

Dialysis for acute renal failure

Cardio-pulmonary resuscitation

APPENDIX C:

INFORMED CONSENT

Protocol Title: Psychiatric sequelae and mental health aftercare experiences of women who have had a severe life-threatening event related to pregnancy and those who have uncomplicated pregnancies: "An explorative-descriptive study.

Principal Investigator: Dr N Khamker

Room 5, Auditorium

Weskoppies Hospital

Pretoria

012 3199811

Introduction:

You are requested to take part in a research study. The reason for doing this study is to understand the difficulties that women who have complicated/uncomplicated pregnancies, experience during and after the birth of their baby. We would like to know the needs of women who become very ill during and after their pregnancies and the type of care they would require. We think that these women who become very ill would need additional monitoring and care and may need to be seen by health care providers for a longer period after their delivery.

This information leaflet is meant to give you the details of the study so that you can decide if you want to take part in the study. You are free to choose whether or not you would like to participate.

The study is conducted by The Department of Psychiatry at the University of Pretoria. Patients will be seen at the Steve Biko Hospital and Kalafong Hospital. We would like to know about the problems that women who become very ill after their pregnancy experience, and what care they would need.

The person who is going to conduct this study is Dr N Khamker, who will interview women who had severe complications during the pregnancy as well as women who have had normal deliveries. Information will be collected about yourself and the problems you experienced. To help you understand the reason for the study, you need to understand the risks and benefits, so that you can make an informed decision. If you have any questions or do not understand anything in this leaflet, you are free to ask any questions.

Once the details of the study have been explained to you, you will be asked to sign this form. The reason for signing this form is merely telling us that you wish to take part in the study and that you are giving us permission to interview you and collect information about you, the pregnancy and your baby.

This information will help us to understand your problems better and help us in improving the quality of care that you and the women who have had similar problems will receive in the future. You will not be able to take part in this study if you do not sign this form.

Procedure

We are asking you to help us find out about the problems that women have in the long-term after they have had a baby, either through a normal delivery or those who had serious complication during their pregnancy and delivery. When we study these problems, we can find out what extra care the women who have similar problems will need and how we can help them.

You will be interviewed at different times during your visits to the hospital. The interviews will take place after you have delivered, then at 6weeks, 3 months and 6 months after your delivery. The interview will take place in a quiet place in the hospital. There won't be other people in the room, but if you do not understand English we can ask a health care provider who speaks your language to be present. During the interview you will be asked questions about your mental and emotional health and the problems you have experienced since your last visit. You will be requested to complete two questionnaires namely a Level 1 questionnaire regarding the symptoms you have experienced and the second questionnaire namely the WHODAS will allow you to explain how and to what degree these symptoms have affected your functioning. _The information will be written down. You will also be requested to keep a diary of all the events that take place in your life after you leave the hospital.

I will complete the following questionnaires and rating scales, depending on the information that you have provided, namely;

Level 2 questionnaires for;

- Anxiety
- Depression
- Mania
- Substance abuse
- Repetitive thoughts and behaviours
- Sleep disturbances

Rating scales

- Brief Psychiatric Rating Scale
- Becks Depression Inventory
- Hamilton Anxiety Scale

None other than the afore-mentioned questionnaires will be used and all the information given will be confidential. If there is any information that you cannot remember or provide, I request your permission to obtain the information from your medical files.

What are your rights if you take part in this study?

Your participation is entirely voluntary. You can refuse to participate or stop at any time during the interview. We are asking you to share some very confidential and personal

information. If you do not have an answer during the interview or do not wish to answer the questions you feel uncomfortable with, you may do so. If there are things during the interview that you do not understand, you can ask me to explain them to you. Your honest answers will help us gather valuable information.

Risks

This study consists only of interviews. The study has no known risks except for the confidentiality of the information you provide. It is possible that some questions may make you feel uncomfortable or may upset you. A recourse will be available to you, the participant, in case you are upset by the study or by the life-threatening event

The interviews will also take up some of your time and can last approximately 3hours per session

The information you provide will be kept confidential and no information will be given to any other person other than the researchers. The information you provide will be identified by code numbers and not your name. No reports will include any information that may identify you.

Benefits

The research may benefit you personally if we are able to identify and treat you for a condition that you were not aware of. It may also be that you may not experience any immediate benefit after taking part in the study, but your participation will provide information about the mental health problems women who have normal deliveries and those who have severe complications during pregnancy experience. This will help us provide better health services to others in future.

Compensation

There is no incentive remuneration involved in this study. You will receive money to pay for your transportation to attend the interviews but not for your participation in the study.

Right to withdraw from the study

Your participation in the research is voluntary. You may decide not to participate in the study or stop this study at any time without any penalty or loss. Your care and treatment at Steve Biko or Kalfong Hospital will not be affected in any way.

I understand the information in this leaflet and I hereby wish to participate in this study.

----------	----------
Signature of Research Participant	Name and Surname of Research Participant
Signed at:	
----------	----------
Date:	Time:
Signature of Next of Kin	Name and Surname of Next of Kin
----------	----------
Signature of Researcher	Name and Surname of Researcher.
Date:	Time:

----------	----------
Signature of Witness	Name and Surname of Witness

APPENDIX D

Questionnaires

DSM-5 Self-Rated Level 1 Cross-Cutting Symptom Measure—Adult

Name: _____ Age: ____ Sex: ❑ Male ❑ Female Date:_____

If this questionnaire is completed by an informant, **what is your relationship with the individual?** _____
In a typical week, approximately how much time do you spend with the individual? _____ **hours/week**

Instructions: The questions below ask about things that might have bothered you. For each question, circle the number that best describes how much (or how often) you have been bothered by each problem during the **past TWO (2) WEEKS.**

	During the past **TWO (2) WEEKS**, how much (or how often) have you been bothered by the following problems?	**None** Not at all	**Slight** Rare, less than a day or two	**Mild** Several days	**Moderate** More than half the days	**Severe** Nearly every day	**Highest Domain Score** (clinician)
I.	1. Little interest or pleasure in doing things?	0	1	2	3	4	
	2. Feeling down, depressed, or hopeless?	0	1	2	3	4	
II.	3. Feeling more irritated, grouchy, or angry than usual?	0	1	2	3	4	
III.	4. Sleeping less than usual, but still have a lot of energy?	0	1	2	3	4	
	5. Starting lots more projects than usual or doing more risky things than usual?	0	1	2	3	4	
IV.	6. Feeling nervous, anxious, frightened, worried, or on edge?	0	1	2	3	4	
	7. Feeling panic or being frightened?	0	1	2	3	4	
	8. Avoiding situations that make you anxious?	0	1	2	3	4	
V.	9. Unexplained aches and pains (e.g., head, back, joints, abdomen, legs)?	0	1	2	3	4	
	10. Feeling that your illnesses are not being taken seriously enough?	0	1	2	3	4	
VI.	11. Thoughts of actually hurting yourself?	0	1	2	3	4	
VII.	12. Hearing things other people couldn't hear, such as voices even when no one was around?	0	1	2	3	4	
	13. Feeling that someone could hear your thoughts, or that you could hear what another person was thinking?	0	1	2	3	4	
VIII.	14. Problems with sleep that affected your sleep quality over all?	0	1	2	3	4	
IX.	15. Problems with memory (e.g., learning new information) or with location (e.g., finding your way home)?	0	1	2	3	4	
X.	16. Unpleasant thoughts, urges, or images that repeatedly enter your mind?	0	1	2	3	4	
	17. Feeling driven to perform certain behaviors or mental acts over and over again?	0	1	2	3	4	
XI.	18. Feeling detached or distant from yourself, your body, your physical surroundings, or your memories?	0	1	2	3	4	
XII.	19. Not knowing who you really are or what you want out of life?	0	1	2	3	4	
	20. Not feeling close to other people or enjoying your relationships with them?	0	1	2	3	4	
XIII.	21. Drinking at least 4 drinks of any kind of alcohol in a single day?	0	1	2	3	4	
	22. Smoking any cigarettes, a cigar, or pipe, or using snuff or chewing tobacco?	0	1	2	3	4	
	23. Using any of the following medicines ON YOUR OWN, that is, without a doctor's prescription, in greater amounts or longer than prescribed [e.g., painkillers (like Vicodin), stimulants (like Ritalin or Adderall), sedatives or tranquilizers (like sleeping pills or Valium), or drugs like marijuana, cocaine or crack, club drugs (like ecstasy), hallucinogens (like LSD), heroin, inhalants or solvents (like glue), or methamphetamine (like speed)]?	0	1	2	3	4	

Instructions to Clinicians

The DSM-5 Level 1 Cross-Cutting Symptom Measure is a self- or informant-rated measure that assesses mental health domains that are important across psychiatric diagnoses. It is intended to help clinicians identify additional areas of inquiry that may have significant impact on the individual's treatment and prognosis. In addition, the measure may be used to track changes in the individual's symptom presentation over time.

