

UNDERSTANDING HELLP SYNDROME IN THE SOUTH AFRICAN  
CONTEXT: A FEMINIST STUDY

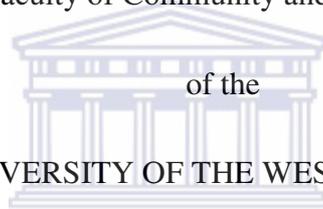
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## ABSTRACT

This thesis is about HELLP Syndrome (hemolysis, elevated liver enzymes, low platelet count in pregnancy): a devastating maternal hypertensive complication that results in multi-system changes that can rapidly deteriorate into organ failure and death. Despite rapid advances in medical technology and medical science this disease continues to take the lives of women and their infants. The only effective intervention for this disorder is immediate termination irrespective of the gestational stage of the pregnancy.

The primary objective of this thesis was to explore the subjective experiences and meaning-making processes of women in and through their high-risk pregnancies. This objective crystallised into the following aims: to facilitate and listen to the voices of women who were HELLP Syndrome survivors; to explore the reported bodily, psychological and emotional experiences of HELLP Syndrome survivors; to understand the role medical intervention and biomedical discourses play in these women's experiences and finally to explore the subjective experiences of HELLP Syndrome in the context of traditionally held notions of motherhood.

The study was couched in a feminist poststructuralist epistemology. A material-discursive framework which comprised phenomenological and poststructuralist theorising was used in an attempt to understand both the lived experiences as well as the discursively constructed nature of those subjective experiences. Thus the analysis encompassed both a broadly phenomenological framework to understand the lived experiences of HELLP Syndrome, and a discourse analysis to explore the meaning-making processes of participants in relation to larger social discourses, in particular the dominant biomedical and motherhood discourses.

A qualitative approach using in depth semi-structured interviews was utilised to gather data. Eleven participants from very diverse backgrounds consented to be part of this study. The findings of the study highlighted the immense trauma, difficulties and challenges participants faced in these high-risk situations. What was evident from the analysis was that their experiences were so diverse and were completely shaped by the severity of the disorder and the gestational stage of the pregnancy. Some women ended up in the Intensive Care Units (ICU) and had near-death experiences, some had very premature babies, while some of the participants lost their babies during the process. With regards to the emotional, psychological and corporeal aspects of the disorder, participants described their situations as a disaster,

painful and difficult. Due to the rapid deterioration of symptoms, they described the tempo of these events as a whirlwind in which they felt they had no control. Emotions ranged from shock, total disbelief and surprise to anger, helplessness and powerlessness. Lacking knowledge and access to appropriate information further compounded the situation for participants. The participants who had premature babies found the Neonatal Intensive Care Unit experience (NICU) extremely challenging and stressful.

A discourse analysis revealed that women's talk was shaped by the disciplinary frameworks of technocratic medicine and patriarchal notions of gender. Participants' discourses about their encounters in the medical context were located in, and shaped by, the structure of health care in our country. In this regard binaries (like private versus public health care, women versus men and nurses versus doctors) were evident. Furthermore their hospital stay reflected their experiences in the Intensive Care (ICU) and the Neonatal Intensive Care Units (NICU) both of which are highly technologically orientated and managed. Biomedical discourses that filtered through the participants' talk were: medicine as indisputable truth; mechanistic model of the body as machine; medical doctors as gods and the foetus as 'super subject'. Discourses of risk were inevitably taken up as participants tried to make sense of both their current pregnancies and the potential ones to follow.

The passage into motherhood for these participants was dependent on whether they had live babies or not. For those who had live babies it was a difficult time as they had to contend with their own recovery as well as the prematurity of their infants. The NICU experience was described as tiring, trying and cumbersome. For mothers who lost their babies it was a time of profound sadness and loss coupled to the notion that motherhood itself was lost. This loss of their children symbolised broken dreams, severed connections and a powerful taboo. In addition, discourses in which motherhood was naturalised and normalised saturated their talk and framed their experience in a narrative of deficit and failure. The ideologies of mother blame and the 'all responsible' mother were pervasive in their discussions. In conclusion, this high-risk situation represented a time of tremendous uncertainty and unpredictability for all participants and was powerfully shaped by dominant discourses about motherhood and the biomedical discursive and institutional framework in which participants were subjugated.

The study thus highlights how the HELLP syndrome experience illuminates the erasure of women's subjectivities while the foetus/infants' life takes precedence. This has significant

implications for scholarship in general and feminist scholarship in particular and highlights the need for this type of engagement in an area that has remained on the periphery of feminist research.



## DECLARATION

I hereby declare that this dissertation, unless specifically indicated to the contrary in the text, is my original work and that I have not submitted it, or any part thereof, for a degree at another university.

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## ACKNOWLEDGEMENTS

“Where do I begin, to tell the story.....”Let me commence the story with a quote by Anais Nin “ *And the day came when the risk to remain tight in a bud was more powerful than the risk it took to blossom*” This quote captures both my pain and my pleasure throughout this journey: a journey with many moments, many lifetimes it feels; a journey which symbolises my absolute coming out of and into mySelf. And with the unfolding of these moments there are many people to whom I am extremely grateful. Words can be so limiting, therefore I will attempt to infuse what I wish to express with an absolute vibration of love.

In writing up this thesis, I often felt adrift, lost at sea, many a times in the still of the night. Despite this symbolic darkness, I felt the gentle Presence of a guiding light –sometimes faintly lit, other times beaming, lighting up the course to be chartered. Whether dimly lit or brightly beaming, this Presence remained throughout the journey, until my final destination. Now standing on the gangway, disembarking, I reverently thank God for being a co-creator, a co-navigator on my journey to wholeness.

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## TABLE OF CONTENTS

<b>Abstract</b> .....	<b>i</b>
<b>Declaration</b> .....	<b>iv</b>
<b>Acknowledgements</b> .....	<b>v</b>
<b>CHAPTER 1: INTRODUCTION</b> .....	<b>1</b>
1.1. Introduction.....	1
1.2. Why study HELLP syndrome?.....	2
1.3. Conceptualising and birthing the study.....	3
1.4. Theoretical Framework.....	4
1.4.1. Feminist Poststructuralist Epistemology.....	4
1.4.2. Tracing the contours of a Material-Discursive Perspective.....	5
1.5. Contexts.....	8
1.5.1. Health Care in South Africa.....	8
1.5.2. The context of motherhood.....	9
1.6. Outline of the thesis.....	13
<b>CHAPTER 2: THEORETICAL FRAMEWORK</b> .....	<b>14</b>
2.1. Epistemological home of study.....	14
2.1.1. Feminist empiricism.....	16
2.1.2. Feminist standpoint epistemology.....	16
2.1.3. Feminist Poststructuralism.....	18
2.2. Childbirth research and Feminist theory.....	21
2.3. Defining Material-Discursive approaches.....	22
2.3.1. Exploring Material-Discursive Reality.....	24
2.4. ‘The turn to bodies’.....	27
2.4.1. Reproductive bodies: The body in process.....	29
2.4.2. The discursive production of pregnant bodies.....	31
2.4.2.1.Reproculture.....	32
2.4.2.2.Popular culture.....	32
2.4.2.2.1.Separation of woman and foetus.....	33

2.4.2.2.2.Woman as Container .....	34
2.5. Conclusion.....	35
<b>CHAPTER 3: THE MEANINGS OF RISK AND NON-NORMATIVE PREGNANCY .....</b>	<b>37</b>
3.1. Normative understandings of risk, pregnancy and childbirth .....	37
3.2. The medicalisation of childbearing .....	39
3.3. Understanding the concept ‘risk’ .....	42
3.4. Shifting understandings of ‘risk’ .....	43
3.4.1. Governmentality.....	45
3.4.1.1.Disciplinary technology, surveillance and bio-power.....	46
3.5. Historical overview of high-risk pregnancy.....	49
3.5.1. Toxaemia and the twentieth century .....	50
3.6. Historical background of the term ‘high-risk’ pregnancy.....	51
3.7. Towards a definition of high-risk pregnancy .....	55
3.8. HELLP Syndrome: A high-risk condition of pregnancy?.....	55
3.9. Psychological aspects of pregnancy and childbirth .....	58
3.10. Psychological aspects of ‘high-risk’ pregnancies .....	62
3.11. HELLP syndrome experiences.....	71
3.12. Conclusion.....	74
<b>CHAPTER 4 :MOTHERHOOD .....</b>	<b>75</b>
4.1. Ideologies underpinning motherhood .....	77
4.2. Feminism and motherhood.....	80
4.2.1. Feminist poststructuralism and motherhood .....	84
4.2.2. Foucault and motherhood.....	85
4.3. Deconstructing motherhood .....	86
4.4. Motherhood in South Africa .....	88
4.5. Normative mothering practices .....	91
4.6. Voicing subjectivity .....	92

<b>CHAPTER 5: METHODOLOGY .....</b>	<b>100</b>
5.1. Feminist perspectives on locating knowledge.....	100
5.2. Beginnings.....	102
5.3. Recruiting Participants .....	104
5.4. Brief particulars of women interviewed.....	106
5.5. Making data: The interviews.....	108
5.5.1. Data Analysis .....	111
5.5.2. Phenomenological analysis .....	111
5.5.3. Discourse Analysis.....	113
5.6. Reflexivity and Positionality.....	116
5.7. Ethical considerations .....	121
5.8. Conclusion.....	123
<b>CHAPTER 6: EMOTIONAL AND PSYCHOLOGICAL EXPERIENCES OF HELLP SYNDROME .....</b>	<b>125</b>
6.1. Descriptions and meanings made of the HELLP syndrome experience.....	126
6.1.1. The Intensive Care Unit (ICU) experience .....	126
6.1.2. Women who had live births .....	126
6.1.3. Women who had miscarriages or stillbirths.....	127
6.2. Emotional Aspects .....	128
6.2.1. Intuitive sense that something was amiss .....	128
6.2.2. Feelings of Loss of Control .....	129
6.2.3. Feelings of Guilt and Negligence.....	133
6.2.4. Deep seated feelings were experienced.....	135
6.2.5. Experiences of shock and disbelief.....	136
6.2.6. Feelings of vulnerability and vependency.....	137
6.2.7. feelings that process disrupted/interrupted.....	139
6.2.8. Feeling cheated.....	141
6.2.9. Feelings of confusion and bewilderment .....	142
6.2.10. Profound sadness.....	143

6.2.11 Feelings of anger .....	144
6.2.12. Feelings of helplessness and powerlessness .....	145
6.3. Psychological/Cognitive Responses.....	147
6.3.1. Thoughts of dying and near-death dxperiences .....	148
6.3.2. Lack of knowledge and understanding .....	149
6.3.3. Feeling unprepared for such an experience.....	152
6.3.4. Locating blame.....	152
6.3.5. Use of defence mechanisms .....	156
6.4. Bodily Aspects .....	157
6.4.1. Intensive Care Unit Experience .....	157
6.4.2. Experience and the meaning of pain .....	157
6.4.3. Body betrayal and failure .....	159
6.5. Conclusion.....	162
<b>CHAPTER 7: FRAMEWORKS OF MEDICAL INTERVENTION AND BIOMEDICAL DISCOURSES.....</b>	<b>164</b>
7.1. Private versus Public Healthcare.....	164
7.1.2. Disparities in care: Nursing versus Medical Care.....	166
7.1.3. Context: A culture of technology .....	170
7.1.3.1The ICU: A highly monitored environment.....	170
7.2. Biomedical Discourses.....	175
7.2.1 Medicine as indisputable scientific truth.....	175
7.2.2. Mechanistic model of the body .....	177
7.2.3. Medical doctors as gods .....	179
7.2.4. Infantilisation of the patient .....	180
7.2.5. The foetus as ‘super subject’ .....	182
7.2.6. Risk Discourse .....	184
<b>CHAPTER 8: ANALYSIS OF MOTHERHOOD.....</b>	<b>189</b>
8.1. To be or not to be a mother? .....	190
8.1.1. Being a mother is primary.....	191

8.1.2. Correcting one's own experiences .....	192
8.2. Motherhood thwarted .....	193
8.3. Passage into Motherhood .....	194
8.3.1. After the ICU experience : The practice of motherhood delayed .....	195
8.3.2. Motherhood sidelined.....	196
8.3.3. Being a new mother in hospital.....	197
8.3.4. Motherhood and the NICU.....	197
8.4. First months of motherhood .....	201
8.4.1 Early days of motherhood: Work as salvation .....	201
8.5. Body of (m)other .....	203
8.6. Motherhood lost? .....	204
8.6.1. Broken dreams .....	205
8.6.2. Severed connections.....	206
8.6.3. Powerful taboo-infant mortality and maternal death .....	207
8.6.4. Many reminders .....	208
8.6.5. Loss and culture .....	211
8.7. Discourses of motherhood.....	212
8.7.1. Your child(ren) always come(s) first .....	213
8.7.2. Mothers are responsible for life and death.....	214
8.7.3. Motherhood: The natural thing .....	215
8.7.4. Maternal Instinct .....	217
8.8. Making meaning of the experience of HELLP syndrome .....	218
8.8.1. Discourses of religion and spirituality .....	218
8.8.2. Existentialist Discourse .....	220
8.9. Conclusion.....	222
<b>CHAPTER 9: CONCLUSION.....</b>	<b>223</b>
9.1. Summary of the core findings .....	223
9.2. Reflections on study .....	227
9.2.1. Reflections on Feminist .....	227

9.2.2. Reflections on theoretical framework .....	229
9.2.3. Reflections of methodology .....	231
9.2.4. Implications of study for practice .....	223
9.3. Recommendations for future research .....	234
9.4 Final words .....	235
<b>REFERENCES.....</b>	<b>236</b>
Appendix 1: Demographic details.....	275
Appendix II: Interview schedule.....	276
Appendix III: Consent form .....	277





## CHAPTER 1: INTRODUCTION

### 1.1. Introduction

The primary purpose of this thesis is to explore the subjective experiences and meaning-making of women in and through their encounters with high-risk pregnancies. Although high-risk pregnancies have been examined fairly extensively, the most commonly documented complications in pregnancy include infertility/involuntary childlessness, severe vomiting, placenta previa, premature rupture of the membranes and pregnancy-induced hypertension (PIH) (Bachman & Lind, 1997). While PIH is written about, the variant thereof, namely HELLP (hemolysis, elevated liver enzymes and low platelet count) syndrome, is not even mentioned.

This thesis is about HELLP syndrome, a mortifying maternal hypertensive complication that results in multi-system changes which can rapidly deteriorate into organ failure and death. Although the condition had been described decades ago, Weinstein first coined the term in 1982 (Curtin & Weinstein, 1999).

Despite rapid advances in medical technology, maternal and infant deaths continue to occur (Isler, *et al.*, 1999). In South Africa in 1998 and 1999, seven and three women respectively, died due to HELLP syndrome. From 1999 to 2001 maternal deaths ranged from 175 to 200 per 100 000 live births. According to the Saving Mothers and Babies Report on Confidential Enquiries into Maternal Deaths the “big five” causes of death are hypertension, postpartum haemorrhage, antepartum haemorrhage and pregnancy-related infections, such as septic abortion and puerperal sepsis (Saving Mothers and Babies, 2008). The need to define and recognize HELLP syndrome has been emphasised as one of the crucial aspects in preventing maternal and perinatal mortality.