This adult version of the measure consists of 23 questions that assess 13 psychiatric domains, including depression, anger, mania, anxiety, somatic symptoms, suicidal ideation, psychosis, sleep problems, memory, repetitive thoughts and behaviors, dissociation, personality functioning, and substance use. Each item inquires about how much (or how often) the individual has been bothered by the specific symptom during the past 2 weeks. If the individual is of impaired capacity and unable to complete the form (e.g., an individual with dementia), a knowledgeable adult informant may complete the measure. The measure was found to be clinically useful and to have good test-retest reliability in the DSM-5 Field Trials that were conducted in adult clinical samples across the United States and in Canada.

Scoring and Interpretation

Each item on the measure is rated on a 5-point scale (0=none or not at all; 1=slight or rare, less than a day or two; 2=mild or several days; 3=moderate or more than half the days; and 4=severe or nearly every day). The score on each item within a domain should be reviewed. Because additional inquiry is based on the highest score on any item within a domain, the clinician is asked to indicate that score in the "Highest Domain Score" column. A rating of mild (i.e., 2) or greater on any item within a domain (except for substance use, suicidal ideation, and psychosis) may serve as a guide for additional inquiry and follow up to determine if a more detailed assessment for that domain is necessary. For substance use, suicidal ideation, and psychosis, a rating of slight (i.e., 1) or greater on any item within the domain may serve as a guide for additional inquiry and follow-up to determine if a more detailed assessment is needed. The DSM-5 Level 2 Cross-Cutting Symptom Measures may be used to provide more detailed information on the symptoms associated with some of the Level 1 domains (see Table 1 below).

Frequency of Use

To track change in the individual's symptom presentation over time, the measure may be completed at regular intervals as clinically indicated, depending on the stability of the individual's symptoms and treatment status. For individuals with impaired capacity, it is preferable that the same knowledgeable informant completes the measures at follow-up appointments. Consistently high scores on a particular domain may indicate significant and problematic symptoms for the individual that might warrant further assessment, treatment, and follow-up. Clinical judgment should guide decision making.

Table 1: Adult DSM-5 Self-Rated Level 1 Cross-Cutting Symptom Measure: domains, thresholds for further inquiry, and associated Level 2 measures for adults ages 18 and over

Domain	Domain Name	Threshold to guide further inquiry	DSM-5 Level 2 Cross-Cutting Symptom Measure available online
I.	Depression	Mild or greater	LEVEL 2—Depression—Adult (PROMIS Emotional Distress—Depression—Short Form)[1]
II.	Anger	Mild or greater	LEVEL 2—Anger—Adult (PROMIS Emotional Distress—Anger—Short Form)[1]
III.	Mania	Mild or greater	LEVEL 2—Mania—Adult (Altman Self-Rating Mania Scale)
IV.	Anxiety	Mild or greater	LEVEL 2—Anxiety—Adult (PROMIS Emotional Distress—Anxiety—Short Form)[1]
V.	Somatic Symptoms	Mild or greater	LEVEL 2—Somatic Symptom—Adult (Patient Health Questionnaire 15 Somatic Symptom Severity [PHQ-15])
VI.	Suicidal Ideation	Slight or greater	None
VII.	Psychosis	Slight or greater	None
VIII.	Sleep Problems	Mild or greater	LEVEL 2—Sleep Disturbance - Adult (PROMIS—Sleep Disturbance—Short Form)[1]
IX.	Memory	Mild or greater	None
X.	Repetitive Thoughts and Behaviors	Mild or greater	LEVEL 2—Repetitive Thoughts and Behaviors—Adult (adapted from the Florida Obsessive-Compulsive Inventory [FOCI] Severity Scale [Part B])
XI.	Dissociation	Mild or greater	None
XII.	Personality Functioning	Mild or greater	None
XIII.	Substance Use	Slight or greater	LEVEL 2—Substance Abuse—Adult (adapted from the NIDA-modified ASSIST)

[1]The PROMIS Short Forms have not been validated as an informant report scale by the PROMIS group.

LEVEL 2—Depression—Adult*

*PROMIS Emotional Distress—Depression—Short Form

Name: _____ Age: ____ Sex: ❑ Male ❑ Female Date:_____

If the measure is being completed by an informant, what is your relationship with the individual receiving care? _____

In a typical week, approximately how much time do you spend with the individual receiving care? _____ hours/week

Instructions: On the DSM-5 Level 1 cross-cutting questionnaire that you just completed, you indicated that *during the past 2 weeks* you (the individual receiving care) have been bothered by "no interest or pleasure in doing things" and/or "feeling down, depressed, or hopeless" at a mild or greater level of severity. The questions below ask about these feelings in more detail and especially how often you (the individual receiving care) have been bothered by a list of symptoms **during the past 7 days. Please respond to each item by marking (✓ or x) one box per row.**

							Clinician Use
In the past SEVEN (7) DAYS....							Item Score
		Never	Rarely	Sometimes	Often	Always	
1.	I felt worthless.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
2.	I felt that I had nothing to look forward to.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
3.	I felt helpless.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
4.	I felt sad.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
5.	I felt like a failure.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
6.	I felt depressed.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
7.	I felt unhappy.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
8.	I felt hopeless.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
						Total/Partial Raw Score:	
						Prorated Total Raw Score:	
						T-Score:	

Instructions to Clinicians

The DSM-5 Level 2—Depression—Adult measure is the 8-item PROMIS Depression Short Form that assesses the pure domain of depression in individuals age 18 and older. The measure is completed by the individual prior to a visit with the clinician. If the individual receiving care is of impaired capacity and unable to complete the form (e.g., an individual with dementia), a knowledgeable informant may complete the measure as done in the DSM-5 Field Trials. However, the PROMIS Depression Short Form has not been validated as an informant report scale by the PROMIS group. Each item asks the individual receiving care (or informant) to rate the severity of the individual's depression **during the past 7 days**.

Scoring and Interpretation

Each item on the measure is rated on a 5-point scale (1=never; 2=rarely; 3=sometimes; 4=often; and 5=always) with a range in score from 8 to 40 with higher scores indicating greater severity of depression. The clinician is asked to review the score on each item on the measure during the clinical interview and indicate the raw score for each item in the section provided for "Clinician Use." The raw scores on the 8 items should be summed to obtain a total raw score. Next, the T-score table should be used to identify the T-score associated with the individual's total raw score and the information entered in the T-score row on the measure.

Note: This look-up table works only if all items on the form are answered. If 75% or more of the questions have been answered; you are asked to prorate the raw score and then look up the conversion to T-Score. The formula to prorate the partial raw score to Total Raw Score is:

(Raw sum x number of items on the short form)
Number of items that were actually answered

If the result is a fraction, round to the nearest whole number. For example, if 6 of 8 items were answered and the sum of those 6 responses was 20, the prorated raw score would be 20 X 8/ 6 = 26.67. The T-score in this example would be the T-score associated with the rounded whole number raw score (in this case 27, for a T-score of 64.4).

The T-scores are interpreted as follows:

Less than 55	= None to slight
55.0—59.9	= Mild
60.0—69.9	= Moderate
70 and over	= Severe

Note: If more than 25% of the total items on the measure are missing the scores should not be used. Therefore, the individual receiving care (or informant) should be encouraged to complete all of the items on the measure.

Depression 8b
Short Form Conversion Table

Raw Score	T-score	SE*
8	37.1	5.5
9	43.3	3.4
10	46.2	2.8
11	48.2	2.4
12	49.8	2.2
13	51.2	2.0
14	52.3	1.9
15	53.4	1.8
16	54.3	1.8
17	55.3	1.7
18	56.2	1.7
19	57.1	1.7
20	57.9	1.7
21	58.8	1.7
22	59.7	1.8
23	60.7	1.8
24	61.6	1.8
25	62.5	1.8
26	63.5	1.8
27	64.4	1.8
28	65.4	1.8
29	66.4	1.8
30	67.4	1.8
31	68.3	1.8
32	69.3	1.8
33	70.4	1.8
34	71.4	1.8
35	72.5	1.8
36	73.6	1.8
37	74.8	1.9
38	76.2	2.0
39	77.9	2.4
40	81.1	3.4

*SE = Standard Error on T-score metric

Frequency of Use

To track change in the severity of the individual's depression over time, the measure may be completed at regular intervals as clinically indicated, depending on the stability of the individual's symptoms and treatment status. For individuals with impaired capacity, it is preferred that completion of the measures at follow-up appointments is by the same knowledgeable informant. Consistently high scores on a particular domain may indicate significant and problematic areas for the individual that might warrant further assessment, treatment, and follow-up. Your clinical judgment should guide your decision.