Although the incidence of HELLP syndrome has not been definitively established (Saphier & Repke, 1998), most writers estimate the incidence to be between 4% and 35% of all pregnancies complicated by preeclampsia (Curtin & Weinstein, 1999; Saphier & Repke, 1998; Sibai, Ramada, Chari & Friedman, 1994; Van Pampus *et al.*, 1998). In the United States, 4000 to 12000 (0.1% to 0.3%) of all pregnancies are complicated by this syndrome (Kidner, 2000). South African statistics are fairly incomplete regarding the incidence of this syndrome. However, a retrospective study conducted in Cape Town from 1995 to 1998 at

Grootte Schuur hospital, found that 36 of 72 women (50%) with severe preeclampsia and renal failure had HELLP syndrome (Drakeley, Le Roux, Anthony & Penny, 2002).

The consequences of HELLP syndrome are varied and the implications for the mother-infant duo are far-reaching. In terms of the mother, symptoms include stomach pain, swelling, high blood pressure, nausea, proteinuria, vision changes, seizures and cardiac arrest (HELLP Syndrome survey, 2000). Maternal mortality has been reported to be between 1% and 24% (Isler *et al.*, Portis *et al.*, 1997; Sheik, Yasmeeen & Riegler, 1999). As far as infants are concerned, HELLP syndrome babies have more severe intrauterine growth retardation, have abnormal blood smears similar to the mothers (Curtin & Weinstein, 1999) and they are lower in birth weight than their premature counterparts (Joern, Funk & Rath, 1999). Perinatal mortality can be as high as 367 per 1000 live births (Portis *et al.*, 1997). Given this traumatic experience, coupled with its grave consequences, the impact of this disorder cannot be underestimated.

Because of the insidiousness and difficulty in diagnosing this disorder, up to 80% of all cases are misdiagnosed, which can have fatal consequences for the mother and infant (Kidner, 2000). There is a tendency for this syndrome to progress so swiftly that decisions to deliver the foetus, regardless of the gestational age, often have to be made and implemented within hours of diagnosis. To date the only way to reverse the syndrome is to terminate the pregnancy (Sibai, 1992).

Given the extreme risks for the mother-infant dyad, HELLP syndrome is classified as a high-risk condition of pregnancy. Although there is variation in the literature regarding what condition(s) merit the label of high-risk, there is general agreement that the term should be used to mark a pregnancy in which physiological and/or psychological factors exist in the mother or foetus that imply a threat to the maternal-foetal unit (Hatmaker & Kemp, 1997; Kemp and Page, 1984).

## **1.2. Why study HELLP syndrome?**

This journey is both a personal and an academic one. Having experienced two pregnancies in which I was diagnosed with HELLP syndrome played a major role in my decision to pursue and study this area. At the time of my first encounter with this disorder (1997), very little was known about this illness. In my attempt to understand and make sense of this traumatic event, I relentlessly searched for answers, both on a personal and an intellectual level.

My experience with HELLP syndrome at the time left me feeling dazed, confused and voiceless. Although I was an academic, I felt powerless and the silence surrounding my experience of both HELLP syndrome and the associated loss was deafening. These factors propelled me to take this issue forward in a more formal way. In this way, I believe the voices of women can be heard and their experiences validated.

On the intellectual front, my search led me to many studies located within the medical arena. The majority of studies focused on understanding the pathophysiology of the disorder, variation in the incidence of the syndrome (Williams & Wilson, 1997); case studies (both typical and atypical) maternal and neonatal outcomes (see Harms, Rath, Herting & Kuhn, 1995; Sibai *et al.*, Van Pampus *et al.*, 1997; Abroug *et al.*) and management and treatment of the illness (Saphier, 1998; Magann *et al.*, 1994).

At the time of planning the study, only one study had been conducted examining the emotional experiences of women diagnosed with HELLP syndrome (Kidner, 2000). This study both heralded the beginning of this type of engagement, and highlighted the need for further research in this area, particularly among South African women. In addition, a comprehensive search of the literature revealed that the psychological component of this disorder is definitely under-researched.

### **1.3. Conceptualising and birthing the study**

Originally I set out merely to explore the bodily and emotional experiences of women who have had HELLP syndrome. In my readings I encountered the work of Maria Kidner (2000) who examined this from a grounded theoretical position. Her study was useful in that it was the first attempt in an area not yet researched. As with all research methods, grounded theory has its strengths and limitations. While the philosophical perspectives in the grounded theory tradition range from a critical realist ontology to a social constructivist ontology, Kidner's study was conducted in a critical realist paradigm. The critique of conducting grounded theory from this vantage point is that the emphasis is almost entirely on the empirical reality at the expense of paying sufficient attention to the discursive complexities of the data emerging from it (Henning, Smit & Van Rensburg, 2004).

My reading, particularly in the area of Health Psychology, ignited a spark and I became more interested in issues related to the meaning-making process when specifically women are faced with various illnesses. This interest soon migrated to my own interest and study

ofHELLP syndrome. With renewed zest and fervour I re-envisioned the study and decided to incorporate how women who have had HELLP syndrome made sense of such a traumatic event in their lives.

In an attempt to comprehend the totality of this experience for women, I crystallised my interest into the following aims:

- to facilitate and listen to the voices of women who were HELLP syndrome survivors;
- to explore the bodily and emotional experiences of HELLP syndrome survivors;
- to understand the role the medical context plays in women's understandings of their experience;
- to explore the subjective experience of HELLP syndrome in the context of traditionally held notions of motherhood.

Subsequent to the articulation of my aims, the daunting task of locating the study philosophically and theoretically became important. While medical researchers continue to seek for causes, psychologists and social science researchers are compelled to expand their knowledge and understanding of these experiences as well as the meanings that these events hold for women. Since these meanings are located in broader social discourses of pregnancy, birthing and mothering/motherhood, it is critical to interrogate these taken-for-granted constructions that present themselves as unitary, essentialist and universal.

## **1.4. Theoretical Framework**

### **1.4.1. Feminist Poststructuralist Epistemology**

Making sense of the fundamental, basic premise(s) of a feminist approach is not easy as feminism consists of a complex, multifaceted body of theory, methods and positions (Poynton, 2003; Shefer, 1998). Rather than consisting of one single, unitary feminist theory or methods, there are many different feminist projects, each with their own distinct agendas and practices, resulting in a spectrum of epistemological and methodological standpoints (Ussher, 1997). Sandra Harding (1986) classifies these projects as feminist empiricism, feminist standpoint theory and feminist poststructuralism. Feminist empiricism and standpoint theories favor feminist ways of knowing, with standpoint theorists arguing that men's dominant position in life results in one-sided and perverse understandings, whereas

women's oppressed position provides the possibility for more complete and less perverse understandings (Harding, 1986; 1990).

While the debate about keeping feminism in modernity or moving it to post-modernity continues, Morawski (1997) cautions against seeing these issues in such narrow terms. By insisting that feminism belongs to either modernism or post-modernism, we imply that fixed and rigid boundaries exist, where in fact the dividing lines are not so distinct. While both epistemological positions have their merits and demerits, Enns (1997) indicates that if we place feminism in a poststructuralist epistemology and use it in a strategic way, we can still continue to champion the rights of women.

Given the above arguments, I have chosen to use a feminist poststructuralist epistemology, which rejects the notion of a distinctive, universal female standpoint and acknowledges that personal identities are influenced by many intersecting axes and standpoints including race, class, ethnicity, disability and sexual orientation. Furthermore, feminist poststructuralists argue that judgments about truth and falsity are always socially constructed, and therefore as feminist researchers we cannot claim less partiality than non-feminist or male researchers. What is required is for researchers to be conscious of their gaze, of the influence of their own subjectivity about the research process, and of the moral, political and cultural concerns that shape us as researchers, the research process as well as the lives of women we research (Ussher, 1999).

#### **1.4.2. Tracing the contours of a Material-Discursive Perspective**

How does one theorise the HELLP syndrome experience taking into account both the medical aspects as well as the examining the discursive constructions of that experience? In other words, how do we talk about the pregnant body? Ussher (1997) problematises the issues as follows: When talking about the body do we only talk about flesh and physical processes, or do we talk only signs, signifiers and text? Both Ussher (1997) and Yardley (1997) refer to these issues as the 'material-discursive dichotomy'. 'Material' according to Yardley (1997) refers to the physical features of human lives, which include our bodies, corporeal activities, our environments, institutions and technologies. 'Discursive' on the other hand, refers to a range of approaches that endorse the socially mediated nature of human experience (Yardley, 1997).

Material-discursive approaches came into being because of the dissatisfaction with the bio-psychosocial model in Health Psychology. While this model attempted to incorporate the psychological and social with the biomedical aspects of illness, it did so in a realist, reductionist way. In an attempt to overcome this reductionism, health psychologists swung from one end (bio-psychosocial) to the other end of the pendulum, focusing almost exclusively on subjective experiences or health-related discourse (Stam, 2002; Yardley, 1997). Insistence on the primacy of either the physical or discursive dimensions of health/illness simply re(produces) the dualism of the biomedical model.

Material-discursive frameworks therefore attempt to bypass dichotomies of mind-body, subjective-objective, individual-society. However, reconciling material with discursive frameworks is no easy task. It has been argued though, that any approach to material being that could be married with discursive analysis would need to recognise that the physical dimension of human beings is not an objective domain of neutral physical matter and mechanical processes, but is itself instilled with meaning and is continuously shaped by dynamic interaction with the environment (Yardley, 1997).

Given the above challenges, many researchers in Health Psychology have set out to illustrate and develop theoretical and methodological approaches that attempt to address this divide. For example, researchers like Stoppard (1997) examined depression in women; Swann (1997) studied the discourses of premenstrual syndrome, Woollett and Marshall (1997) researched discourses of pregnancy and childbirth, while Noble (1997) examined social and material ecologies for hearing impairment. In short, these projects demonstrated the utilisation of a range of diverse theoretical and methodological positions.

In focusing on high-risk pregnancy and particularly HELLP syndrome, the need exists to place the current study's theorising in a framework that would enable a critical analysis of bodily practices and processes as well as how these are constructed in the symbolic realm. However, Malston (1997) argued that many discursive approaches focusing on discourse analysis of female reproductive bodies often failed to recognise the corpo-reality of the body. In an attempt to address this issue, I will draw on elements of poststructuralist discursive theorising. The reasons for this are twofold: firstly, poststructural accounts are extremely compatible with feminist epistemologies as the both address issues of power; and

secondly, this kind of theorising can hold both the material as well as the discursive dimensions of illness (Malston, 1997).

Indiscursive theory, language has been re-conceptualised and thus plays a prominent role in constituting 'realities' (Parker, 1992). However, in a poststructural framework researchers are concerned with the role of discourse in broader social processes of legitimating and power. For example, inbiomedical discourses, being positioned as 'patient' implies allowing one's body to be scrutinised, touched and invaded as the body in medicine is legitimately sanctioned as object to health care professionals (Parker in Willig, 2001)

Having briefly outlined how a poststructural discursive account addresses the meanings of a phenomenon, how does it attend to the physicality of the body? According to McNay (in Malston ,1997) just as discourses form and control the body, so they also rest on the body to support their 'truths'.

Thus in an attempt to facilitate theorising, the currentstudy will be couched in a feminist poststructuralist epistemology to understand women's diverse positions. Viewing the issues through this type of lens is appropriate as it will be able to embrace issues of differences between women as well as how they understand, and make sense of their HELLP syndrome experiences. What is particularly alluring about this approach is that it guarantees the acknowledgement of the complexities of women's lives. From the literature it is clear that the 'difference' issue has been largely overlooked in various projects. For example, in research on birth, most research has been conducted with white, middle-class, Western women. While some projects have focused on class, many have done so at the expense of race. Within South African society these issues become even more important as our countryis riddled with deep divisions, particularly in the health care system (see Chadwick, 2003). Therefore, in trying to understand the meaning-making process for women who have had HELLP syndrome, it is imperative to understand the health care context as well as the context of motherhood in South Africa.

## 1.5. Contexts

### 1.5.1. Health Care in South Africa

Any study or discussion on pregnancy and childbirth in this country needs to acknowledge the history, subsequent changes and remaining challenges in the health care system. Apartheid South Africa was characterised by racial segregation and extreme discrimination. All South Africans of colour were denied political, economic, social and basic health rights. The public sector health system was fragmented into separate state health departments and was characterised by geographical and racial inequalities (Cooper *et al.*, 2004). Prior to 1994, there were no comprehensive reproductive health policies in South Africa. Women's health services during that era comprised primarily maternal and child health services with contraceptive services enjoying prominence because of the racial undertones and the aim of limiting population growth especially among black people. Other services offered were riddled with racial divisions and centered on cervical screening and selective termination of pregnancy. Gender-based violence was not adequately acknowledged, nor effectively dealt with by the apartheid government (Cooper *et al.*, 2004).

Despite democratic changes, the experiences of maternity continue to be based on and determined by issues of race, class and economics. As will be discussed, there has been an awakening and a myriad of coordinated efforts both locally and internationally to improve maternal health care, but progress in implementation has been racked with difficulties.

September 2008 heralded the international community's (including South Africa) declaration to create an environment that would promote the eradication of poverty. This culminated in the articulation of eight goals, named the Millennium Development Goals (MDGs). Two of these objectives pertain to maternal and child health. The MDG-4 refers to reducing child mortality, while the MDG-5 speaks to improving maternal health (Saving Babies Report 2003 – 2005). The accomplishment of these two objectives would thus require prominent improvements in both the coverage and quality of care provided to pregnant women and their infants, as well as guaranteeing that the health system is appropriately structured and functional.

Progress towards MDG -5 is disturbing with the HIV epidemic being one of the major obstacles. AIDS was reported to be the most common primary obstetric cause of death,

with statistics indicating the disease claiming two out of every five maternal lives. Furthermore, the 2002 – 2004 Saving Mothers document highlights the lack of progress regarding the implementation of recommendations tabled for ways of improving quality of care and preventing many avoidable maternal and infant deaths in South Africa.

Despite all measures taken by the South African government since 1994 to redress all past imbalances, there remains a steady increase in maternal mortality rates. The 1999 to 2001 Saving Mothers report revealed that maternal deaths occurred mainly in level 2 hospitals (35.6%) followed by level 3 hospitals (31.3%). Fewer maternal deaths were reported outside public hospitals (2% at homes and 1.5% in public hospitals).

The portrait sketched of maternal mortality in our country certainly seems pessimistic, and it is definitely not my intention to be deterministic about the matter. Rather, my intention is to provide a context in which at-risk pregnant women find themselves. More particularly, women with HELLP syndrome find themselves in an even more precarious situation, since instant and accurate diagnosis implies the difference between life and death.

Health care and the medical arena is the space in which HELLP syndrome plays itself out. As with all pregnancies, a woman's experience and her meaning-making process are not only influenced by the medical context she finds herself in, but is also influenced by the broader ideology and institution of motherhood.