LEVEL 2—Anxiety—Adult*

*PROMIS Emotional Distress—Anxiety—Short Form

Name: _____ Age: ____ Sex: ❑ Male ❑ Female Date:_____

If the measure is being completed by an informant, what is your relationship with the individual? _____

In a typical week, approximately how much time do you spend with the individual? _____hours/week

Instructions to patient: On the DSM-5 Level 1 cross-cutting questionnaire that you just completed, you indicated that *during the past 2 weeks* you (individual receiving care) have been bothered by "feeling nervous, anxious, frightened, worried, or on edge", "feeling panic or being frightened", and/or "avoiding situations that make you anxious" at a mild or greater level of severity. The questions below ask about these feelings in more detail and especially how often you (individual receiving care) have been bothered by a list of symptoms **during the past 7 days.** **Please respond to each item by marking (✓ or x) one box per row.**

							Clinician Use
In the past SEVEN (7) DAYS....							Item Score
		Never	Rarely	Sometimes	Often	Always	
1.	I felt fearful.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
2.	I felt anxious.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
3.	I felt worried.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
4.	I found it hard to focus on anything other than my anxiety.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
5.	I felt nervous.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
6.	I felt uneasy.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
7.	I felt tense.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
						Total/Partial Raw Score:	
						Prorated Total Raw Score:	
						T-Score:	

Instructions to Clinicians

The DSM-5 Level 2—Anxiety—Adult measure is the 7-item PROMIS Anxiety Short Form that assesses the pure domain of anxiety in individuals age 18 and older. The measure is completed by the individual prior to a visit with the clinician. If the individual receiving care is of impaired capacity and unable to complete the form (e.g., an individual with dementia), a knowledgeable informant may complete the measure as done in the DSM-5 Field Trials. However, the PROMIS Anxiety Short Form has not been validated as an informant report scale by the PROMIS group. Each item asks the individual receiving care (or informant) to rate the severity of the individual's anxiety **during the past 7 days**.

Scoring and Interpretation

Each item on the measure is rated on a 5-point scale (1=never; 2=rarely; 3=sometimes; 4=often; and 5=always) with a range in score from 7 to 35 with higher scores indicating greater severity of anxiety. The clinician is asked to review the score on each item on the measure during the clinical interview and indicate the raw score for each item in the section provided for "Clinician Use." The raw scores on the 7 items should be summed to obtain a total raw score. Next, the T-score table should be used to identify the T-score associated with the total raw score and the information entered in the T-score row on the measure.

Note: This look-up table works only if all items on the form are answered. If 75% or more of the questions have been answered; you are asked to prorate the raw score and then look up the conversion to T-Score. The formula to prorate the partial raw score to Total Raw Score is:

(Raw sum x number of items on the short form)
Number of items that were actually answered

If the result is a fraction, round to the nearest whole number. For example, if 6 of 7 items were answered and the sum of those 6 responses was 20, the prorated raw score would be 20 X 7/ 6 = 23.33. The T-score in this example would be that T-score associated with the rounded whole number raw score (in this case 23, for a T-score of 63.8).

The T-scores are interpreted as follows:

Less than 55	= None to slight
55.0—59.9	= Mild
60.0—69.9	= Moderate
70 and over	= Severe

Note: If more than 25% of the total items on the measure are missing the scores should not be used. Therefore, the individual receiving care (or informant) should be encouraged to complete all of the items on the measure.

Frequency of Use

To track change in the severity of the individual's anxiety over time, the measure may be completed at regular intervals as clinically indicated, depending on the stability of the individual's symptoms and treatment status. For individuals with impaired capacity, it is preferred that completion of the measures at follow-up appointments is by the same knowledgeable informant. Consistently high scores on a particular domain may indicate significant and problematic areas for the individual that might warrant further assessment, treatment, and follow-up. Your clinical judgment should guide your decision.

Anxiety 7a
Short Form Conversion Table

Raw Score	T-score	SE*
7	36.3	5.4
8	42.1	3.4
9	44.7	2.9
10	46.7	2.6
11	48.4	2.4
12	49.9	2.3
13	51.3	2.3
14	52.6	2.2
15	53.8	2.2
16	55.1	2.2
17	56.3	2.2
18	57.6	2.2
19	58.8	2.2
20	60.0	2.2
21	61.3	2.2
22	62.6	2.2
23	63.8	2.2
24	65.1	2.2
25	66.4	2.2
26	67.7	2.2
27	68.9	2.2
28	70.2	2.2
29	71.5	2.2
30	72.9	2.2
31	74.3	2.2
32	75.8	2.3
33	77.4	2.4
34	79.5	2.7
35	82.7	3.5

*SE = Standard Error on T-score metric

LEVEL 2—Anger—Adult*

*PROMIS Emotional Distress—Anger—Short Form

Name: _____ Age: ____ Sex: ❑ Male ❑ Female Date:_____

If the measure is being completed by an informant, what is your relationship with the individual receiving care? _____

In a typical week, approximately how much time do you spend with the individual receiving care? _____ hours/week

Instructions: On the DSM-5 Level 1 cross-cutting questionnaire that you just completed, you indicated that *during the past 2 weeks* you (the individual receiving care) have been bothered by "feeling irritated, grouchy, or angry" at a mild or greater level of severity. The questions below ask about these feelings in more detail and especially how often you (the individual receiving care) have been bothered by a list of symptoms **during the past 7 days. Please respond to each item by marking (✓ or x) one box per row.**

							Clinician Use
In the past SEVEN (7) DAYS....							Item Score
		Never	Rarely	Sometimes	Often	Always	
1.	I was irritated more than people knew.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
2.	I felt angry.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
3.	I felt like I was ready to explode.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
4.	I was grouchy.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
5.	I felt annoyed.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
						Total/Partial Raw Score:	
						Prorated Total Raw Score:	
						T-Score:	

Instructions to Clinicians

The DSM-5 Level 2—Anger—Adult measure is a 5-item version of the PROMIS Anger Short Form that assesses the pure domain of anger in individuals age 18 and older. The measure is completed by the individual prior to a visit with the clinician. If the individual receiving care is of impaired capacity and unable to complete the form (e.g., an individual with dementia), a knowledgeable informant may complete the measure as done in the DSM-5 Field Trials. However, the PROMIS Anger Short Form has not been validated as an informant report scale by the PROMIS group. Each item asks the individual receiving care (or informant) to rate the severity of the individual's anger **during the past 7 days**.

Scoring and Interpretation

Each item on the measure is rated on a 5-point scale (1=never; 2=rarely; 3=sometimes; 4=often; and 5=always) with a range in score from 5 to 25 with higher scores indicating greater severity of anger. The clinician is asked to review the score on each item on the measure during the clinical interview and indicate the raw score for each item in the section provided for "Clinician Use." The raw scores on the 5 items should be summed to obtain a total raw score. Next, the T-score table should be used to identify the T-score associated with the individual's total raw score and the information entered in the T-score row on the measure.

Raw Score	T-Score	SE
5	32.9	5.3
6	38.1	4
7	41.3	3.7
8	44	3.5
9	46.3	3.4
10	48.4	3.3
11	50.5	3.3
12	52.6	3.2
13	54.7	3.2
14	56.7	3.2
15	58.8	3.2
16	60.8	3.2
17	62.9	3.2
18	65	3.2
19	67.2	3.2
20	69.4	3.3
21	71.7	3.3
22	74.1	3.3
23	76.8	3.4
24	79.7	3.5
25	83.3	3.9

Note: This look-up table works only if all items on the form are answered. If 75% or more of the questions have been answered; you are asked to prorate the raw score and then look up the conversion to T-Score. The formula to prorate the partial raw score to Total Raw Score is:

(Raw sum x number of items on the short form)
Number of items that were actually answered

If the result is a fraction, round to the nearest whole number. For example, if 4 of 5 items were answered and the sum of those 4 responses was 15, the prorated raw score would be 15 X 5/4 = 18.75. The T-score in this example would be that T-score associated with the rounded whole number raw score (in this case 19, for a T-score of 67.2).

The T-scores are interpreted as follows:

Less than 55	= None to slight
55.0—59.9	= Mild
60.0—69.9	= Moderate
70 and over	= Severe

Note: If more than 25% of the total items on the measure are missing the scores should not be used. Therefore, the individual receiving care (or informant) should be encouraged to complete all of the items on the measure.