### **1.5.2. The context of motherhood**

Despite global shifting trends such as conscious childlessness, parenthood and more particularly motherhood, a normative social expectation remains (Becker & Nachtigall, 1994, Daniluk, 1994; Edelman, Humphery & Owens, 1994). The way in which most societies valorize children more often than not reflects the role they fulfill in their social contexts (Hoffman & Hoffman, 1973). Consequently, the ability to conceive and produce healthy children is considered a huge personal and social-cultural accomplishment, particularly for women (Daniluk, 1997; Mahlstedt, 1994).

Watson (2006) asserts that in South African society the title of 'mother' seems to be a crucial indicator of women's strength and social standing. Lewis (1999) argues that for black

South African women, the title 'mother' has very little bearing on individual women's experience, but instead becomes a validating title which seems to embody the essence of their social standing. In many African cultures it is well documented that children are highly valued. In these studies it was reported that parents had children to continue the family legacy and lineage, for social and economic status and for the provision of burial rites (Koster-Oyekan, 1999; Pearce, 1999; Sundby & Jacobus, 1997; Tilson & Larsen, 2000). Friedman (1973) commented that in African cultures fertility is a requisite and women who struggled to conceive or were childless were often ridiculed and vulnerable to divorce and polygamy.

South African society is still deeply rooted in patriarchal culture. Not only in black African cultures but in traditional Afrikaner cultures, boy children play a pivotal role in the acquisition and supremacy status in patrilineage. In many African cultures producing a son is the only security an African woman has to ensure her survival since it is only the sons who can lay claim to the father's land (Hollas, 2003). Becoming a mother in this context is thus deemed critical to women. However, women's own views and ideas about these issues seem completely erased in these contexts. This becomes evident when one examines the literature on motherhood in South Africa which is sparse (Kruger, 2006).

Internationally, there seems to have been a proliferation of studies on mothering and motherhood over the last decade (Arendall, 2000). While earlier studies focused on the quality of mothering and its impact on the child, more contemporary scholars examined mothers' own experiences and activities. However, it was feminist scholars who chartered the way for conceptualising and researching mothering and motherhood, and prioritised studies of identities and experiences (Arendall, 2000).

In an attempt to capture the broad arena of mothering, feminist constructionists examined the ideology of motherhood. The prevailing ideology seems to be one of intensive mothering, which is exclusive, totally child-focused, emotionally all-encompassing and time-consuming (Hays, 1996). The portrait sketched is thus one of complete dedication to the care of others; the woman is self-sacrificing and has no needs apart from those of her offspring.

Allied to this ideology is the assumption that these activities and practices are based on notions of family that depict the image of the 'normatively desirable family' that is white, middle class, where the couple is heterosexual (Bozalek, 2006, p153). Furthermore this self-contained unit includes children.

Kruger (2006) asserts that despite the great strides made in feminism to highlight the contexts in which women mother, and their varied experiences of mothering South African psychological research on motherhood, remains scant. The literature that is available however seems to focus on mothers and children at risk. A cursory glance at this literature seems to suggest that these projects on motherhood were conducted in the framework of instrumentalist motherhood discourses which promote pervasive assumptions of what constitutes 'good mothering' (Kruger, 2006).

Scholarship surrounding the subjective experiences of motherhood in South Africa is virtually non-existent. To date, only a few studies could be traced. Jeannes and Sheffer (2004), for example, zoomed in on the subjectivity of five white middle-class women; Kruger (2003) unpacked the narratives of middle-class women in an attempt to comprehend to what extent the personal stories of women can subvert motherhood ideologies and effect social change; Daniels (2004) explored the representations of motherhood in photographs of women living in informal settlements; and Kantor (2006) examined discourses of infertility.

Given the paucity of research in this area, it becomes extremely challenging to sketch a portrait of motherhood in South Africa. It is important to note that any such attempt should always be considered partial and incomplete. As mentioned previously, South African society is characterised by deep inequalities in spite of political changes that have taken place. Discourses of inequality remain pervasive, making the entrance for a discourse of equality difficult (Jeannes & Shefer, 2004).

In the discourse of inequality, the subject of gender becomes not only a positioning feature, but is also constructed through difference, which implies that men and women are differently endowed for taking care of children and the home (Jeannes & Shefer, 2004). In the study conducted by Jeannes and Shefer (2004), the majority of participants seemed to draw on discourses that have been constructed in master narratives of gender inequality.

While gender certainly seems to be a positioning factor within South African society, it is not the only one. In an interesting study conducted by Youngleson (2006), socio-economic positioning is highlighted as playing an important role in positioning ‘good’ and ‘bad’ mothers. This study revealed as the title suggests “the impossibility of ideal motherhood” due to the socio-economic conditions of women from poverty-stricken communities.

What is interesting to note from the two studies which were conducted in almost diametrically opposing communities (namely white middle-class women and semi-rural poor women), the majority of them drew on the ideology of intensive mothering and positioned themselves in instrumental discourses of the self-sacrificing and all-giving mother (Jeannes & Shefer, 2004; Kruger, 2006; Youngleson, 2006).

While some of the referenced studies provide one with a platform from which to launch further studies, the authors of these studies identify gaps in their own studies. Jeannes and Shefer (2004) assert that the motherhood construct has to be researched in more diverse contexts so as to mirror the complexities of South African society.

Given some of these concerns, this study attempted to explore how women who experienced a high-risk pregnancy with the potential of losing their babies, made sense of such an experience with the taken-for-granted assumptions of the primacy of motherhood. The experience of their HELLP syndrome pregnancies therefore becomes the backdrop for these women who become mothers.

In sum, the study aims to examine and understand the HELLP syndrome experience in the South African context which is diverse, and in which discourses of inequality are pervasive. In an attempt to muster such an understanding, I believe a feminist poststructuralist epistemology is well-suited and appropriate. Furthermore material-discursive frameworks are well-suited to ensure such an understanding albeit one of many such understandings. Below, I provide the reader with an outline of the thesis.

## **1.6. Outline of the thesis**

In Chapter 2 a discussion of the epistemological positioning of the study (which is feminist poststructuralism) is provided. In addition, the material-discursive theoretical framework which is utilised to theorise the HELLP syndrome experience is discussed.

Chapter 3 presents discussions about the notion of risk, how it is utilised in the study and how it plays itself out in these pregnancies.

Chapter 4 examines issues of motherhood both experientially and discursively.

In Chapter 5 the methodological framework, methodological choices and decisions, and all other methodologically related issues are discussed.

The analytic section is spread over three chapters. Chapter 7 provides an overview of the results and discussion regarding the emotional/psychological experiences of HELLP syndrome.

Chapter 8 presents the findings of the frameworks of medical intervention and biomedical discourses.

Chapter 9 explores the ways in which women who have had HELLP syndrome and live babies, have journeyed into motherhood. It also presents the meaning-making process for those women who lost their babies. The final section of this chapter examines the discourses women utilised in their understandings of becoming a mother.

The final chapter of the thesis functions as a concluding reflection. In this chapter, the key arguments of the thesis are summarised and reiterated, methodological issues and limitations are discussed, and theoretical issues are reflected upon.

## CHAPTER 2: THEORETICAL FRAMEWORK

### 2.1. Epistemological home of study

Prior to positioning my own study on high-risk pregnancy, it is important to provide an overview of the central and different epistemic tendencies that have materialised in feminism. However, right at the outset I wish to avoid reifying epistemology, and draw on Lynn Nelson's insight that epistemology "is a contested and dynamic notion" (in Cosgrove, 2003, p. 86). Comprehending epistemology in this way permits social scientists to rethink rather than replace terms used in the different feminist epistemological positions (Cosgrove, 2003). In addition, it should be noted that any attempt to map out such a contested terrain, always runs the risk of reductionism or misrepresentation (Chadwick, 2006). Or as Tong (2007) states, this will inevitably invite criticism from various feminist scholars, each of whom will have valid reason either to revise or refute the proposed categorisation in epistemology as restricted or completely off track.

Epistemology is defined as a theory of knowledge and originates from the Greek word, 'episteme' (Henning, Van Rensburg & Smit, 2004). However, thinking epistemologically entails the contemplation of the relationship between the knower and what can be known, as well as how this relates to issues of ontology (Terre Blanche, Durrheim & Painter, 2006). Epistemology thus is concerned with what constitutes legitimate knowledge and what can be known. In short, the definition of epistemology incorporates both theories of knowledge and theories of knowledge production (Letherby, 2003). Stanley and Wise (1993, p.188) sum up these issues by suggesting that:

*An 'epistemology' is a framework or theory for specifying the constitution and generation of knowledge about the social world; that is, it concerns how to understand the nature of 'reality'. A given epistemological framework specifies not only what 'knowledge' is and how to recognize it, but who are the 'knowers' and by what means someone becomes one, and also the means by which competing knowledge-claims are adjudicated and some rejected in favour of another/others.*

Different historical periods and places have witnessed various epistemologies ranging from Greek rationalism to seventeenth and eighteenth-century empiricisms, eighteenth-century Enlightenment and twentieth-century poststructuralism (Oakley, 2000). Based on an examination of these epistemologies, it is fair to argue that the history of knowledge production and science until fairly recently has been symbolised as masculine, since mainly

men produced and had access to it (Letherby, 2003). Consequently, through these processes male identity was confirmed and major status was conferred upon it. Morgan (1981) thus asserts that in reality, academic discourse is a male discourse disguised in labels of science, rationality and scholarship. Millman and Kanter (1975) comment that the social sciences assume a singular society which makes generalisations about both men and women, when in reality the social worlds which men and women inhabit are often vastly different.

Twenty years ago, Evelyn Fox Keller (1982) commented on the juxtaposition of ‘feminism’ and ‘science’, discussing the implicit conflict when these terms are conjoined (Cosgrove, 2003). She argued that “as scientists we have real difficulties in thinking about the kinds of issues that, as feminists, we have been raising” (1982, p.589). However, rather than ignoring this tension, she proposed that a radical feminist critique of science would result in a very different conception of science. Undoubtedly, we have witnessed huge strides over the past two decades and the term ‘feminist science studies’ is no longer considered a contradiction in terms.

Feminist research originated in the context of second wave feminism and was based on the need to reconcile the contradictions between the dominant research narratives, models, studies and findings of the time and the lived experiences of women (Brooks & Hesse-Biber, 2007). Banister, Burman, Parker, Taylor & Tindall (1994) argue that feminist research thus derived from feminist epistemological critiques of dominant (masculinist) notions of knowledge. It is important to note at this point that feminist research does not exemplify a unified endeavour. In the feminist project, an array of perspectives, diverse research questions and varied methods and methodologies serve researchers in their quest to illuminate the experiences of women, resulting in a gamut of epistemological and methodological standpoints (Ussher, 1997). As previously mentioned, any attempt to present these differing viewpoints in a logical coherent fashion runs the risk of dividing feminist explanations into disparate positions, which implicitly signals mutual exclusivity and contradicts the notion that many feminists draw on different aspects of each approach (Letherby, 2003; Morawski, 1997). In addition, such delineation could also signify a historical linear development of ideas which is also inaccurate (Stanley & Wise, 1993). Therefore, rather than succumbing to any of the above temptations, I will discuss two of the modernist approaches (feminist empiricism and feminist standpoint theory) first as this provides the backdrop for my own positioning in this project, namely the poststructuralist approach.

### **2.1.1. Feminist empiricism**

Feminist empiricism is premised on philosophical realism. These ideas originated in the modernist Enlightenment era and the proponents of this worldview adhere to the notions of a unitary and universal social world where truth exists independent of the knower. Feminist empiricists subscribe to a positivist ontology and therefore engage in investigating and presenting 'real' rather than flawed science that results from masculine assumptions and ways of working (Harding, 1991; Letherby, 2003). Feminist empiricism therefore challenges our traditional conceptions of science and suggests the need for a successor science: an enterprise that will explore and theorise the social world from the vantage point of women.

Sandra Harding challenges these views by asserting that while feminist empiricists question the way science has been conducted, this framework fails to question the inherent logic and values of the scientific endeavour. Feminist empiricism thus fails to provide a satisfactory framework since hegemonic assumptions and male-oriented paradigms remain unchallenged (Boonzaier & Shefer, 2006). Letherby (2003) argues that the strategy of feminist empiricism overestimates the power of women's perspectives to increase objectivity.

### **2.1.2. Feminist standpoint epistemology**

In contrast to empiricists, standpoint theorists subscribe to Marxists beliefs in the epistemological superiority of the perspective of oppressed people (Babbie & Mouton, 2001). Standpoint theory contends that while the oppressor's social location creates distortions of reality on one hand, the social position of an oppressed group (i.e. women) on the other hand, can expose hidden intended meanings and therefore gain an accurate and systemic understanding of the world. Experiential knowledge is the starting point for knowledge production. Furthermore, if that experience comes from the position of an outsider skirting the margins of hegemonic ideologies, practices and discourses, then a perspective is developed that allows those who are positioned as 'other', through reflexive engagement, to see more clearly the modus operandi of the dominant structures than those positioned as inside and invested (Harding, 1987; 1991; Letherby, 2003). It is therefore argued that women, as an oppressed group, have the ability to not only understand their own experiences of oppression, but to understand their oppressors, and hence the world in general. Thus to obtain a feminist standpoint, the prerequisite seems to be intellectual and

political engagement in order to see natural and social life from the perspective of women, instead of viewing it from the biased and curtailed perspective of the ruling gender (i.e. men) (Harding, 1991).

While feminist standpoint theory contends that knowledge varies across different historical moments and cultures, there are elements in this polemic that seem to contradict this claim (Bart, 1998). Arguing that women have a unique perspective that gives them privileged insight into the nature of reality seems tantamount to claiming the existence of a uniform and universal women's experience that produces this insight. This claim therefore ignores the social, historical and cultural differences that exist between women. In addition, it fails to explain why some women are able to see 'truth' while others do not. In the final analysis Bart (1998) argues that a universal women's standpoint theory lacks strength and persuasion as there is no singular, uniform women's experience and consequently no unitary women's experience. A further difficulty with claiming that oppressed groups have a clearer view of the world relates to the dispute that would arise when deciding which group is more oppressed than another, and hence which group has the greatest potential for knowledge. This line of argument would result in an almost senseless argument about hierarchies of oppression (Letherby, 2003).

The above discussion on feminist empiricism and standpoint theory brings into full view the polarity which seems inherent in feminist theory and research. A quote by Wylie, Okrulik, Thielen-Wilson & Morto (1989) sums up this dilemma:

*The problem confronting feminists at this juncture is not just that of developing models of scientific rationality which take gender into account...but that of articulating regulative ideals for research practice which show how science can be (or should be) reformulated so that it incorporates feminist values*(in Cosgrove, 2003,p.87).