Frequency of Use

To track change in the severity of the individual's anger over time, the measure may be completed at regular intervals as clinically indicated, depending on the stability of the individual's symptoms and treatment status. For individuals with impaired capacity, it is preferred that completion of the measures at follow-up appointments is by the same knowledgeable informant. Consistently high scores on a particular domain may indicate significant and problematic areas for the individual that might warrant further assessment, treatment, and follow-up. Your clinical judgment should guide your decision.

LEVEL 2—Mania—Adult*

*Altman Self-Rating Mania Scale (ASRM)

Name: _____ Age: ____ Sex: ❑ Male ❑ Female Date:_____

If the measure is being completed by an informant, what is your relationship with the individual receiving care? _____

In a typical week, approximately how much time do you spend with the individual receiving care? _____ hours/week

Instructions: On the DSM-5 Level 1 cross-cutting questionnaire you just completed, you indicated that *during the past 2 weeks* you (the individual receiving care) have been bothered by "sleeping less than usual, but still having a lot of energy" and/or "starting lots more projects than usual or doing more risky things than usual" at a mild or greater level of severity. The five statement groups or questions below ask about these feelings in more detail.

1. **Please read each group of statements/question carefully.**
2. Choose the one statement in each group that best describes the way you (the individual receiving care) have been feeling for the past week.
3. Check the box (✓ or x) next to the number/statement selected.
4. **Please note:** The word "occasionally" when used here means once or twice; "often" means several times or more and "frequently" means most of the time.

		Clinician Use
Question 1		**Item score**
❑ 1	I do not feel happier or more cheerful than usual.	
❑ 2	I occasionally feel happier or more cheerful than usual.	
❑ 3	I often feel happier or more cheerful than usual.	
❑ 4	I feel happier or more cheerful than usual most of the time.	
❑ 5	I feel happier of more cheerful than usual all of the time.	
Question 2		
❑ 1	I do not feel more self-confident than usual.	
❑ 2	I occasionally feel more self-confident than usual.	
❑ 3	I often feel more self-confident than usual.	
❑ 4	I frequently feel more self-confident than usual.	
❑ 5	I feel extremely self-confident all of the time.	
Question 3		
❑ 1	I do not need less sleep than usual.	
❑ 2	I occasionally need less sleep than usual.	
❑ 3	I often need less sleep than usual.	
❑ 4	I frequently need less sleep than usual.	
❑ 5	I can go all day and all night without any sleep and still not feel tired.	
Question 4		
❑ 1	I do not talk more than usual.	
❑ 2	I occasionally talk more than usual.	
❑ 3	I often talk more than usual.	
❑ 4	I frequently talk more than usual.	
❑ 5	I talk constantly and cannot be interrupted.	
Question 5		
❑ 1	I have not been more active (either socially, sexually, at work, home, or school) than usual.	
❑ 2	I have occasionally been more active than usual.	
❑ 3	I have often been more active than usual.	
❑ 4	I have frequently been more active than usual.	
❑ 5	I am constantly more active or on the go all the time.	
	Total/Partial Raw Score:	
	Prorated Total Raw Score:	

Instructions to Clinicians

The DSM-5 Level 2—Mania—Adult measure is the Altman Self-Rating Mania Scale. The ASRM is a 5-item self-rating mania scale designed to assess the presence and/or severity of manic symptoms. The measure is completed by the individual prior to a visit with the clinician. If the individual receiving care is of impaired capacity and unable to complete the form (e.g., an individual with dementia), a knowledgeable informant may complete the measure. Each item asks the individual (or informant) to rate the severity of the individual's manic symptoms **during the past 7 days**.

Scoring and Interpretation

Each item on the measure is rated on a 5-point scale (i.e., 1 to 5) with the response categories having different anchors depending on the item. The ASRM score range from 5 to 25 with higher scores indicating greater severity of manic symptoms. The clinician is asked review the score on each item on the measure during the clinical interview and indicate the raw score for each item in the section provided for "Clinician Use". The raw scores on the 5 items should be summed to obtain a total raw score and should be interpreted using the Interpretation Table for the ASRM below:

Interpretation Table for the ASRM

- A score of 6 or higher indicates a high probability of a manic or hypomanic condition
- A score of 6 or higher may indicate a need for treatment and/or further diagnostic workup
- A score of 5 or lower is less likely to be associated with significant symptoms of mania

Note: If 2 or more items are left unanswered on the measure (i.e., more than 25% of the total items are missing) the scores should not be used. As such, the individual (or informant) should be encouraged to complete all of the items on the measure. If only 4 of the 5 items on the measure are answered, you are asked to calculate a prorated score. The prorated score is calculated by summing the scores of items that were answered to get a **partial raw score**. Next, multiply the partial raw score by the total number of items on the ASRM (i.e., 5). Finally, divide the value by the number of items that were actually answered (i.e.,4).

$$\text{Prorated score} = \frac{\text{(Partial Raw Score x number of items on the ASRM)}}{\text{Number of items that were actually answered}}$$

If the result is a fraction, round to the nearest whole number.

The prorated total raw score should be interpreted using the Interpretation Table for the ASRM above.

Frequency of Use

To track change in the severity of the individual's manic symptoms over time, the measure may be completed at regular intervals as clinically indicated, depending on the stability of the individual's symptoms and treatment status. For individuals of impaired capacity, it is preferred that completion of the measures at follow-up appointments is by the same knowledgeable informant. Consistently high scores on a particular domain may indicate significant and problematic areas for the patient that might warrant further assessment, treatment, and follow-up. Your clinical judgment should guide your decision.

LEVEL 2—Repetitive Thoughts and Behaviors—Adult*

*Adapted from the Florida Obsessive-Compulsive Inventory (FOCI) Severity Scale (Part B)

Name: _____ Age: ____ Sex: ❑ Male ❑ Female Date:_____

If the measure is being completed by an informant, what is your relationship with the individual receiving care? _____

In a typical week, approximately how much time do you spend with the individual receiving care? _____ hours/week

Instructions: On the DSM-5 Level 1 cross-cutting questionnaire that you just completed, you indicated that *during the past 2 weeks* you have been bothered by "unwanted repeated thoughts, images, or urges" and/or "being driven to perform certain behaviors or mental acts over and over" at a mild or greater level of severity. The questions below ask about these feelings in more detail and especially how often you have been bothered by a list of symptoms **during the past 7 days. Please respond to each item by marking (✓ or x) one box per row.**

						Clinician Use
During the past SEVEN (7) DAYS....						Item Score
1. On average, how much *time* is occupied by these thoughts or behaviors each day?	❑ 0—None	❑ 1—Mild (Less than an hour a day)	❑ 2—Moderate (1 to 3 hours a day)	❑ 3—Severe (3 to 8 hours a day)	❑ 4—Extreme (more than 8 hours a day)	
2. How much *distress* do these thoughts or behaviors cause you?	❑ 0—None	❑ 1—Mild (slightly disturbing)	❑ 2—Moderate (disturbing but still manageable)	❑ 3—Severe (very disturbing)	❑ 4—Extreme (overwhelming distress)	
3. How hard is it for you to *control* these thoughts or behaviors?	❑ 0—Complete control	❑ 1—Much control (usually able to control thoughts or behaviors)	❑ 2—Moderate control (sometimes able to control thoughts or behaviors)	❑ 3—Little control (infrequently able to control thoughts or behaviors)	❑ 4—No control (unable to control thoughts or behaviors)	
4. How much do these thoughts or behaviors cause you to *avoid* doing anything, going anyplace, or being with anyone?	❑ 0—No avoidance	❑ 1—Mild (occasional avoidance)	❑ 2—Moderate (regularly avoid doing these things)	❑ 3—Severe (frequent and extensive avoidance)	❑ 4 - Extreme (nearly complete avoidance; house- bound)	
5. How much do these thoughts or behaviors *interfere* with school, work, or your social or family life?	❑ 0—None	❑ 1—Mild (slight interference)	❑ 2— Moderate; (definite interference with functioning, but still manageable)	❑ 3—Severe (substantial interference)	❑ 4—Extreme (near-total interference; incapacitated)	
					Total/Partial Raw Score:	
					Prorated Total Raw Score (if 1 item is left unanswered):	
					Average Total Score:	

Instructions to Clinicians

The DSM-5 Level 2—Repetitive Thoughts and Behavior—Adult measure is an adapted version of the 5-item Florida Obsessive-Compulsive Inventory (FOCI) Severity Scale (Part B) that is used to assess the domain of repetitive thoughts and behaviors in individuals age 18 and older. The measure is completed by an individual prior to a visit with the clinician. If the individual receiving care is of impaired capacity and unable to complete the form (e.g., an individual with dementia), a knowledgeable informant may complete the measure. Each item asks the individual (or informant) to rate the severity of the individual's repetitive thoughts and behaviors **during the past 7 days**.

Scoring and Interpretation

Each item on the measure is rated on a 5-point scale (i.e., 0 to 4) with the response categories having different anchors depending on the item. The total score for the measure can range of score from 0 to 20, with higher scores indicating greater severity of repetitive thoughts and behaviors. The clinician is asked to review the score of each item on the measure during the clinical interview and indicate the raw score for each item in the section provided for "Clinician Use." The raw scores on the 5 items should be summed to obtain a total raw score. If the individual has a score of 8 or higher, you may want to consider a more detailed assessment for an obsessive compulsive disorder. In addition, the clinician is asked to calculate and use the **average total score.** **The average total score** reduces the overall score to a 5-point scale, which allows the clinician to think of the individual's repetitive thoughts and behavior in terms of none (0), mild (1), moderate (2), severe (3), or extreme (4). The use of the average total score was found to be reliable, easy to use, and clinically useful to the clinicians in the DSM-5 Field Trials. The **average total score** is calculated by dividing the raw total score by number of items in the measure (i.e., 5).

Note: If 2 or more items are left unanswered on the measure (i.e., more than 25% of the total items are missing), the total scores should not be calculated. Therefore, the individual (or informant) should be encouraged to complete all of the items on the measure. If only 4 of the 5 items on the measure are answered, you are asked to prorate the raw score by first summing the scores of items that were answered to get a **partial raw score**. Next, multiply the partial raw score by the total number of items on the measure (i.e., 5). Finally, divide the value by the number of items that were actually answered (i.e., 4) to obtain the prorated total raw score.

$$\text{Prorated Score} = \frac{\text{(Partial Raw Score x number of items on the measure)}}{\text{Number of items that were actually answered}}$$

If the result is a fraction, round to the nearest whole number.

Frequency of Use

To track change in the severity of the individual's repetitive thoughts and behavior over time, the measure may be completed at regular intervals as clinically indicated, depending on the stability of the individual's symptoms and treatment status. For individuals of impaired capacity, it is preferred that completion of the measure at follow-up appointments is by the same knowledgeable informant. Consistently high scores on the measure may indicate significant and problematic areas for the individual that might warrant further assessment, treatment, and follow-up. Your clinical judgment should guide your decision.

LEVEL 2—Sleep Disturbance—Adult*

*PROMIS—Sleep Disturbance—Short Form

Name: _____ Age: ____ Sex: ❑ Male ❑ Female Date:_____

If the measure is being completed by an informant, what is your relationship with the individual receiving care? _____

In a typical week, approximately how much time do you spend with the individual receiving care? _____ hours/week

Instructions to patient: On the DSM-5 Level 1 cross-cutting questionnaire that you just completed, you indicated that *during the past 2 weeks* you (the individual receiving care) have been bothered by "problems with sleep that affected your sleep quality over all" at a mild or greater level of severity. The questions below ask about these feelings in more detail and especially how often you (the individual receiving care) have been bothered by a list of symptoms **during the past 7 days.** **Please respond to each item by marking (✓ or x) one box per row.**

						Clinician Use
In the past SEVEN (7) DAYS....						
	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**	
1. My sleep was restless.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
2. I was satisfied with my sleep.	❑ 5	❑ 4	❑ 3	❑ 2	❑ 1	
3. My sleep was refreshing.	❑ 5	❑ 4	❑ 3	❑ 2	❑ 1	
4. I had difficulty falling asleep.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
In the past SEVEN (7) DAYS....						
	Never	**Rarely**	**Sometimes**	**Often**	**Always**	
5. I had trouble staying asleep.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
6. I had trouble sleeping.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	
7. I got enough sleep.	❑ 5	❑ 4	❑ 3	❑ 2	❑ 1	
In the past SEVEN (7) DAYS....						
	Very Poor	**Poor**	**Fair**	**Good**	**Very good**	
8. My sleep quality was...	❑ 5	❑ 4	❑ 3	❑ 2	❑ 1	
					Total/Partial Raw Score:	
					Prorated Total Raw Score:	
					T-Score:	

Instructions to Clinicians

The DSM-5 Level 2—Sleep Disturbance—Adult measure is the 8-item PROMIS Sleep Disturbance Short Form that assesses the pure domain of sleep disturbance in individuals age 18 and older. The measure is completed by the individual prior to a visit with the clinician. If the individual receiving care is of impaired capacity and unable to complete the form (e.g., an individual with dementia), a knowledgeable informant may complete the measure as done in the DSM-5 Field Trials. However, the PROMIS Sleep Disturbance Short Form has not been validated as an informant report scale by the PROMIS group. Each item asks the patient (or informant) to rate the severity of the patient's sleep disturbance **during the past 7 days**.

Scoring and Interpretation

Each item on the measure is rated on a 5-point scale (1=never; 2=rarely; 3=sometimes; 4=often; and 5=always) with a range in score from 8 to 40 with higher scores indicating greater severity of sleep disturbance. The clinician is asked to review the score on each item on the measure during the clinical interview and indicate the raw score for each item in the section provided for "Clinician Use." The raw scores on the 8 items should be summed to obtain a total raw score. Next, the T-score table should be used to identify the T-score associated with the individual's total raw score and the information entered in the T-score row on the measure.

Note: This look-up table works only if all items on the form are answered. If 75% or more of the questions have been answered; you are asked to prorate the raw score and then look up the conversion to T-Score. The formula to prorate the partial raw score to Total Raw Score is:

(Raw sum x number of items on the short form)
Number of items that were actually answered

If the result is a fraction, round to the nearest whole number. For example, if 6 of 8 items were answered and the sum of those 6 responses was 20, the prorated raw score would be 20 X 8/6 = 26.67. The T-score in this example would be that T-score associated with the rounded whole number raw score (in this case 27, for a T-score of 57.3).

The T-scores are interpreted as follows:

Less than 55	= None to slight
55.0—59.9	= Mild
60.0—69.9	= Moderate
70 and over	= Severe

Note: If more than 25% of the total items on the measure are missing the scores should not be used. Therefore, the individual receiving care (or informant) should be encouraged to complete all of the items on the measure.

Frequency of Use

To track change in the severity of the individual's sleep disturbance over time, the measure may be completed at regular intervals as clinically indicated, depending on the stability of the individual's symptoms and treatment status. For individuals with impaired capacity, it is preferred that completion of the measures at follow-up appointments is by the same knowledgeable informant. Consistently high scores on a particular domain may indicate significant and problematic areas for the individual that might warrant further assessment, treatment, and follow-up. Your clinical judgment should guide your decision.

Sleep Disturbance 8b
Short Form Conversion Table

Raw Score	T-score	SE*
8	28.9	4.8
9	33.1	3.7
10	35.9	3.3
11	38.0	3.0
12	39.8	2.9
13	41.4	2.8
14	42.9	2.7
15	44.2	2.7
16	45.5	2.6
17	46.7	2.6
18	47.9	2.6
19	49.0	2.6
20	50.1	2.5
21	51.2	2.5
22	52.2	2.5
23	53.3	2.5
24	54.3	2.5
25	55.3	2.5
26	56.3	2.5
27	57.3	2.5
28	58.3	2.5
29	59.4	2.5
30	60.4	2.5
31	61.5	2.5
32	62.6	2.5
33	63.7	2.6
34	64.9	2.6
35	66.1	2.7
36	67.5	2.8
37	69.0	3.0
38	70.8	3.2
39	73.0	3.5
40	76.5	4.4

*SE = Standard Error on T-score metric

LEVEL 2—Substance Use—Adult*

*Adapted from the NIDA-Modified ASSIST

Name: _____ Age: ____ Sex: ❑ Male ❑ Female Date: _____

If the measure is being completed by an informant, what is your relationship with the individual receiving care? _____

In a typical week, approximately how much time do you spend with the individual receiving care? _____ hours/week

Instructions: On the DSM-5 Level 1 cross-cutting questionnaire that you just completed, you indicated that *during the past 2 weeks* you (the individual receiving care) have been bothered by "using medicines on your own without a doctor's prescription, or in greater amounts or longer than prescribed, and/or using drugs like marijuana, cocaine or crack, and/or other drugs" at a slight or greater level of severity. The questions below ask how often you (the individual receiving care) have used these medicines and/or substances **during the past 2 weeks. Please respond to each item by marking (✓ or x) one box per row.**