The debate regarding how research is to be conducted, which advocates for women, has become polarised into two distinct traditions, namely standpoint theory and empiricism. The question arises how precisely is psychological research to be reformulated? Lisa Cosgrove offers some valuable insights in this regard. She asserts that one should not view either of these approaches as 'wrong'. Instead, she proposes that a 'third-ness' be inserted into the polarising debate with the aim of developing a more emancipatory feminist psychology. One way of transcending the deadlock is to engage in 'boundary dissolving' and 'binary

dissolving' discourses, and deconstruct the epistemological issues at the core of these debates. Cosgrove (2003) thus suggests that incorporating poststructuralist tenets into feminist research in general, and psychology in particular, will enable us to move away from the either/or empiricism/standpoint debate.

### **2.1.3. Feminist Poststructuralism**

As previously alluded to regarding the terms 'feminism' and 'science', a similar tension surfaces when the terms 'feminism' and 'poststructuralism' are juxtaposed. The concomitant fear that is induced is that such a perspective will neutralise political action because it silences women and atomises women out of existence (Cosgrove, 2003; Long & Zietkiewicz, 2006). In reply to this comment, it has been demonstrated that poststructuralism and political action are not necessarily diametrically opposed. On the contrary, poststructuralism may be employed effectively in strategic political action (Zietkiewicz & Long, 1999). In addition, Cosgrove (2003) argues that poststructuralism has the potential to provide an influential epistemological grounding for deconstructing gender difference and gender norms and therefore can assist feminist psychology by highlighting the complex processes and matrices through which gender is produced.

The term 'poststructuralism' signifies more than an approach to theory. In fact it signifies a dizzying array of cultural practices, writers, artists, thinkers and theoretical accounts of late modernity (Waugh, 1998). With reference to feminist poststructuralism, Smart (1990) argues we should not see it as a way to resolve the problems of empiricism or standpoint theory, but as a completely different starting place and proceeding in other directions.

Millen (1997, p.7) sums up the 'essence' of a feminist poststructuralist approach in the following way:

*Instead of privileging female or feminine standpoint, feminist post structuralism suggests that there is a variety of contradictory and conflicting standpoints, of social discourses, none of which should be privileged: there is no point trying to construct a standpoint theory which will give us a better, fuller, more power-neutral knowledge because such knowledge does not exist (Hekman, 1990; Nicholson, 1990). The search for a unitary notion of 'truth' about the world is impossible, a relic of the sterile Enlightenment: knowledge is 'partial, profane and fragmented' (McLennan, 1995).*

*Rather than seeking out a unifying epistemology, albeit one that incorporates gender, we should be constructing multiple discourses.*

From this vantage point, the aim of feminism translates into the deconstruction of truth and is no longer considered to be viewed as the establishment of truth. The understanding shifts from knowledge being treated as objective to acknowledging that knowledge is power and that power is pervasive (Hesse-Biber, 2007; Letherby, 2003). This perspective reserves the space for multiple truths, none of which are privileged, and these truths exist in various discourses (Flax, 1987). The analytical work in this framework concerns itself with explaining the discursive procedures from which women gain an understanding of their common world. Debates occur in discourses and these discourses define what is permissible to think or not to think in a prescribed context.

Given the poststructuralist view that no universal scientific truths exist, and that scientific discourse is just one among many other discourses, does feminist research become superfluous? The answer to this question is multi-layered and Cosgrove (2003) suggests that adopting a poststructuralist perspective encourages us to challenge the ontological status of gender and experience and this in turn promotes reflexivity and a greater ethical engagement. By insisting that the status of gender is not transcendental, we must continually interrogate the conditions under which experience is constituted as gendered. For Burman (1998) the central question that needs to be articulated is: under which conditions where we have no control, do we become speaking bodies who feel obliged to speak ourselves into gendered positions?

A partial response to this dilemma is for researchers to commence with women's experiences, while concurrently questioning the assumption that women's narrative accounts contain real meanings that can be revealed by authorised persons (i.e. by researchers).

According to Cosgrove (2003) the epistemological shift from understanding experience as foundational to viewing it as situated in specific discursive relations has profound methodological implications. She cites Alcoff's (1997, p.10) question in this regard:

*How can women confer epistemic authority on their own interpretation of experience without relying on a naive empiricist methodology?*

In terms of challenging the transparency of meaning, feminist researchers therefore became interested in the link between discourse, power and experience.

Acknowledging that neither gender nor experience can be accorded foundational status is important in my own study as this is a project which seeks to explore the subjective experiences and meaning-making of women (in a non-essential way) in and through their experience of high-risk pregnancies. Rejecting gender as a foundational category assists us in considering the role of the socio-political realm in the constitution of experience.

A further important contribution of a poststructuralist perspective to my study relates to the suspension of our commitment to conventional unquestioned meanings of concepts, such as 'women's voice'. By defining women's voice as a psychological entity or as the psychological centre of femininity, the process of identity construction and reproduction is masked by researchers (Davis 1994 in Cosgrove, 2003). To strengthen this point, Lykes (1994) argues that the problem does not reside with the metaphor of voice per se. Rather, the 'problem is that the implicit assumptions made about gender, experience and identity – and the metaphors used to gather data about them (for example, voice) do not allow for an analysis of the complexity of the power relations of which gender, identity and experience are embedded' (Cosgrove, 2003, p.89). In sum, I draw on Lisa Cosgrove's articulation of the voice metaphor for hearing participants' stories, as that which is contextualised in an understanding of identity which is not only complex, contradictory and fragmented – and always constituted in matrices of unequal power relations – but which in and of itself is socially constructed.

In the final analysis, the poststructuralist epistemology in which my research is located acknowledges that the experience of high-risk pregnancy is a gendered experience. However, my epistemological slant avoids two of the principle weaknesses of standpoint theory, namely, the belief in gender essentialism and the belief in the role of the researcher as "omniscient narrator and summariser" (Flyvber, 2001, p82 in Cosgrove, 2003).

Having outlined the epistemological strategies of feminism and having embedded my study in a feminist poststructuralist epistemology, how does one explore pregnancy with such an understanding? In order to accomplish this, I believe a starting point for such an engagement lies in exploring the interface between childbirth research and feminist theory/ies.

## 2.2. Childbirth research and Feminist theory

Chadwick (2006) asserts that while many feminists have worked extensively in the area of theory and research on childbirth not many efforts have been made to examine the interface between research on childbirth and feminist theory. This deadlock was broken by Ellen Annandale and Judith Clark in 1996 when they declared that those engaged in childbirth research have overlooked the main contemporary issues and shifts in feminist theory. They argued that research on reproduction in general, and childbirth in particular, was based on the flawed assumption that feminism constituted a homogenous corpus of knowledge. Rather than fully engaging with the differences and debates in feminism, many researchers merely touched the proverbial tip of the iceberg. Thus Annandale and Clarke (1996) categorise childbirth research as 'modernist' and argue that it was based on an archaic binary mode of thinking hinging on the binarism of men-women and sex-gender. They also critique modernist childbirth research on grounds of universalism (representative of all women), valorising gender difference, not presenting any viable alternatives and an over-emphasis on women as opposed to gender.

The solution to this impasse according to Annandale and Clark (1996) is the espousal of a poststructuralist approach. Although their critique of modernist research on women's health is extensive, their suggestions on how a poststructuralist approach might revolutionise the study of reproduction is limited (Chadwick, 2006). What their work does suggest is that we need to rethink the body and appreciate the use of technology that might assist people to transcend a gendered understanding of their bodies. In addition, they extend a call to develop new metaphors for the body (i.e. cyborg) that might undermine normative binaries. While their work seems to represent a step in a new direction, Chadwick (2006) critiques the work of Annandale and Clark (1996) and argues that the discursive is privileged over and above the historical/material and contextual relations that saturate and limit the subversive potential of high technology. She further argues that 'technology', 'gender' and 'the body' are presented as disembodied constructs that can 'be glued/unglued at will' (p74), all in the name of undermining binaries. The question that looms large therefore remains whether unsettling these binaries at the discursive level brings about any concrete shifts to practices and material conditions generally.

Given the above dilemma, the issue remains: how would one theorise the material and the discursive in a way that sets them up neither in opposition to each other nor privileging either

one, but in a more integrative way, according each realm equal status and in this way affirming the role that each dimension plays in aiding women to understand and make sense of their bodies, their reproductive capacities and their lives. One way of conceptualising these issues would be to turn to what has become known as the ‘material-discursive’ approaches.

### **2.3. Defining Material-Discursive approaches**

I would like to argue that a material-discursive perspective holds advantage in understanding the meaning-making processes associated with high-risk pregnancy in general and HELLP syndrome in particular. Karen Barad (1998) in her work poses childbirth as a material-discursive phenomenon. Material-discursive she further contends has important explanatory components: firstly birth is a material event, or it can be construed as the intra-action of certain bodies with others which is significant in part because they are composed of physical matter. Secondly, birth is positioned discursively in that a discourse of birth exists and the material reality of birth is not only communicated but also produced. Lastly, the dashed word conjunction conveys the inseparability of the discursive and the material reality of birth. Barad (1998) thus asserts that how we think about, talk about and are able to comprehend birth are inseparable from how we do birth.

Luyt (2003, p46) in discussing the material-discursive framework expresses the intent of these approaches beautifully: material discursive approaches “seek to integrate dominant approaches that appear anaemic in their failure to capture the interplay between the material and discursive realms of human existence”. The strength of such a perspective I believe lies in its ability to recognise that human experience arises through the complex intersections between both material and discursive reality. In other words, it is my view that human experience is constituted by the interplay of bodily, material experiences as these are shaped by language, culture and discourse which in turn influence and shape how we experience what we experience. Thus human experience cannot be understood in any singular dimension.

To understand the gist of this discussion, it is useful to initially define what have been construed as two opposing perspectives to understanding the individual reality that underpins this approach. These approaches may be defined as ‘material-naturalistic’ (psychological) or ‘material-realist and discursive-constructionist’ (Luyt, 2003; Ussher, 1997; Yardley, 1997). Quintessentially the material-realist approach mirrors Enlightenment thought. This approach argues that all experience, including the body and the surrounding environment which are

thought of as distinct and mutually exclusive, may be explained only in physically observable terms. Jane Ussher (1997) argues that the arenas where these issues become so poignant are madness, sexuality and reproduction, where the material body occupies centre stage. For example, she argues that reproduction is reduced to evolutionary explanations of mating, hormones or to the physical functioning of the womb. In addition, classificatory systems such as the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM) are completely premised on what can be observed and measured, thus fortifying the emphasis on material phenomena and consequently resulting in the reification of the positivist approach.

The failure of this approach to acknowledge the interplay between material and social worlds has culminated in subjective experiences completely being ignored (Luyt, 2003). Furthermore, realist thinking leads to a denunciation of the meaning of 'symptomatology', or of aetiological factors based in the social domain (Ussher, 1997). What this in turn sets up is that the expert is paramount (see Foucault, 1977). Feminists in particular have vehemently opposed the overly deterministic nature that this limited and static depiction of reality suggests. It has been argued that this very thinking has served to perpetuate and legitimise inequalities between men and women (Nettleton, 2000).

In antithesis the discursive-constructionist approach reflects post-modern thinking. In this view, the socio-linguistically shaped nature of human experience is privileged and in its extreme form, bodies and objects merely reflect the discourses that describe and are inscribed on them (Yardley, 1997). The body therefore is perceived to exist as a tabula rasa, upon which social text is inscribed, having taken form in pre-existing discourses of power (Luyt, 2003; Ussher, 1997; Yardley, 1997). This argument is extended through the assertion that bodies are materialised and thus thought to be real through the physical performance of these texts rather than due to any essential individuality. In the final analysis the discursive-constructionist approach is ruthless in its critique of material-realist explanations that neglect to acknowledge human subjective experience in its rigid claim to objective reality (Luyt, 2003). Yardley (1977) argues that these dogmatic claims in material-realist explanations thus critically fail to account for the reproduction of discursive meaning in structural relations of power.

The discursive-constructionist approach however, has not enjoyed the widespread support it was expected to acquire, particularly in mainstream psychology (Luyt, 2003). Its critique

concerning many of the discipline's core doctrines, as well as its inability to fully appreciate the materiality of human life, continues to relegate this perspective to the periphery (Yardley, 1997). The study of embodiment which refers to the bodily as well as linguistic practices which constitute human subjectivity, poses challenges to many social constructionist accounts. Willig (2000) examines the ways in which social constructionists have theorised the body and concludes that this perspective fails to grant the body a role in the production of meaning. Instead, the body is construed as merely dramatising discursively constructed cultural resources. What appears lacking in this approach to 'the body' is its role in the constitution of subjectivity. In other words, Willig (2000) argues that constructionists need to rethink what it means to 'be a body' rather than to 'have a body'. In addition Willig (2000) contends that a more complete understanding of the social construction of 'health' and 'illness' should include an account of how we 'become' sick and/or healthy bodies, that is, how discourses of health and illness are interspersed with our material bodies, and how this is echoed in our subjective experiences of these bodies (Grosz, 1994; Yardley, 1997). Burkitt (1999) points out the flaws evident in this approach when encountering individual challenge to normative practice. In other words, this perspective privileges overarching structural influences in describing human experience, to the disadvantage of individual agency, which 'presumably lurks unseen behind prevailing societal discourse' (Luyt, 2003, p48). In sum, the discursive-constructionist perspective emphasises the body's existence as a textual product, but disavows its role as active producer. Therefore the material-realist and discursive-constructionist perspectives solely provide a limited understanding of human experience. Each displays reductionist thinking, evident in either a neglect of the material or discursive dimension of experience (Yardley, 1997).

### **2.3.1. Exploring Material-Discursive Reality**

Any reconciliation between material and discursive dimensions should be cognisant that the material dimension of human experience does not constitute an objective realm of physical matter and mechanical processes, but is permeated with purpose and is continuously moulded and modified by dynamic interaction with the environment (Yardley, 1997). Many writers have explored material-discursive reality from a variety of theoretical positions and epistemological standpoints, including psychoanalysis, social representations theory, feminist standpoint theory, critical realism, poststructuralism and social constructionism. What unites these diverse analyses is the move away from the perennial

binary divide. What distinguishes these perspectives from each other is the way in which the material-discursive question is addressed (Ussher, 1997).

A number of writers have argued that phenomenology provides a useful framework for studying the meaning of embodied experience in health and illness (for example, see Radley, 1995; Yardley, 1997). Philosophers such as Kant, Hegel and Husserl questioned realism by focusing attention to the way in which our consciousness of the world is mediated and transformed by subjective processes. More recently, philosophers such as Heidegger and Merleau-Ponty added to these existing thoughts by emphasising the inherently meaningful and intentional nature of embodied 'being-in-the-world'. In fact, Merleau-Ponty overturns realism by arguing that our physical being is an embodiment of our will to exist, and that embodied selfhood is an achievement actively maintained by processes spanning from the biological to the psycho-social (In Yardley, 1997). This understanding of embodied existence therefore renders Cartesian dualism powerless. Yardley (1997) cites examples from research on pain to demonstrate how the phenomenological self transcends the mind-body dichotomy.

Another approach that foregrounds the reciprocal relationship between self and environment is the ecological psychology of James Gibson (1986) and his notion of an 'affordance' (cited in Yardley 1997). For example, water 'affords' a drink to a thirsty animal, life to fish, but death to a non-swimmer. An ecological understanding thus not only highlights that many properties attributed to the individual and their environment actually exist at the intersection of the individual and their environment, but also exposes how alterable this interface can be.

While the analytical approaches briefly outlined recognise the relational and communicative meaning of embodied being, they do not fully address the unique and pervasive influence of language on human experience and activity (Yardley, 1997). The realist view of the world sees the role of language in a representational way, asserting that words derive their meaning from their relationship with the 'real' thing they represent. However, philosophers from a post-modern perspective argue that language does not merely describe, it plays a functional role. Words thus gain their meaning from the social context in which they are used and from their relationships to other words. Meaning therefore is not immutable, but is ambiguous as it is created not only by the word's context and usage, but also by the intentions and understanding of the speaker-writer and the listener-reader (Hollway, 1989).

Instead of treating texts as more or less accurate accounts of some underlying concrete reality, discursive writers suggest that we should ask what kind of meaning is being formulated by a certain kind of language and for what purpose. Since discourses seem to define what can be said, whilst simultaneously providing the opportunities for making new statements, it is critical to examine the way in which language produces or constructs particular versions of what we construe as reality.

It is therefore this fascination with the manner in which language generates its own systems of meaning that can create the impression that discursive theory disregards the material dimension. However, discourse does not exist in a vacuum. Poststructuralists like Foucault, have been instrumental in exposing the ideological interests and power relations in which specific discourses are entrenched and to which they contribute. Foucault (1980) writes: “nothing is more material, physical, and corporeal than the exercise of power” (pp57-58). His work exposed the more subtle and intimate connections between the discursive and the material. In *The Birth of the Clinic* (1989) he explained how the development of the ‘clinical gaze’ was directly related to the introduction of the physical practice of dissecting cadavers. Moreover in his writings of how the individualised bodies of members of modern society have been constituted by what he called ‘technologies of the self’ (discussed in Chapter 3), he describes how discourses about the healthy body are coupled with the regulatory practices of exercising, dieting or wearing fashionable clothes (Foucault, 1980).

The dialectic of the relationship between the physical and the discursive is: because we are inherently social and embodied beings, the physical dimension of human lives is always socialised – arbitrated by language and consciousness and modified by social activity. Likewise, the discursive dimension is inescapably physically manifested, in our talk, behaviour, institutions and technology (Yardley, 1997).

Yardley (1997) argues that Derrida (1974) presents the last word against dualism. His writings suggest that language produces these false dichotomies. For example, it is through naming ‘nature’ that we alienate ourselves from it, and thus create ‘culture’; conversely, there could be no concept of culture without the idea of something outside culture – nature. Derrida therefore recommends that our task is to deconstruct the binary oppositions created by language in order to understand these connections.

The exploration of material-discursive reality convincingly demonstrates that binary oppositions are not very helpful in explaining health and illness. What is required is an analysis of the interplay of both the material and discursive dimensions of reality to facilitate a more integrative understanding of health-related issues. Having discussed the material-discursive framework in a more generic way and relating it to health and illness in general, how does one begin to think about these issues as they relate to pregnancy and high-risk pregnancy in particular? How does the material-discursive framework relate to the HELLP Syndrome experience? In addition, when examining pregnancy and high-risk pregnancy specifically, how do we talk about the pregnant body? It is evident that we cannot only talk flesh and physical processes, nor can we only refer to signs, signifiers or text (Ussher, 1997). It is the interface of these subjective experiences with such signs, signifiers and text that constitutes the subject matter for my thesis.

#### **2.4. 'The turn to bodies'**

Elizabeth Grosz (1994) argues that the body has remained a conceptual blind spot in both mainstream Western philosophical thought and in contemporary feminist thought. Moulaison (2007, p341) writes that "the body itself is a slippery concept, whose meaning, in spite of its seeming self-evidence, is by no means shared, particularly among feminist theorists". For second-wave feminists such as Gloria Steinem, Catharine MacKinnon, Andrea Dworkin and Mary Daly, the female body was thought of as a battleground; a site where women were to take back from medicine, law and pornography what was rightfully theirs. To their daughters, third-wave feminists, the body was a site of experimentation, subversion and self-defined pleasure (Moulaison, 2007).

Debates concerning the body have become important in feminist theory particularly as it pertains to the re-conceptualisation of the feminist project more generally (Chadwick, 2006). Since its beginnings feminism has always been uneasy with questions relating to the significance of the body. Any references to biology or our organic existence, traditionally would 'raise the heckles on good feminist necks' (Thiele, 1999, p1) and rightfully so. These references inevitably stir concerns about biological determinism. As Bev Thiele (1999, p1) writes, "Anti-feminist forces of darkness and evil" have historically justified women's oppression with reference to our bodies and biology, particularly to our reproductive bodies. It is therefore not surprising that many feminists are sceptical towards this renewed interest in

the body. However, it is acknowledged by many that the time has arrived to question assumptions that biology necessarily invokes determinism and essentialism (Thiele, 1999).

In the past two decades, the continued juxtaposition of woman with body has pushed feminists to pursue a strategy of disassociation of the body. Based on Ann Oakley's early refutation of biological determinism, feminists veered to some version of social constructionism. Initially it was argued that gender and not biological sex was the crucial variable in sexual politics. Thus the sex/gender distinction of second-wave feminism served to render biology unimportant in a feminist analysis. During the 1980s that distinction came under severe fire, but its only accomplishment then was an almost complete erasure of biology. Feminists from very diverse perspectives (such as Haraway, Grosz and Butler) now concur that sex is an historical construct as well as a political category. Bodies are therefore always cultural and therefore one cannot refer to a pre-social or biological body. Contemporary feminist theory on corporeality and embodiment views the body as a shell, a surface to be inscribed, a discursive fiction. Diana Fuss (1989) sums up this dilemma and asserts that our choice is between the essentialist who believes that the natural is subdued by the social, and the constructionist who argues that the natural is brought into being by the social. Thiele (1999) articulates the critical question that I believe needs to be addressed in this thesis: how do we make sense of our physical bodies and embodiment so that we may acknowledge the organic without resorting to biological determinism and the discursive without effacing the biological? In other words, how do we re-conceptualise our body's biology, particularly reproductive bodies, taking into account both material and discursive dimensions of being?

In an attempt to examine reproductive bodies, taking into account both material and discursive dimensions, I wish to argue that the body is not merely heir to cultural inscriptions and disciplines, but instead sets constantly changing agendas which shape and are shaped by cultural inscriptions/acts. In other words, the body's biology should be construed as more than an object; in fact it could be seen as more a source and a resource (Thiele, 1999). Drawing on some of the works of Iris Marion Young, Helene Cixous, Adrienne Rich and Mary O'Brien, I will attempt to provide a framework for understanding pregnant embodiment.

### **2.4.1. Reproductive bodies: The body in process**

There are a myriad number of ways of living a pregnancy, of either having or not having a relationship of another intensity with this still-invisible other (Thiele, 1999). Pregnancy and childbirth dramatically remind one that one's biological state is by no means fixed and immutable. Cixous (1987, p.90) describes this bodily transformation as "really experiencing metamorphosis" Thiele (1999) uses her own experience of pregnancy and graphically reflects on some of these issues, describing pregnancy as a "fountain of unexpected, unanticipated and unimagined sensations"; the hardness of her belly; her body's specific reactions to food and other stimuli; the body's almost refusal to be ignored or regulated; the constant changing shape and texture and the wonder and the inexplicable sense of the inner. She further asserts that there are very few certainties in pregnancy as pregnant women live with uncertainty, with the unfamiliar, with the unknown and with their own particular and intimate process. Lurking in the background there is always the possibility of miscarriage, decisions to be made about whether to continue with the pregnancy, the possibility of premature labour, of being overdue or induced and the chances of a caesarean. Pregnancy thus seems to represent a time of enormous uncertainty and unpredictability and these issues are exacerbated in a high-risk pregnancy.

Iris Marion Young (2005, p.49) describes her experience of pregnant embodiment very explicitly and contends that "pregnancy challenges the integration of my body experience by rendering fluid the boundary between what is within myself, and what is outside, separate". She asserts that experiencing one's insides as "belonging to another, another that is nevertheless my body" is itself something that develops over time (p.63). Thiele (1999) correctly argues that although pregnant women are not privy to what the foetus feels, the exterior proof of movement and the internal sensation of the baby alive within refutes the simple interior/exterior of the body into intimate multiples. Karpin (1992) argues as other feminists have that until the baby is born the foetus is the female body. It is part of her body/self.

To further highlight the corporeality of pregnancy, Thiele (1999) argues that the bodily process of pregnancy is acutely collapsed by the drama of birth itself. In her account she articulates that she had no visual images of her labouring body, only an inner account of the hard work, the rhythm of sheer effort/endurance and rest/reprieve. In this process she explains how the body could surprise in a myriad of ways; it definitely determines the terms

of the labour. Some of her experiences of labour (for example, the anterior lip which resisted effacement for a number of hours) were not her idea, she laments (Thiele, 1999). She continues with her story and discusses the amazing capacities her body had that completely astounded her.

The idea of time also seems to become a contested issue in pregnancy and childbirth (Thiele, 1999; Rich, 1976; Young, 2005). In her description of pregnancy, Young (2005) delineates how the dominant culture casts pregnancy as a time of quiet waiting. Adrienne Rich (1976) also describes this waiting, this female fate, in her own pregnancy. This portrait of the 'expecting' woman waiting demonstrates how much of the discourse of pregnancy omits the subjectivity of women. While others view pregnancy as a time of waiting – for the maternal subject, it is a time of movement, growth and constant change. Thiele (1999) refers to the process of time during labour and birth and talks about the mismatch between her internal birthing time and linear time. She vividly describes the midwife's account of her body as "tiring and in need of respite" as sharply in contrast with her own inner sense of not being tired at all. Young (2005) argues that the pregnant subject is not just a splitting, but is a dialectic in which the pregnant woman experiences herself as both participant in, and source of, an extremely creative endeavour.

Bodily transformations do not end with the dramatic transformation accomplished during birth. In fact after the birth the body takes its time to heal and recover and for women the process encompasses the coming to terms with a body that looks different, feels different, reacts and responds differently (Thiele, 1999). Pregnancy and labour is thus a complex biological process lived out in very complex and diverse ways. The diversity in pregnant embodiment needs to be embraced as it points towards the incredible variety and uncertainties in a biological process which simultaneously resists efforts to be defined as a normative bodily experience, and interacts in very complex ways with the multiplicity of social contexts (Thiele, 1999). Pregnancy may thus progress through a multitude of possible physical expressions ranging from an astonishing sense of well-being to chronic discomfort which occurs during pregnancies where the mother and baby may be at risk. This diversity of possibilities in the body and the interplay of various social contexts, thus renders this process unpredictable, unforeseeable and in that sense indeterminate (Thiele, 1999).

While pregnancy and labour are complex biological processes expressed in an assortment of ways, they are lived out in an equally complex set of social and power relations. Within those multi-layered complexities, Thiele (1999) argues there is sufficient scope for viewing biology as having an undetermined and active relation with the social. In other words, understanding the relation between the two as interweaving – in which the biological can alter social experience and the social in turn can alter biological experience – facilitates how we can contemplate biology but escape biological determinism and contemplate the social without erasing the biological (Thiele, 1999).

In short, I would like to argue that while pregnancy and childbirth are a universal phenomenon, the experiences thereof at both material and discursive levels are unique and individual. Nonetheless, whatever the individual configuration of pregnancy and birth, it is unlike any other physiological experience as its project is the creation of another, of that which comes from me but is not me (Thiele, 1999; Young, 2005). Therefore in an attempt to theorise and understand pregnancy and childbirth, both biological processes and social contexts interact to produce very particular experiences for women. Having briefly examined some of the biological processes associated with pregnancy, I turn to a discussion of how pregnant bodies are discursively produced.

#### **2.4.2. The discursive production of pregnant bodies**

One way of examining the discursive production of 'the' pregnant body is to focus on the female body as a contested site of legislative activity and political control. In addition, I believe that a shift away from the detail of reproductive technologies to foregrounding the patrolling of the shape and understanding of the female body may be useful in this regard.

Karpin (1992) argues that the current shape of the female body, as it is described in various discourses, is not based upon scientifically verifiable facts and asserts that these conceptions are directed towards the disempowerment of women. Multiple depictions of the material female body make it accessible for political use by feminists and non-feminists alike. Isabel Karpin (1992) in her article examines the female body in the context of pregnancy and demonstrates how women's pregnant bodies are constructed and reconstructed in a system of patriarchal description and control.

Many discourses including law, science and culture assume a singular, uncontested received notion of the 'nature' of the female body (Karpin, 1992). Each of these discourses seeks to

legislate and regulate this body in an attempt to substantiate its claims about the 'nature' of the female body. The insistence of these discourses that an omnipresent female body exists that we all know, agree upon and understand needs to be examined and challenged (Karpin, 1992). In an attempt to examine the politics of the reproductive body it is important to examine how the construction of 'woman' is manifested in popular culture as well as in dominant discourses on reproduction and motherhood.

#### **2.4.2.1. Reproculture**

Popular depictions of a woman's pregnant body, describe it as being trapped by nature or as being subjected to biological destiny (Karpin, 1992). However, affording women autonomy opens up numerous possibilities of how she interprets her body. In the latter instance, pregnancy could be interpreted as that process which a woman undergoes, rather than interpreted as the gestation of a foetus or a baby. Mary O' Brian (1981) argued that re-conceptualising biology as process assists in taking us away from the idea that biology is immutable and set, and in effect paves the way for contemplating not only labour and pregnancy, but also all the common place minutia of bodily changes which we all undergo as we age (Thiele, 1999). Thus interpreting the woman as being at the cause of her experience allows for an understanding of the woman's body as neither separate from nor container to the foetus. Karpin (1992) argues that fostering these kinds of understandings of women's bodies by disciplines like science and law should be seen as attempts to reconstruct the woman in an attempt to control and subjugate her. In an attempt to examine the politics of the female body, it is important to explore these representations in cultural discourse.

#### **2.4.2.2. Popular culture**

Karpin (1992) cites various media accounts of how reproductive technology exposes the way in which popular culture is both shaping and re-shaping women. Technology currently plays an important role in the cultural discourse about women, making the reconstructed woman something of a 'techno-cultural' production (Karpin, 1992, p.4). In this techno-cultural production women are positioned in opposition to their foetuses and to science, law and society at large.

Karpin (1992) cites two examples in the media of how reproductive technology often completely erases the significance of the existence of the women. In the first example, a two-year-old boy from a local family in the United States needed a bone marrow transplant

and the doctors were planning to harvest the placenta of his mother in an attempt to secure a donor match. The headlines of the newspaper read: “Unborn child may save brother’s life”. In this instance the mother is completely ignored and the foetus becomes the hero with the power to heal that which the ‘defective’ mother had already given birth to.