During the past **TWO (2) WEEKS**, about how often did you use any of the following medicines ON YOUR OWN, that is, without a doctor's prescription, in greater amounts or longer than prescribed?							Clinician Use
		Not at all	One or two days	Several days	More than half the days	Nearly every day	Item Score
a.	Painkillers (like Vicodin)	❑ 0	❑ 1	❑ 2	❑ 3	❑ 4	
b.	Stimulants (like Ritalin, Adderall)	❑ 0	❑ 1	❑ 2	❑ 3	❑ 4	
c.	Sedatives or tranquilizers (like sleeping pills or Valium)	❑ 0	❑ 1	❑ 2	❑ 3	❑ 4	
Or drugs like:							
d.	Marijuana	❑ 0	❑ 1	❑ 2	❑ 3	❑ 4	
e.	Cocaine or crack	❑ 0	❑ 1	❑ 2	❑ 3	❑ 4	
f.	Club drugs (like ecstasy)	❑ 0	❑ 1	❑ 2	❑ 3	❑ 4	
g.	Hallucinogens (like LSD)	❑ 0	❑ 1	❑ 2	❑ 3	❑ 4	
h.	Heroin	❑ 0	❑ 1	❑ 2	❑ 3	❑ 4	
i.	Inhalants or solvents (like glue)	❑ 0	❑ 1	❑ 2	❑ 3	❑ 4	
j.	Methamphetamine (like speed)	❑ 0	❑ 1	❑ 2	❑ 3	❑ 4	
						Total Score:	

Instructions to Clinicians

The DSM-5 Level 2—Substance Use—Adult is an adapted version of the NIDA-Modified ASSIST. The 15-item measure is used to assess the pure domain of prescription medicine, and illicit substance use in adults age 18 and older. It is completed by the individual prior to a visit with the clinician. If the individual receiving care is of impaired capacity and unable to complete the form (e.g., an individual with dementia), a knowledgeable informant may complete the measure. Each item asks the individual receiving care (or informant) to rate the severity of the individual's use of various substances **during the past 2 weeks.**

Scoring and Interpretation

Each item on the measure is rated on a 5-point scale (i.e., 0=not at all; 1=1 or 2 days; 2=several days; 3=more than half the days; 4=nearly every day). The clinician is asked to review the score of each item on the measure during the clinical interview and indicate the raw score for each item in the section provided for "Clinician Use." Scores on the individual items should be interpreted independently because each item inquires about the use of a distinct substance. The rating of multiple items at scores greater than 0 indicates greater severity and complexity of substance use.

Frequency of Use

To track change in the severity of the individual's use of alcohol, tobacco/nicotine, prescription or illicit substance over time, the measure be may completed at regular intervals as clinically indicated, depending on the stability of the individual's symptoms and treatment status. For individuals of impaired capacity, it is preferred that completion of the measures at follow-up appointments is by the same knowledgeable informant. Consistently high scores on the measure may indicate significant and problematic areas that might warrant further assessment, treatment, and follow-up. Your clinical judgment should guide your decision.

WHODAS 2.0

World Health Organization Disability Assessment Schedule 2.0

36-item version, self-administered

Patient Name: _____ **Age:** _____ **Sex:** ❑ Male ❑ Female **Date:**_____

This questionnaire asks about difficulties due to health/mental health conditions. Health conditions include **diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.** Think back over the **past 30 days** and answer these questions thinking about how much difficulty you had doing the following activities. For each question, please circle only **one** response.

							Clinician Use Only		
Numeric scores assigned to each of the items:		1	2	3	4	5	Raw Item Score	Raw Domain Score	Average Domain Score
In the last 30 days, how much difficulty did you have in:									
Understanding and communicating									
D1.1	Concentrating on doing something for ten minutes?	None	Mild	Moderate	Severe	Extreme or cannot do		___ 30	___ 5
D1.2	Remembering to do important things?	None	Mild	Moderate	Severe	Extreme or cannot do			
D1.3	Analyzing and finding solutions to problems in day-to-day life?	None	Mild	Moderate	Severe	Extreme or cannot do			
D1.4	Learning a new task, for example, learning how to get to a new place?	None	Mild	Moderate	Severe	Extreme or cannot do			
D1.5	Generally understanding what people say?	None	Mild	Moderate	Severe	Extreme or cannot do			
D1.6	Starting and maintaining a conversation?	None	Mild	Moderate	Severe	Extreme or cannot do			
Getting around									
D2.1	Standing for long periods, such as 30 minutes?	None	Mild	Moderate	Severe	Extreme or cannot do		___ 25	___ 5
D2.2	Standing up from sitting down?	None	Mild	Moderate	Severe	Extreme or cannot do			
D2.3	Moving around inside your home?	None	Mild	Moderate	Severe	Extreme or cannot do			
D2.4	Getting out of your home?	None	Mild	Moderate	Severe	Extreme or cannot do			
D2.5	Walking a long distance, such as a kilometer (or equivalent)?	None	Mild	Moderate	Severe	Extreme or cannot do			
Self-care									
D3.1	Washing your whole body?	None	Mild	Moderate	Severe	Extreme or cannot do		___ 20	___ 5
D3.2	Getting dressed?	None	Mild	Moderate	Severe	Extreme or cannot do			
D3.3	Eating?	None	Mild	Moderate	Severe	Extreme or cannot do			
D3.4	Staying by yourself for a few days?	None	Mild	Moderate	Severe	Extreme or cannot do			
Getting along with people									
D4.1	Dealing with people you do not know?	None	Mild	Moderate	Severe	Extreme or cannot do		___ 25	___ 5
D4.2	Maintaining a friendship?	None	Mild	Moderate	Severe	Extreme or cannot do			
D4.3	Getting along with people who are close to you?	None	Mild	Moderate	Severe	Extreme or cannot do			
D4.4	Making new friends?	None	Mild	Moderate	Severe	Extreme or cannot do			
D4.5	Sexual activities?	None	Mild	Moderate	Severe	Extreme or cannot do			

							Clinician Use Only		
Numeric scores assigned to each of the items:		1	2	3	4	5	Raw Item Score	Raw Domain Score	Average Domain Score
In the last 30 days, how much difficulty did you have in:									
Life activities—Household									
D5.1	Taking care of your household responsibilities?	None	Mild	Moderate	Severe	Extreme or cannot do			
D5.2	Doing most important household tasks well?	None	Mild	Moderate	Severe	Extreme or cannot do			
D5.3	Getting all of the household work done that you needed to do?	None	Mild	Moderate	Severe	Extreme or cannot do		20	5
D5.4	Getting your household work done as quickly as needed?	None	Mild	Moderate	Severe	Extreme or cannot do			
Life activities—School/Work									
If you work (paid, non-paid, self-employed) or go to school, complete questions D5.5–D5.8, below. Otherwise, skip to D6.1.									
Because of your health condition, in the past 30 days, how much difficulty did you have in:									
D5.5	Your day-to-day work/school?	None	Mild	Moderate	Severe	Extreme or cannot do			
D5.6	Doing your most important work/school tasks well?	None	Mild	Moderate	Severe	Extreme or cannot do			
D5.7	Getting all of the work done that you need to do?	None	Mild	Moderate	Severe	Extreme or cannot do		20	5
D5.8	Getting your work done as quickly as needed?	None	Mild	Moderate	Severe	Extreme or cannot do			
Participation in society									
In the past 30 days:									
D6.1	How much of a problem did you have in joining in community activities (for example, festivities, religious, or other activities) in the same way as anyone else can?	None	Mild	Moderate	Severe	Extreme or cannot do			
D6.2	How much of a problem did you have because of barriers or hindrances around you?	None	Mild	Moderate	Severe	Extreme or cannot do			
D6.3	How much of a problem did you have living with dignity because of the attitudes and actions of others?	None	Mild	Moderate	Severe	Extreme or cannot do			
D6.4	How much time did you spend on your health condition or its consequences?	None	Some	Moderate	A Lot	Extreme or cannot do		40	5
D6.5	How much have you been emotionally affected by your health condition?	None	Mild	Moderate	Severe	Extreme or cannot do			
D6.6	How much has your health been a drain on the financial resources of you or your family?	None	Mild	Moderate	Severe	Extreme or cannot do			
D6.7	How much of a problem did your family have because of your health problems?	None	Mild	Moderate	Severe	Extreme or cannot do			
D6.8	How much of a problem did you have in doing things by yourself for relaxation or pleasure?	None	Mild	Moderate	Severe	Extreme or cannot do			
						General Disability Score (Total):		180	5

WHODAS 2.0

World Health Organization Disability Assessment Schedule 2.0

36-item version, self-administered

The adult self-administered version of the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) is a 36-item measure that assesses disability in adults age 18 years and older. It assesses disability across six domains, including understanding and communicating, getting around, self-care, getting along with people, life activities (i.e., household, work, and/or school activities), and participation in society. If the adult individual is of impaired capacity and unable to complete the form (e.g., a patient with dementia), a knowledgeable informant may complete the proxy-administered version of the measure, which is available at www.psychiatry.org/dsm5. Each item on the self-administered version of the WHODAS 2.0 asks the individual to rate how much difficulty he or she has had in specific areas of functioning during the past 30 days.

WHODAS 2.0 Scoring Instructions Provided by World Health Organization

WHODAS 2.0 Summary Scores: There are two basic options for computing the summary scores for the WHODAS 2.0 36-item full version.

Simple: The scores assigned to each of the items—"none" (1), "mild" (2), "moderate" (3), "severe" (4), and "extreme" (5)—are summed. This method is referred to as simple scoring because the scores from each of the items are simply added up without recoding or collapsing of response categories; thus, there is no weighting of individual items. This approach is practical to use as a hand-scoring approach, and may be the method of choice in busy clinical settings or in paper-and-pencil interview situations. As a result, the simple sum of the scores of the items across all domains constitutes a statistic that is sufficient to describe the degree of functional limitations.

Complex: The more complex method of scoring is called "item-response-theory" (IRT)–based scoring. It takes into account multiple levels of difficulty for each WHODAS 2.0 item. It takes the coding for each item response as "none," "mild," "moderate," "severe," and "extreme" separately, and then uses a computer to determine the summary score by differentially weighting the items and the levels of severity. The computer program is available from the WHO Web site. The scoring has three steps:

- Step 1—Summing of recoded item scores within each domain.
- Step 2—Summing of all six domain scores.
- Step 3—Converting the summary score into a metric ranging from 0 to 100 (where 0 = no disability; 100 = full disability).

WHODAS 2.0 Domain Scores: WHODAS 2.0 produces domain-specific scores for six different functioning domains: cognition, mobility, self-care, getting along, life activities (household and work/school) and participation.

WHODAS 2.0 Population Norms: For the population norms for IRT-based scoring of the WHODAS 2.0 and for the population distribution of IRT-based scores for WHODAS 2.0, please see http://www.who.int/classifications/icf/Pop_norms_distrib_IRT_scores.pdf

Additional Scoring and Interpretation Guidance for DSM-5 Users

The clinician is asked to review the individual's response on each item on the measure during the clinical interview and to indicate the self-reported score for each item in the section provided for "Clinician Use Only." However, if the clinician determines that the score on an item should be different based on the clinical interview and other information available, he or she may indicate a corrected score in the raw item score box. Based on findings from the DSM-5 Field Trials in adult patient samples across six sites in the United States and one in Canada, DSM-5 recommends calculation and use of average scores for each domain and for general disability. The **average scores** are comparable to the WHODAS 5-point scale, which allows the clinician to think of the individual's disability in terms of none (1), mild (2), moderate (3), severe (4), or extreme (5). The average domain and general disability scores were found to be reliable, easy to use, and clinically useful to the clinicians in the DSM-5 Field Trials. The **average domain score** is calculated by dividing the raw domain score by the number of items in the domain (e.g.,

if all the items within the "understanding and communicating" domain are rated as being moderate then the average domain score would be 18/6 = 3, indicating moderate disability). The **average general disability score** is calculated by dividing the raw overall score by number of items in the measure (i.e., 36). The individual should be encouraged to complete all of the items on the WHODAS 2.0. If no response is given on 10 or more items of the measure (i.e., more than 25% of the 36 total items), calculation of the simple and average general disability scores may not be helpful. If 10 or more of the total items on the measure are missing but the items for some of the domains are 75%–100% complete, the simple or average domain scores may be used for those domains.

Frequency of Use

To track change in the individual's level of disability over time, the measure may be completed at regular intervals as clinically indicated, depending on the stability of the individual's symptoms and treatment status. Consistently high scores on a particular domain may indicate significant and problematic areas for the individual that might warrant further assessment and intervention.

Beck's Depression Inventory

This depression inventory can be self-scored. The scoring scale is at the end of the questionnaire.

1.
- 0 I do not feel sad.
- 1 I feel sad
- 2 I am sad all the time and I can't snap out of it.
- 3 I am so sad and unhappy that I can't stand it.

2.
- 0 I am not particularly discouraged about the future.
- 1 I feel discouraged about the future.
- 2 I feel I have nothing to look forward to.
- 3 I feel the future is hopeless and that things cannot improve.

3.
- 0 I do not feel like a failure.
- 1 I feel I have failed more than the average person.
- 2 As I look back on my life, all I can see is a lot of failures.
- 3 I feel I am a complete failure as a person.

4.
- 0 I get as much satisfaction out of things as I used to.
- 1 I don't enjoy things the way I used to.
- 2 I don't get real satisfaction out of anything anymore.
- 3 I am dissatisfied or bored with everything.

5.
- 0 I don't feel particularly guilty
- 1 I feel guilty a good part of the time.
- 2 I feel quite guilty most of the time.
- 3 I feel guilty all of the time.

6.
- 0 I don't feel I am being punished.
- 1 I feel I may be punished.
- 2 I expect to be punished.
- 3 I feel I am being punished.

7.
- 0 I don't feel disappointed in myself.
- 1 I am disappointed in myself.
- 2 I am disgusted with myself.
- 3 I hate myself.

8.
- 0 I don't feel I am any worse than anybody else.
- 1 I am critical of myself for my weaknesses or mistakes.
- 2 I blame myself all the time for my faults.
- 3 I blame myself for everything bad that happens.

9.
- 0 I don't have any thoughts of killing myself.
- 1 I have thoughts of killing myself, but I would not carry them out.
- 2 I would like to kill myself.
- 3 I would kill myself if I had the chance.

10.
- 0 I don't cry any more than usual.
- 1 I cry more now than I used to.
- 2 I cry all the time now.
- 3 I used to be able to cry, but now I can't cry even though I want to.

11.

0 I am no more irritated by things than I ever was.
1 I am slightly more irritated now than usual.
2 I am quite annoyed or irritated a good deal of the time.
3 I feel irritated all the time.

12.

0 I have not lost interest in other people.
1 I am less interested in other people than I used to be.
2 I have lost most of my interest in other people.
3 I have lost all of my interest in other people.

13.

0 I make decisions about as well as I ever could.
1 I put off making decisions more than I used to.
2 I have greater difficulty in making decisions more than I used to.
3 I can't make decisions at all anymore.

14.

0 I don't feel that I look any worse than I used to.
1 I am worried that I am looking old or unattractive.
2 I feel there are permanent changes in my appearance that make me look unattractive
3 I believe that I look ugly.

15.

0 I can work about as well as before.
1 It takes an extra effort to get started at doing something.
2 I have to push myself very hard to do anything.
3 I can't do any work at all.

16.

0 I can sleep as well as usual.
1 I don't sleep as well as I used to.
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
3 I wake up several hours earlier than I used to and cannot get back to sleep.

17.

0 I don't get more tired than usual.
1 I get tired more easily than I used to.
2 I get tired from doing almost anything.
3 I am too tired to do anything.

18.

0 My appetite is no worse than usual.
1 My appetite is not as good as it used to be.
2 My appetite is much worse now.
3 I have no appetite at all anymore.

19.

0 I haven't lost much weight, if any, lately.
1 I have lost more than five pounds.
2 I have lost more than ten pounds.
3 I have lost more than fifteen pounds.

20.

0 I am no more worried about my health than usual.
1 I am worried about physical problems like aches, pains, upset stomach, or constipation.
2 I am very worried about physical problems and it's hard to think of much else.
3 I am so worried about my physical problems that I cannot think of anything else.

21.

0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I have almost no interest in sex.
3 I have lost interest in sex completely.

INTERPRETING THE BECK DEPRESSION INVENTORY

Now that you have completed the questionnaire, add up the score for each of the twenty-one questions by counting the number to the right of each question you marked. The highest possible total for the whole test would be sixty-three. This would mean you circled number three on all twenty-one questions. Since the lowest possible score for each question is zero, the lowest possible score for the test would be zero. This would mean you circles zero on each question. You can evaluate your depression according to the Table below.