In the second example she cites The San Francisco Chronicle in which the headline states “Brain-dead mother has her baby”. In this instance Karpin (1992) argues that the woman is not rhetorically absent, but her presence is important only in the face of her mental absence. The journalist who wrote the article writes: “ The coherence of this statement rests, in part, on a very particular understanding of motherhood” – an understanding in which motherhood is equated with pregnancy and thereby reduced to a physiological function, a biologically rooted, passive – indeed, in this case literally mindless – state of being. The author Hartouni furthers her argument by stating that if mothering is defined as a historically specific set of social practices, an activity that is socially and politically constructed and conditioned by relations of power that differs according to class, race, history and culture, then it is impossible to equate a brain-dead female body with a mother. The headline subtly therefore obscures our understanding of motherhood and takes us right back to the biological female. In the final analysis, despite all the advances we have made, these rhetorical strategies serve to relegate and subordinate women to their biological destiny to procreate, even in death. These examples serve to highlight how diffuse the female body is as a corporeal entity, and how these different discourses sustain each other. The discourses that emerge from these excerpts relate to the female body as container. Women are also framed as equivalent to their biology while simultaneously equating that biology to the maternal.

#### **2.4.2.2.1. Separation of woman and foetus**

Popular representations of mothers and their foetuses insist on their separation. These representations conceive of the female body as a space to house the foetus. In a legal case to illustrate this, Karpin (1992) quotes a case Lynch versus Lynch in which the court upheld the right of a child to sue its mother for injuries sustained in a motor vehicle accident. In this case the mother was held responsible and liable for the accident. The contradictions of the case are pointed out as there is the argument that the mother’s body and the foetus’ body are conjoined as the foetus is injured through the mother’s body. Yet the mother is held responsible as she is viewed as a separate being.

Karpin (1992) therefore argues that as scientific advances reveal more in-depth understandings of the role the mother plays in the development of the unborn child, these very understandings are used to set the mother up against the child. These intimate connections are therefore recast as vulnerabilities. Karpin further contends that these decisions to almost pit mother against foetus are neither scientifically objective nor legally reasoned. Rather, they are political decisions which afford the possibility of greater control over the female body and women. In other words, scientific objectivity and legal rationality serve to naturalise what is in fact highly contentious and political. In addition, it is important to note that the female bodies most often targeted for this type of control are those of colour and economically impoverished. Karpin (1992) maintains that the information provided by reproductive technologies should signify the connection rather than the separation of the female body/woman and the foetus. The female body must therefore be transformed in such a way that would place the woman in control of her body/self and the foetus and not as she was constructed in the pre-technological era, as subject to her body, nor as subject to her foetus. In separating woman from the foetus, women's bodies are positioned as container for the foetus.

#### **2.4.2.2.2. Woman as Container**

The use of ultra-sonography for foetal imaging seems to have compromised the assumed opacity of the uterus, rendering it breathtakingly visible. It has been argued that this technology has culminated in an understanding of the female body as a permeable outer layer with its boundaries so open and flexible that it is available and accessible to public intervention. In this understanding the foetus seems to have more bodily integrity and closure afforded to it than the female body (Karpin, 1992).

This construction of the woman as container is an ambivalent one. On one hand the woman is seen as a passive container for the foetus; on the other hand she is denied the ability to actively contain the foetus, in the sense of establishing its boundaries. Karpin (1992) proposes that the nature of that containment and the construction of the female body as porous can be understood via this changed representation of the womb. Technology has transformed the image of the uterus from an opaque, unknowable haven for the foetus to a space of danger and permeability. This argument is upheld when one considers the legal implications when pregnant women smoke, drink or take drugs. Women in the United States have been charged with supplying illegal substances to their unborn children (Karpin,

1992). Karpin (1992) therefore contends that the woman is no longer considered the protector of the foetus, and the modern project has therefore consisted of transferring control of the 'endangered' foetus from the woman to a place of masculine scrutiny and control: the clinic, the laboratory, and if necessary the courtroom. In the event she refuses to relinquish this control, it is construed to be either an act of radical resistance or an ignorant reaction that appears to induce a pre-technological irrationality.

What the above discussion highlights is that pregnancy does not belong to the woman herself. It is viewed as either a state of the developing foetus for which the woman is the container, or as an objective empirical process captured by scientific examination; or else it becomes objectified by the woman herself as a condition in which she must take care of herself (Young, 2005). What is glaringly obvious is that cultural constructions and representations of pregnancy and childbirth completely omit subjectivity. This very omission is what my project aims to include so that pregnancy can be viewed as simultaneously material and also discursively constructed.

## **2.5. Conclusion**

In this chapter I have provided a discussion of feminist epistemologies and argued that a feminist poststructuralist epistemology is the most suitable one for my study as it has the potential to provide fertile grounds for deconstructing gender difference and gender norms, and can aid feminist psychology and scholarship by foregrounding the complex processes and matrices through which gender is produced and re-produced. This epistemology acknowledges the complexity of experiences and allows for the recognition of multiple truths as well as the notion that these very truths can be located in various discourses.

Having embedded my study in a feminist poststructuralist epistemology, I have also argued for utilising a material-discursive framework to theorise the HELLP syndrome experience. The efficacy of this framework lies in its capacity to hold both the material and the constructed nature of being. In my thesis I wish to argue that pregnancy is both lived and produced in many diverse ways and resists any attempts to be defined as a normative bodily experience. This is blatantly obvious when one begins to examine pregnancies that are regarded as medically at risk, like HELLP syndrome pregnancies. When theorising the HELLP Syndrome experience, this understanding becomes useful. Theorising the pregnant body as a lived body, coupled with the recognition of the constitutive powers of regulatory

discourses, may offer me a more nuanced way of thinking through maternal experiences of HELLP syndrome. Approaching women's bodies as 'lived' would mean considering how women themselves make meaning from their material bodies. The body thus becomes the critical location at which gender, race, class and other struggles could be 'read'. Reading individual women's lives/situations in this way would also allow insight into the more general situation of women, for example, it would provide insight into the ways in which social structures and regulatory discourses might operate to structure or inhibit women's freedom, particularly under extreme high-risk conditions of pregnancy. Finally this thesis will provide an account of how women developed HELLP syndrome and in a sense became sick bodies – and this in some way should provide a more complete understanding of both the subjective account and the social construction of that experience.

However, as previously acknowledged, material-discursive approaches are varied and heterogeneous. In my project, in an attempt to explore material-discursive dimensions of high-risk pregnancy, I draw primarily on the works of (broadly speaking) phenomenologist-poststructuralist feminist work. In exploring the emotional/psychological experiences of HELLP syndrome, I draw on a broadly phenomenological framework that allows me to provide a structural description of the phenomenon. In examining biomedical frameworks of intervention and social discourses of mothering and motherhood, I utilise a more poststructuralist analysis to understand the complexities and diverse social practices which contribute to how the women who have had HELLP syndrome experienced their pregnancies. Having provided a framework in which to conduct this study and a theoretical framework for understanding the HELLP syndrome experience, I will provide a discussion of HELLP syndrome in the next chapter.

## CHAPTER 3: THE MEANINGS OF RISK AND NON-NORMATIVE PREGNANCY

*The failure to address preventable maternal disability and death represents one of the greatest social injustices of our times (W)omen's reproductive health risks are not mere misfortunes and unavoidable natural disadvantages of pregnancy, but, rather, injustices that societies are able and obliged to remedy....(Cook & Dickens World Health Organisation, 2001).*

As previously stated, the principal objective of my study is to examine the subjective experiences and meaning-making of women during and via their encounters with HELLP Syndrome, which is defined as a high-risk condition of pregnancy. The social science literature that provides coverage of women's experiences of pregnancy, birth and motherhood seems to contain some notable silences as motherhood remains an extremely contested terrain. The process of becoming a mother exists in a troubled space between internal reality and external discourses (Long, 2009). Dominant discourses perpetuating notions of the 'perfect, natural mother' set up powerful normative expectations that all women can mother, want to mother, naturally mother both physically and emotionally. Failure to accomplish these ideals thus sets women up as deficient in some way, particularly in high-risk pregnancies where the 'failure' is biological. It should not be surprising then, to note that one of the silences in the literature relates to the experiences of women who suffer major illness during their pregnancies. To date, most of the medical sociological, psychological, anthropological and other related disciplines' material has primarily concentrated on the critique of the medicalisation of normal pregnancy and childbirth, rendering the experiences of women with major health problems invisible (Thomas, 2004). It is this silence that my thesis attempts to address.

A key concept in my study relates to the issue of risk in pregnancy and therefore I will commence this discussion by describing how the term 'risk' came to be instituted and now is naturalised and normalised in pregnancy and birth. Thereafter, I will provide an historical overview of high-risk pregnancy, define the term 'high-risk' and provide an overview of the literature and research in this area.

### **3.1. Normative understandings of risk, pregnancy and childbirth**

RobbieDavis-Floyd (2003) in her anthropological analysis of childbirth contends that the medical model, or as she terms it, the 'technocratic model' is based on an "ideology of

technological progress” (p.47) which underpins post-industrial, technocratic culture more broadly. According to Davis-Floyd, childbirth challenges technocratic societies with unique dilemmas that can only be addressed via complex obstetric procedures. For example, because birth is a quintessential female process it constitutes a “conceptual threat to male dominance” (p.61) emphasising the notion that men need women for the continuation of life itself. In an attempt to address this dilemma, Davis-Floyd contends that childbirth procedures have been developed to mask the fact that women are the real producers of babies. In addition, she asserts that obstetric practices and procedures served very particular functions, namely to remove birth from public and cultural visibility to the private domain, compelled birth to be made predictable through the utilisation of scientific norms and timetables, neutralised the creative energy of birthing women, and stripped birth of its sexual and erotic nature.

Furthermore Davis-Floyd (1994; 2003) describes the approach to the body that underpins the techno-scientific approach. According to a technocratic approach, the body is conceptualised as a machine, and in this instance the female body is considered as an abnormal or defective version of the male prototype. This conceptualisation of the female body is seen as foundational to obstetrics and consequently female reproductive processes are regarded as “constantly at risk of serious malfunction and breakdown” (2003, p.53). It was this understanding of reproductive processes that laid the foundation for the medicalisation and subsequent social control of women (Cahill, 2001).

Chadwick (2006) discusses the cultural story line of birth’s medicalisation and describes how it has been positioned as progress and salvation. She argues that the immovable ‘truth’ underlying this narrative is that for childbirth to be safe it has to take place in a hospital with medical intervention. Implicit in this understanding is that the historical story of medical birth is one of increased safety and decreasing numbers of childbirth deaths. Through reading the stories of many women who have had medicalised births she concludes that this particular ‘truth’ (that medicalised birth is salvation from risk, complication and death) is cast far too strongly. This point will be demonstrated and discussed later when I explore this issue in medically-complicated pregnancies.

At this point one may ask: why have women bought into the medicalisation of childbirth? Many suggestions have been made in this regard. Shorter (1982) comments that prior to the twentieth century mortality rates for women were high, primarily because of infection and

haemorrhaging. For women at that time, pregnancy and childbirth were considered normal but extremely dangerous. Women would prepare themselves for marriage and childbearing, uncertain if they would survive to see their children (Shorter, 1982).

Chadwick calls this fear the 'shadow of death' (p39) and argues that this has been an important determining factor in women being co-opted into this story line. This collective fear of death during pregnancy and childbirth is so deeply ingrained in the psyches of pregnant and birthing women (Northrup, 1997) that it is understandable that women may have bought into the promise of safety that medical progress offers. In addition, Arney (1982) proposes that medicine also had a role to play in getting women to accept this narrative. In other words, medicine had to change both the meaning of pregnancy and its corollary practices but such an understanding of the role of technology had to be introduced into what he called an "ideologically fertile social field" (p.27). The 'field' at that time comprised middle classes, expanding in numbers and aspirations and thus the recasting of birth from a 'normal' and 'attended' life event to an abnormal and managed crisis he argued, was fundamental to the success of medicine. Chadwick similarly questions why women were so quick to accept medicalisation. Oakley (1980) asserts that this process was anything but quick. In fact she states that it was achieved over time and through the process of ideological claims to greater medical expertise, rather than through any demonstrable benefits to women.

Cahill (2001) contends that while it may be difficult to understand how pregnancy can ever be defined as a disease, in contemporary medical discourse and practice it clearly is. Childbirth has been transformed into a clinical crisis and therefore all pregnancies are regarded as being at risk in a similar vein to innocent until proven guilty. It is this risk status which has justified medical interventions and thus the dominant philosophy is one of risk prediction (Rothwell, 1995). Because all women are potentially at risk to experience obstetric complications, they all require surveillance by doctors.

### **3.2. The medicalisation of childbearing**

The arena of medicine with its auxiliary modalities provides very fertile ground for examining how the characteristics of late modernity are played out (Miller, 2005). Regarding reproduction and childbirth, perceptions of risk are increasingly mediated through interaction with expert knowledge. The way in which time and space is fashioned pans out in very particular ways in terms of women's embodied experiences when they become mothers. The success of the medicalisation of childbirth seems to hinge on medicine's construction of birth

as a situation imbued with risk and therefore requiring professional technical management by specialist obstetricians. (Zadoroznyj, 1999 in Crossley, 2007). Viewing birth as implicitly risky legitimises and increases the possibility of invasive technological interventions in an arguably natural event.

Medicalisation and control of childbirth are inextricably bound with patriarchy. Henley-Einion (2005) notes that the ascent of medicine as a political and social force in the female domain of motherhood can be plotted back to the fourteenth century. Physicians at that time who trained at universities obtained the approval of the church and set out to disprove the effectiveness of traditional remedies which people used. This seemed to mark the commencement of medical science's absolute supremacy over the mysteries of the body, health, birth and death (Henley-Einion, 2005). History reveals that childbirth was firmly rooted in the domestic arena up until the seventeenth century (Cahill, 2001). The seventeenth and eighteenth centuries ushered in a surge in power and status of the medical profession. The twentieth century witnessed the most profound and rapid advances in obstetric medicine and reproductive technology, reflecting the advances of science and technology in society at large.

Relocating birth from the home to the hospital over the last century reflected changes occurring in broader society as well as changes occurring in women's lives. This shift has been explained from different quarters in different ways. On one hand, feminist writers like Oakley (1979), Treichler (1990) and Foster (1995) suggest that this shift can be attributed to patriarchy, male dominance and control over women's bodies. On the other hand, women also advocated for access to hospital beds and facilities for childbirth. In addition, policy-makers and doctors concerned with high infant and maternal mortality rates concluded that medicalising childbirth would alleviate these kinds of problems. The improvement of both perinatal and maternal mortality rates as well as issues of safety and perceptions of risk have all been cited as justifications for the shift to hospital-based care and expert management. However, the degree to which safety, using reduced perinatal mortality rates as a yardstick, can be linked to better maternity care has been questioned. For example, the relationship between outcomes and the increased use of technology have been examined. Davis-Floyd and Davis (1997) suggest that the use of electronic foetal monitoring seems to have resulted in increased caesarean rates and it is debatable whether this translates into better maternity care.

A woman pregnant with a child in late modernity inevitably translates into acceptance and compliance with the medical model as this is equated with safety and behaving responsibly. Women who do not utilise antenatal services or who do not comply with particular societal expectations may be seen as irresponsible (Miller, 2005). By conforming to routine antenatal care and other technological interventions, women are seen as preparing for motherhood in a responsible way. Late modernity therefore stands as a period of reliance on a corpus of expert knowledge reinforced by antenatal practices. This has culminated in the re-conceptualisation of childbirth in terms of risk and clinical safety (Miller, 2005).