Total Score	Levels of Depression
1-10	These ups and downs are considered normal
11-16	Mild mood disturbance
17-20	Borderline clinical depression
21-30	Moderate depression
31-40	Severe depression
over 40	Extreme depression

A PERSISTENT SCORE OF 17 OR ABOVE INDICATES THAT YOU MAY NEED MEDICAL TREATMENT. IF YOU HAVE ANY CARDIAC CONCERNS, PLEASE CONTACT CARDIOVASCULAR INTERVENTIONS, P.A. at 407-894-4880

Hamilton Anxiety Rating Scale (HAM-A)

Below is a list of phrases that describe certain feeling that people have. Rate the patients by finding the answer which best describes the extent to which he/she has these conditions. Select one of the five responses for each of the fourteen questions.

0 = Not present, 1 = Mild, 2 = Moderate, 3 = Severe, 4 = Very severe.

1 Anxious mood [0] [1] [2] [3] [4]

Worries, anticipation of the worst, fearful anticipation, irritability.

2 Tension [0] [1] [2] [3] [4]

Feelings of tension, fatigability, startle response, moved to tears easily, trembling, feelings of restlessness, inability to relax.

3 Fears [0] [1] [2] [3] [4]

Of dark, of strangers, of being left alone, of animals, of traffic, of crowds.

4 Insomnia [0] [1] [2] [3] [4]

Difficulty in falling asleep, broken sleep, unsatisfying sleep and fatigue on waking, dreams, nightmares, night terrors.

5 Intellectual [0] [1] [2] [3] [4]

Difficulty in concentration, poor memory.

6 Depressed mood [0] [1] [2] [3] [4]

Loss of interest, lack of pleasure in hobbies, depression, early waking, diurnal swing.

7 Somatic (muscular) [0] [1] [2] [3] [4]

Pains and aches, twitching, stiffness, myoclonic jerks, grinding of teeth, unsteady voice, increased muscular tone.

8 Somatic (sensory) [0] [1] [2] [3] [4]

Tinnitus, blurring of vision, hot and cold flushes, feelings of weakness, pricking sensation.

9 Cardiovascular symptoms [0] [1] [2] [3] [4]

Tachycardia, palpitations, pain in chest, throbbing of vessels, fainting feelings, missing beat.

10 Respiratory symptoms [0] [1] [2] [3] [4]

Pressure or constriction in chest, choking feelings, sighing, dyspnea.

11 Gastrointestinal symptoms [0] [1] [2] [3] [4]

Difficulty in swallowing, wind abdominal pain, burning sensations, abdominal fullness, nausea, vomiting, borborygmi, looseness of bowels, loss of weight, constipation.

12 Genitourinary symptoms [0] [1] [2] [3] [4]

Frequency of micturition, urgency of micturition, amenorrhea, menorrhagia, development of frigidity, premature ejaculation, loss of libido, impotence.

13 Autonomic symptoms [0] [1] [2] [3] [4]

Dry mouth, flushing, pallor, tendency to sweat, giddiness, tension headache, raising of hair.

14 Behavior at interview [0] [1] [2] [3] [4]

Fidgeting, restlessness or pacing, tremor of hands, furrowed brow, strained face, sighing or rapid respiration, facial pallor, swallowing, etc.

BRIEF PSYCHIATRIC RATING SCALE
(BPRS)

Examination Procedure

Either before or after completing the examination procedure, observe the patient unobtrusively at rest (e.g., in the waiting room).
The chair to be used in this examination should be a hard, firm one without arms.

1. Ask the patient whether there is anything in his or her mouth (such as gum or candy) and, if so, to remove it.
2. Ask about the *current* condition of the patient's teeth. Ask if he or she wears dentures. Ask whether teeth or dentures bother the patient *now*.
3. Ask whether the patient notices any movements in his or her mouth, face, hands, or feet. If yes, ask the patient to describe them and to indicate to what extent they *currently* bother the patient or interfere with activities.
4. Have the patient sit in chair with hands on knees, legs slightly apart, and feet flat on floor. (Look at the entire body for movements while the patient is in this position.)
5. Ask the patient to sit with hands hanging unsupported -- if male, between his legs, if female and wearing a dress, hanging over her knees. (Observe hands and other body areas).
6. Ask the patient to open his or her mouth. (Observe the tongue at rest within the mouth.) Do this twice.
7. Ask the patient to protrude his or her tongue. (Observe abnormalities of tongue movement.) Do this twice.
8. Ask the patient to tap his or her thumb with each finger as rapidly as possible for 10 to 15 seconds, first with right hand, then with left hand. (Observe facial and leg movements.)
9. Flex and extend the patient's left and right arms, one at a time.
10. Ask the patient to stand up. (Observe the patient in profile. Observe all body areas again, hips included.)
11. Ask the patient to extend both arms out in front, palms down. (Observe trunk, legs, and mouth.)
12. Have the patient walk a few paces, turn, and walk back to the chair. (Observe hands and gait.) Do this twice.

Scoring Procedure

Please enter the score for the term which best describes the patient's condition 0 = not assessed, 1 = not present, 2 = very mild, 3 = mild, 4 = moderate, 5 = moderately severe, 6 = severe, 7 = extremely severe

1. SOMATIC CONCERN	
Degree of concern over present bodily health. Rate the degree to which physical health is perceived as a problem by the patient, whether complaints have a realistic basis or not.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

2. ANXETY	
Worry, fear, or over-concern for present or future. Rate solely on the basis ot verbal report of patient's own subjective experiences. Do not infer anxiety from physical signs or from neurotic defense mechanisms.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

3. EMOTIONAL WITHDRAWAL	
Deficiency in relating to the interviewer and to the Interviewer situation. Rate only the degree to which the patient gives the impression of tailing to be in emotional contact with other people in the interview situation.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

4. CONCEPTUAL DISORGANIZATION	
Degree to which the thought processes are confused, disconnected, or disorganized. Rate on the basis of integration of the verbal products of the patient; do not rate on the basis of patient's subjective impression of his own level of functioning	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

5. GUILT FEELINGS	
Over-concern or remorse for past behavior. Rate on the basis of the patient's subjective experiences of guilt as evidenced by verbal report with appropriate affect; do not inter guilt feelings from depression, anxiety or neurotic defenses.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

6. TENSION	
Physical and motor manifestations of tension "nervousness', and heightened activation level. Tension should be rated solely on the basis of physical signs and motor behavior and not on the basis of subjective experiences of tension reported by the patient.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

7. MANNERISMS AND POSTURING	
Unusual and unnatural motor behavior, the type of motor behavior which causes certain mental patients to stand out in a crowd of normal people. Rate only abnormality of movements; do not rate simple heightened motor activity here.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

8. GRANDIOSITY	
Exaggerated self-opinion, conviction of unusual ability or powers. Rate only on the basis of patient's statements about himself or self-in-relation-to-others, not on the basis of his demeanor in the interview situation.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

9. DEPRESSIVE MOOD	
Despondency in mood. sadness. Rate only degree of despondency; do not rate on the basis 0 inferences concerning depression based upon general retardation and somatic complaints.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

10. HOSTILITY	
Animosity, contempt, belligerence, disdain for other people outside the interview situation. Pate solely on the basis of the verbal report of feelings and actions of the patient toward others; do not infer hostility from neurotic defenses, anxiety, nor somatic complaints. (Rate attitude toward interviewer under uncooporativeness").☐	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

11. SUSPICIOUSNESS	
Belief (delusional or otherwise) that others have now, w have had in the past, malicious or discriminatory intent toward the patient. On the basis of verbal report, rate only those suspicions which are currently held whether they concern past or present circumstanes.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

12. HALLUCINATORY BEHAVIOR	
Perceptions without normal external stimulus correspondence. Rate only those experiences which are reported to have occurred within the last week and which are described as distinctly different from the thought and imagery processes of normal people.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

13. MOTOR RETARDATION	
Reduction in energy level evidenced in slowed movements. Rate on the basis of observed behavior of the patient only; do not rate on the basis of patient's subjective impression of own energy level.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

14. UNCOOPERATIVENESS	
Evidence d resistance, unfriendliness, resentment and lack of readiness to cooperate with the interviewer. Rate only on the basis of the patients attitude and responses to the interviewer and the interview situation; do not rate on basis of reported resentment or uncooperativeness outside the interview situation.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

15. UNUSUAL THOUGHT CONTENT	
Unusual, odd, strange or bizarre thought content. Rate here the degree of unusualness, not the degree of disorganizations of thought processes.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

16. BLUNTED AFFECT	
Reduced emotional tone, apparent lack of normal feeling or involvement	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

17. EXCITEMENT	
Heightened emotional tone, agitation. increased reactivity.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

18. DISORIENTATION	
Contusion or lack of proper association for person, place or time.	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7