To date the medicalisation of pregnancy and childbirth seems to address issues when pregnancies are considered normal rather than high-risk, although literature indicates that in medical terms, all pregnancies are constructed as being risky. However, what would the medicalisation of pregnancy and childbirth mean when a pregnancy is complicated medically as in the case of HELLP syndrome, when there are real risks to the mother and infant? Can these very procedures and reliance on expert knowledge be written off as being counter-productive? In an attempt to understand the complexity of the medicalisation of pregnancy, the use of prenatal technologies and their specific consequences for women's healthcare and unique experiences of pregnancy could be examined.

In an article examining biomedical authority in prenatal testing, Rapp (1999) argues that women's life experiences and context determine whether reproductive technology will be experienced as either liberating or socially controlling (Kramer, 2010). While acknowledging that the routinisation of prenatal technology has resulted in the erosion of women's reproductive autonomy, the degree to which all women experience prenatal technologies as universally oppressive remains debatable. Farquhar (1996) asserts that women are not merely victims of their reproductive processes; they also accept, summon and use these technologies to their own advantage.

Where the stated aim of prenatal screening (which is to offer reproductive choice) comes unstuck is in the area of disability studies. Both feminists and those writing from a disability perspective argue that prenatal testing in fact reduces women's choices, since termination is expected following a specific diagnosis. It has been suggested by both feminists and those concerned with disability that, rather than exploring individualised choices women make, the social contexts in which these decisions are made should be scrutinised (McLaughlin, 2003).

In the final analysis therefore, one can argue that the medicalisation of pregnancy and childbirth has to be understood both in terms of women's unique and differing conditions of pregnancy as well as their larger constellations of kinship and community. In a study conducted by Searle (1996) the most important anxiety-reducer for women (90.5%) was the availability of routine antenatal screening tests, which seemed to provide the necessary assurance that the foetus was doing well.

It is evident that the concept of risk is generic and is applied to all pregnancies. Pregnancies are only regarded as 'normal' retrospectively after the birth (Polomeno, 1997). This conceptualisation of risk thus becomes quite murky, particularly when one is dealing with medically complicated pregnancies where there are substantial risks to the maternal-foetal dyad. Since HELLP syndrome is classified as a high-risk condition of pregnancy, the concept of risk is important to unpack.

### **3.3. Understanding the concept 'risk'**

Risk is a concept that pervades discourses of health and medical care-giving. 'Risk assessment' and 'risk management' have culminated in resolute requirements which govern a wide range of healthcare issues and nursing care in particular (Godin, 2004).

I agree with Godin (2004) who argues that the pervasive discourse of risk confines rather than facilitates our thinking about everything which frames the term (accident prevention, health promotion, safe clinical practice and so on), particularly in the context of pregnancy and childbirth. Dowie (1999) in Godin contends that risk is a "conceptual pollutant" that reassures us to accept that we know what we are referring to when in fact we do not (p. 1). Furthermore, we use the term 'interchangeably' to refer to both probability and harm, make minor distinction between actions and results, and in this way the effective utility of the concept is seriously undermined. Dowie therefore recommends that we be more circumspect with regard to our understanding and use of the term 'risk', as this will in turn improve decision making in health matters (Dowie, 1999 in Godin, 2004). Given the diverse and widespread use of the term, the questions arising are: how have these understandings arose and what have been their social consequences other than to simply cloud our thoughts? In a book edited by Paul Godin, he and various other authors examine how and why society has become enamoured with risk (Alaszewski, 2004; Godin, Davies, Heyman & Shaw, 2004; MacKinnon & McCoy, 2004). Rather than outline these approaches, I will discuss the shifting understandings of risk and examine the implications and ramifications of risk

discourses in contemporary society and will draw on the work of Foucault to explain how they function in self-surveillance.

### **3.4. Shifting understandings of ‘risk’**

Beck (1992) developed the term ‘risk society’ as an indicator of contemporary Western society. In his theory, he asserts that the threats faced in pre-modern society such as famine, plagues and natural disasters were considered incalculable and their causes were deemed to be supernatural. During early modernity, industrialisation transformed the threats to pre-modern society into calculable risks through rational control. Beck argues that Western societies have now shifted into a transitional phase in which the processes of modernist risk estimation fail. In ‘risk society’ the perils confronting us primarily result from modernity, as scientific and industrial development continually jeopardise the environment. These risks, he contends, are often invisible, unknowable and not easily calculable. For example, the future impact of global warming cannot be established. Moreover, the consequences of these latest threats can be global, long-lasting and perhaps irreparable.

Beck continues his argument by asserting that the modern era was marked by class structure that arose from industrial capitalism, resulting in the production and unequal distribution of goods. Late modernity witnesses a new form of capitalism not entirely based on production-based class identity. The major problem of late modernity is less centred on the production and dispersion of goods, than on the prevention or minimisation of ‘bads’. The dangers created by late modernity are distributed differently to wealth in modern society, as they can equally affect both the affluent and the less affluent. Therefore Beck argues “poverty is hierarchic, smog is democratic” (1992, p.3), although he does acknowledge that the less affluent generally are predisposed to a greater amount of ‘bads’. In this respect he highlights that the inequality does not merely correspond to class, for class has side-stepped and ushered in risk society.

Beck expands on two other concepts which are pivotal to his view of the risk society. Firstly, he discusses the rise in individualism occurring in late modernity and coming from the fragmentation caused by globalisation, which resulted in the erosion of national and cultural boundaries and dwindling influence of the family, welfare state, conventional industries and class-based politics. The erosion of all these traditional structures has thus culminated in uncertainty among the populace who subsequently find themselves liberated from traditional limitations and free to create their own destiny. According to this framework, subjects are

compelled to script their own biographies, and are simultaneously expected to be self-reliant. In addition, society is held accountable for its own fate and people are expected to seek information about risks and manage them in a coherent, rational manner. A critique of Beck's theory based on empirical work suggests that he may be correct in his notion of the increase in individualisation (Godin, 2004). But to suggest that people respond to it in a uniform way is problematic. In addition, I agree with Vaz and Bruno (2003) who assert that risk is a social construct rather than a 'reality' produced by social development and performing social and political functions in which it is applied. What is important to note however, is that the risk society approach has become an ideology that has permeated government thinking and influenced the lives of healthcare professionals and those who are regulated by such bio-power.

In contrast to Beck's risk society approach, Mary Douglas argues that the concept and responses to risk are shaped by structure or culture (Douglas, 1992). Douglas' contribution to theorising risk can be allocated in her ideas about the ways in which our thinking about risk, and cognition more broadly, is socially constructed in the institutions and cultures of which we are a part. This shift in thinking is diametrically opposed to disciplines such as psychology and economics that conceptualise cognition and risk perception as private, individual and rational. The difference in risk perception, she contends, is premised less on individual ability to think logically than on the prejudices of the institutions to which they are committed.

The critique lodged against this approach was that it tended to oversimplify complex and dynamic processes of how risk is managed and experienced (Tulloch & Lupton, 2003). However, this perspective has been influential in linking risk perception and responses to processes of identity construction and group formation by the distinction between Self and Other. Furthermore this approach is credited with attempting to transcend the functionalist view on risk and proposes that risk knowledge be construed as historical and local, as constantly contested, as subject to disputes and debates concerning their nature, their control and where blame is to be located for their creation (Tulloch & Lupton, 2003, Zinn, 2006). Another advantage of this approach is that it highlights the shortcomings of other approaches that assume context-free rationalities like rational choice or over-homogenous risk concepts like risk society, to explain how people deal with and understand risk (Zinn, 2006).

In the final analysis it has been acknowledged that risk represents a key dimension of modernity (1990; 1991), that modern society is plagued by an almost “over-production of risk” (Beck, 1992, p31) and that the selective screening of risks reveals conflicts over power and the multiplicity of the meanings of risk (Douglas, 1992; Douglas & Wildawsky, 1982). What these approaches fail to address however, is how these understandings of risk shape and are shaped by governance in modernity. In this regard the work of Foucault becomes seminal.

### **3.4.1. Governmentality**

Having described modern society as ‘disciplinary’ and ‘carceral’, Foucault (1991) proposes the concept of ‘governmentality’ to explain the emergence of a new form of thinking about and exercising power. Foucault utilises the terms ‘government’ and ‘governmentality’ in interlinked ways. Gordon (1991, p.2) notes that he defined government as the ‘conduct of conduct’, that is, as an activity that concerns itself with shaping, guiding or affecting the behaviour, actions and attitudes of people. The act of governing Foucault argues, occurs at several, interlinked levels. Governmentality is thus both individualising/subjectivising (i.e. concerns itself with the constitution of individualised subjectivity) and totalising/objectivising (i.e. through the operation of bio-power the individual is transformed into an object or docile body). Macleod and Durrheim (2002) argue that governmental analysis attempts to integrate the micro-effects of power (e.g. self-technologies) with the macro-strategies of power without privileging one or the other. These authors contend that the advancement of the science of government emerged in reaction to: the re-centring of the economy on a different plane from that of the family and the emergence of the ‘problem’ of the population. Due to the breakdown of the family in society, regulating the population became the goal of government. However, Foucault (1991) suggests that despite the breakdown in family, it still retained its function as an internal component to the population and continued to serve as a foundational instrument in its government. Foucault also contends that current forms of government are rooted in the disciplinary problems of utility and docility. The mechanisms of power in contemporary governmentality form a complex collective of the rationality and techniques of sovereignty, security, discipline and government.

Insofar as risk is concerned, Donzelot (1993) in Macleod and Durrheim (2002) assert that in governmental institutions and procedures, risk has become socialised. In other words, fate,

fortune and destiny, which are considered subjective issues, have been replaced with the notion of risk, which is construed as being more objective. Risk management therefore operates on both societal and individual levels. On an individual level, government agents utilise a number of governmental techniques including disciplinary surveillance and the incitement of technologies of the self.

#### **3.4.1.1. Disciplinary technology, surveillance and bio-power**

Foucault (1979) in *Discipline and Punish* traces the advent of what he termed 'disciplinary technology'. Prior to the eighteenth century the sovereignty of the king's power was displayed through public punishment. However, during the eighteenth century humanist reformers advocated that crime be considered as a breach of contract affecting society in its entirety. Therefore to reflect this thinking it was proposed that punishment be seen as a way of making amends as well as assisting the transgressor to reform and resume his/her rightful place in society. Thus the body that transgressed was no longer dismembered and /or destroyed as with previous methods of torture and punishment; instead it was trained, exercised and supervised. For this system to function, extensive knowledge of the subject was a necessity.

The primary aim of disciplinary technology therefore is the regulation and normalisation of subjects (Foucault, 1979). Disciplinary technology operates through hierarchical observation and normalising judgement. Surveillance is a central component of the production and control of disciplinary technology. An authority figure, whether real or manifested in the dominant discourse, exercises a regulatory gaze over the 'inmates' of the institution. This gaze is based on normalising judgments concerning individual practices. These judgments however, are located in dominant discourses about what is 'normal' in a particular context. Surveillance becomes formidable by extending itself to self-reflection and self-consciousness (Foucault, 1979). As the individual invests in the principles of a normalising judgment, so s/he begins to be vigilant regarding his/her own behaviours, checking whether s/he fits the norm. In the Foucauldian framework of biopolitics, regulation thus becomes self-regulation as the individual subjects her/himself to an internalised surveillance (Foucault, 1979).

Self-surveillance is linked to what Dean (1994) refers to as 'governmental self-formation', which he theorised as the "ways in which various authorities and agencies seek to shape the conduct, aspirations, needs, desires and capacities of specified categories of individuals, to enlist them in particular strategies and to seek defined goals" (p.156). Rose (1996) argues

that these self-strategies require the explanation of specific techniques for the management of one's relation with oneself. These self-technologies are: know yourself, master yourself and care for yourself. What is key to note is that these technologies of the self are exercised under the influence of some system of 'truth' and under authoritative persons from the theological, psychological and pedagogical disciplines (Rose, 1996). Whether individuals accept these incitements depend on whether they invest in the premises of the underlying normalising assumptions.

In order to explain the operation of disciplinary power on the body, Foucault coined the term 'bio-power' which has two inter-related components (Foucault, 1997). The first is the control of human beings via the population; the second is the control of the body to ensure disciplined citizens. In the former instance, bio-power represents the endeavour to rationalise problems presented by the phenomena characteristic of a group of living human beings constituted as a population: health, sanitation, birth rate, longevity and so on (Foucault, 1997). In the latter instance bio-power splits the body into units that are taken up separately and subjected to precise, calculated and repetitive training. The objective is control and efficiency for the part and the whole. According to Foucault, "Discipline increases the forces of the body (in economic terms of utility) and diminishes the same forces (in political terms of obedience)". The latter body is referred to as the 'docile body' (Foucault, 1977, p.138).

From the above it is evident that the significant societal transition to a modern style of governance can be witnessed through a strategy that targeted persons themselves (with technologies to control bodies and persons directly) to a style that is concerned with populations, abstract factors and indicators (Zinn, 2006). Since the individual serves as a carrier of specific indicators under the core concept of risk, treatment no longer targets specific individuals but rather at-risk groups identified by a number of factors and indicators. In this view, risk is not just situated at the centre of governance, organisations and governments, but is also located within the individual as each one is required to interpret as an autonomous subject and is treated as such by society. Individuals are urged to be autonomous, self-regulating, rational, sensible, entrepreneurial and relentlessly in search of self-improvement. The discourse of risk therefore features significantly in this self-government (Godin, 2006). We are spurred to be mindful of information about risks to our health and to utilise this knowledge to regulate our diets and lifestyles. This becomes especially important during pregnancy where women are expected to be very conscious

of risks to their health that are constructed as impacting on the well-being of their fetuses (Sbisa, 1996). Therefore, individuals who do not comply are considered irrational, mad, simply incapable of self-regulation, or 'bad'. In the final analysis, maintaining one's health becomes a moral enterprise in which the individual is encouraged to be vigilant in the avoidance of risk to her/his health. Key to this understanding of self-management is the expectation of individuals to be able to calculate and manage risk.

Furthermore, power is not merely understood as the prerogative of those in authority but is constituted in practices as well as in knowledge. In research studies on governmentality, concepts such as 'truth programmes', 'power strategies' and 'technologies of the self' have been utilised to demonstrate how risk is appropriated in societal games of power and control. These concepts Zinn (2006) argues, enable researchers to dismantle the production processes of social reality and subjectivity in matrices of power and control.

Based on most theoretical thinking, risk seems to be understood in relation to uncertainty. This seems to be the case for a societal approach to risk where it is construed as a potential rational strategy to transform unmanageable contingency into manageable complexity (Zinn, 2006). It also appears valid for the governmentality approach. In this approach O'Malley (2004) has suggested focusing not purely on the constructions of risks, but also on the management of uncertainties as governmental strategies. The reason for this is that most problems are not constituted as clear risk problems, but rather as problems of unsolvable uncertainty. Since uncertainty cannot be solved by objective means alone, moral and political aspects also become important.

Zinn (2006) points out that there is still the inclination in risk research to distinguish between objective statistical/technical risks as the 'real' risks, and social or subjective risks as biased perceptions of objective risks. Given this distinction it appears that there is no universally accepted definition of risk. This sentiment was also expressed by Mary Carolan (2008) in her paper exploring the concept of risk in pregnancy. She asserts that she was unable to access a universally accepted definition of risk in both lay and medical discourse and found that there was evidence to suggest that the concept of risk was constructed and understood differently by these two groups. For writers such as Zinn (2006) and Alaszewski (2004) the dividing line is expert versus non-expert, the latter referring to the experiencing individual. According to Slavin, Richters and Kippax (2004) the division is based on quantifiable/objectivist and social/subjectivist. The former approach considers risk as an objective term, which is accessible, measurable and thus manageable. According

to this approach, risk is presented numerically, based on calculations of magnitude, gains and losses and the probability of harm. Carolan (2008) states that this approach was presented in the literature she consulted as being the most commonly utilised by medical personnel, which corresponds to a discipline rooted in scientific evaluation. In addition she contends that this approach presupposes a 'rational actor' who will respond to health information by embracing new measures to improve her/his health and thus effect a reduction of potential harm.

The latter social approach considers risk as a cultural category (Slavin, et al., 2004). This seems to be the approach embraced by lay persons including pregnant women (Carolan, 2008). In this case, risk is considered in an individual way and is influenced by the social, cultural and political milieu in which the person resides. The subsequent individual appraisal of risk is dependent on many factors including worldview, previous experience, history and socio-cultural context. Therefore the concept of risk seems to be polarised with the objective component on one end and the subjective on the other. However, in the case of high-risk pregnancy it is not 'either or', but 'both'. In the case of HELLP syndrome, the condition is diagnosed on the basis of objective scores on platelet counts, liver enzymes and hemolysis. On the other hand, there is the subjective experience of the risk condition which is dependent on many factors which Carolan (2008) alludes to. In my thesis I therefore propose that the concept of risk be construed as inclusive of both objective and subjective components. 'Objective' in this case would refer to diagnostic categories and laboratory readings of bodily functions (for example, class 1, class 11 HELLP Syndrome). Having established the basis of the concept of risk, I think it is useful to explore the origin and development of high-risk pregnancy in medicine as this would provide a reference point in the literature for the objective aspect of the concept.

### **3.5. Historical overview of high-risk pregnancy**

Polomeno (1997) argues that certain women have always been more vulnerable than others during pregnancy. This author draws on the works of Lloyd (1983) who analysed the writings of Hippocrates (460 – 377 BC), who is revered as the 'Father of Medicine'. These writings contain many informal references to high-risk pregnancy. For example, Hippocrates hypothesised that there was a relationship between the environment and miscarriage. He believed that the incidence of miscarriage escalated during the period between a humid winter and spring. Interestingly, this relationship is still being investigated today (Polomeno, 1997). In addition, by differentiating the risks prior to pregnancy from those during this time,

Hippocrates was able to identify those factors which contributed to low-weight babies and bleeding during pregnancy. In other words, Hippocrates believed that a woman who was 'delicate' (meaning underweight), stood a greater chance of having a small baby, and he was able to discern the relationship between bleeding during pregnancy and abnormal development of the foetus. Alexander and Keirse (1989) cited in Polomeno, contend that the writings of Hippocrates established the foundation for obstetrical practice in general, and the designation of high-risk in particular.

The vulnerability of women continued during pregnancy and childbirth until the beginning of the twentieth century. Prior to this period the mortality rate for women was high, primarily because of infection and haemorrhaging. Thus many women at that time considered pregnancy and childbirth as normal events, albeit extremely dangerous ones. The ethos thus seemed one of preparation for marriage and childbearing for women, but the uncertainty regarding whether they would survive to see their children prevailed (Shorter, 1982).

Doctors and birth attendants had similar attitudes towards these processes. At this time the context of risk was such that the possibility of complications was ever present during pregnancy, labour and birth. Medical personnel aimed at reducing maternal and infant mortality rates as this subsequently would minimise the risk associated with these processes (Shorter, 1982).

The seventeenth century heralded the beginning of controlling pregnancy-related complications by birth attendants. At this stage they were able to identify placenta previa and hence to recommend bed rest or a swift birth in order to control intrapartum bleeding. By 1850 treatment for bleeding due to placenta previa improved dramatically, resulting in reduced rates of maternal and infant mortality due to this condition (Shorter, 1982). Being able to control medically complicated pregnancies culminated in doctors experiencing feelings of success and this changed the face of obstetrics forever. During the 1890's infection rates and its control improved drastically with the introduction of aseptic techniques and with doctors wearing gloves when examining women in the hospital environment.

### **3.5.1. Toxaemia and the twentieth century**

During this period there was grave concern by doctors about convulsions due to toxaemia during pregnancy and birth. Shorter (1982) cites two references in 1669 and 1671 which identify and describe the condition. It seems apparent at this time that toxaemia was known

to childbearing women since various herbal teas were prescribed to cure the condition. During the 1860s the relationship between toxæmia and diet was hypothesised. The mortality rate due to toxæmia peaked by the end of the 19<sup>th</sup> century.

During the First World War magnesium sulphate was introduced as a cure for toxæmia. At this point pharmacology became more prevalent in obstetrical practice. The control of toxæmia dramatically improved in the 1950's when obstetrics became a well-established medical/surgical discipline supported by scientific knowledge and methods. Furthermore, these were spinoffs of medicine emerging post-World War II, which was symbolic of another period of rapid advancements both medically and surgically (Polomeno, 1997).

### **3.6. Historical background of the term 'high-risk' pregnancy**

Rapin (1986) in Polomeno (1997) writes that the term 'high-risk' pregnancy is a fairly recent one. Shorter (1982) states that this term was completely absent in nineteenth century obstetrics. Instead terms such as 'complications' or 'risks during pregnancy, labour and birth' were used. Although the birth of modern obstetrics is traced to the 1950s, the term 'high-risk pregnancy' was still not employed.

As previously mentioned the period after the 1950s witnessed a decline in maternal mortality associated with medically complicated pregnancies. Doctors during the 1950s invested their energies in identifying cerebral palsy in newborn infants as they had witnessed its association with prematurity, multiple pregnancy, previous stillbirths, toxæmia and abnormal placentas. The demarcation of risk during pregnancy thus gained momentum from this knowledge (Polomeno, 1997).

Systems for calculating risk in pregnancy were developed at the beginning of the 1960s (Stirrat, 1988 in Polomeno, 1997). At that time doctors were preoccupied with the long-term effects of infant morbidity, particularly with handicapped children. Determining the 'causal' factors that could potentially influence the outcome of pregnancy thus became a priority in obstetrics. Subsequently two approaches were established to identify pregnancies with complications. In the first approach, clinical diagnosis and evaluation were employed as mechanisms to detect and confirm such pregnancies. For example, at the first prenatal consultation, potential risk was determined by assessing lifestyle habits, age, culture, weight and height, previous medical and obstetrical history and socioeconomic status (Polomeno, 1997).

In the second approach, the diagnosis of high-risk pregnancy was based exclusively on risk-scoring systems. Risk scores were used as the structuring dynamic to organise care in clinics and hospitals. Obstetrical practice shifted gears in the 1960s to mirror these two approaches. It was at this juncture that the term 'high-risk pregnancy' started being used and made its appearance in the literature (Polomeno, 1997).

Antepartal care continued to be shaped and refined as medical technology was being advanced. Detecting women with complications was expedited which culminated in maternal, infant and perinatal mortality and morbidity rates decreasing. From a medical point of view, obstetrics and gynaecology were looking good as great strides were made with improved obstetrical care and statistics (Polomeno, 1997). While there was an upsurge in the discipline of obstetrics, healthcare professionals were starting to observe, document and publish their findings about the impact of hospitalisation on pregnant women. The stories documented were of disquiet and discontent on the part of pregnant women and their families regarding the hospital environment.

The 1980s thus witnessed the emergence of alternative care to antenatal hospitalisation, namely perinatal home care (Dahlberg, 1988). Peer group support for high-risk mothers flourished, offering emotional support for women. Major research was conducted at this time examining issues like bed-rest, the impact of high-risk pregnancies on women and determining how fathers and families reacted to maternal restriction for preterm labour. In response to these documented reports, interventions like home-based care and other community services became the new fashion for women experiencing high-risk pregnancy (Polomeno, 1997).

Reviewing the history of high-risk pregnancy sheds some light on the influence of obstetrical medicine and the role it continues to play in the lives of women who are faced with high-risk pregnancies. With the changing face of the medical establishment whose primary interest was the improvement on statistics, the clientele of this establishment advocated for a more humane and personalised approach to care. This jostle for more control over what was transpiring was interwoven with the woman's movement at that time. In direct response to this situation, birthing centres and midwifery flourished. Polomeno (1997) contends that perinatal education at this time reflected the sentiments that expectant parents as consumers of healthcare have rights, and the importance of negotiating birth plans as well as the right to advocate for fewer interventions during labour and birth.

On the other hand, hospital-based perinatal education programmes were far less flexible regarding content as they usually reflected the approach practised in those hospitals. High-risk pregnancy was not high on the agenda of such programmes, and when it was discussed, it occupied a very minor percentage of the educational material (Polemeneo, 1997). This scenario seemed to change during the 1980s as perinatal educators began to realise that pregnant women and their families required some basic information about high-risk pregnancy, such as premature labour, preeclampsia, multiple pregnancy and bleeding during pregnancy.

What was notably absent at this time was any substantial discussion on how to cope with the experience of high-risk pregnancy (Polemeneo, 1997). This changed during the 1990s because perinatal home programmes were mushrooming everywhere. Polemeneo (1997) contends that perinatal educators at this stage began searching for the human/subjective dimension of high-risk pregnancy: what it is, how it is assessed, the emotional reactions to antenatal hospitalisation and the relationship with the healthcare team. Research and autobiographical accounts flourished during this time; women were documenting their experiences and providing accounts of how to cope with high-risk pregnancy and bed-rest. Prenatal classes were modified to accommodate bed-ridden hospitalised pregnant women and in an attempt to stay abreast of these changes, obstetrical medicine had to change its approach to become more inclusive.

In the final analysis Polemeneo (1997) argues that high-risk pregnancy stands at the crossroads. While obstetrical medicine continues to be concerned with lowering perinatal mortality and morbidity it cannot continue to do so at the expense of alienating women from themselves and their families. While high-risk pregnancies have come to occupy quite a central space in gynaecology, it has done so by almost erasing women's subjectivity. In terms of high-risk pregnancies, it is difficult to draw blanket conclusions as the group is not homogenous. How women will experience their pregnancies and react to their diagnosis will depend upon the gestational stage at which the pregnancy is identified as at risk, the aetiology of the risk, the nature of the treatment as well as the individual make-up of the pregnant woman (Kemp & Page, 1987; Wolreich, 1986). Therefore in researching high-risk pregnancy, it is necessary to be cognisant of the 'real' dangers to the woman and her foetus, and to be aware of the subjective/emotional components to these situations. It is important to reiterate that in Western-style obstetrics, all pregnancies are regarded as high-risk and are

only retrospectively considered normal. In lieu of this understanding, a definition of what constitutes a high-risk pregnancy becomes important.

### **3.7. Towards a definition of high-risk pregnancy**

According to Ganesh (2008) and Carolan (2008) there is no formal or universally accepted definition of a high-risk pregnancy. Generally it appears that a pregnancy is deemed high-risk when maternal or foetal complications are present that could affect the health or safety of either the mother or the baby. MacKinnon and McIntyre (2006) assert that the term 'risk' as is used in obstetrics is understood as a technical term representing the probability of a poor obstetrical outcome. Philipp and Carr (2001) contend that the notion of high risk can be broken down into medical and psycho-social categories. For the purposes of this study I will draw on the definition provided by Levy-Shiff, Har-Even, Lerman and Hod (2002). They define high-risk pregnancy as any pregnancy in which a medical factor – maternal or foetal – may adversely affect the outcome of pregnancy. Risk factors present before pregnancy, problems in a previous pregnancy, disorders present before pregnancy and risk factors that develop during pregnancy can contribute towards a pregnancy being high-risk (Ganesh, 2008). The intention behind the designation of the term 'high-risk' is to ensure that the mother receives extra attention and appropriate care, thereby significantly contributing towards decreasing maternal and neonatal morbidity and mortality rates.

Ganesh (2008) provides a breakdown of these risk factors and offers some examples of each. While my study focuses particularly on HELLP syndrome, it is useful to gain some idea of the other factors that contribute to pregnancies being labelled high-risk. Risk factors which are present before pregnancy include physical characteristics such as age, weight and height which may affect the pregnancy. In the case of maternal age, for example, girls aged 15 and younger are at increased risk of preeclampsia/eclampsia as well as having low birth-weight babies. As women age, the likelihood of pregnancy-induced hypertension and foetal chromosomal abnormalities, also increases. Problems in a previous pregnancy are more likely to recur in subsequent pregnancies. Such problems include having had a premature baby, an underweight infant, a baby with defects, a previous miscarriage, a post-term delivery, or a delivery that necessitated a caesarean section (Ganesh, 2008). The risk of recurrent abortion after three consecutive losses in early pregnancy is about 35%. Women who have habitual abortions are more likely to have second trimester and early third trimester pre-term labour and stillbirths (Ganesh, 2008). A history of perinatal loss suggests the

possibility of foetal or parental cytogenetic abnormality, maternal diabetes, chronic renal vascular disease, hypertension, connective tissue disease or drug abuse. Aspirin has been used as a treatment but has had mixed results. A woman who has previously had preeclampsia/eclampsia is always at risk during her subsequent pregnancies. Similar to HELLP Syndrome (which will be discussed later in the chapter), this is a disorder specific to pregnancy and is characterised by hypertension, oedema (swelling) and proteinuria. It accounts for the majority of hypertensive gravidas and develops with increasing frequency after the twentieth week of gestation. Eclampsia is preeclampsia with convulsions. The only specific treatment is delivery, but temporisation with bed rest, medications and careful monitoring may be justified if the patient is remote from term (Stotland & Stewart, 2001).

A further category which places women at risk relates to disorders which are present before any pregnancy. When women in this category fall pregnant, they usually require specialised care, often from a multidisciplinary team (Ganesh, 2008). The kinds of disorders that may be present prior to the pregnancy include cardiovascular disease, hypertension, kidney disorders, seizure disorders, sexually transmitted infections like HIV/AIDS, diabetes, asthma, autoimmune disorders and fibroids. Risk factors/disorders that develop during pregnancy like infections, preeclampsia/eclampsia and HELLP syndrome may develop during the pregnancy.

### **3.8.HELLP Syndrome: A high-risk condition of pregnancy?**

Hemolysis, elevated liver enzymes, and low platelets (HELLP syndrome) have been well documented as complications of preeclampsia and eclampsia for many years. However, there does not seem to be complete consensus about its incidence, nature, clinical significance and management. The syndrome was initially described as 'EPH' (oedema, proteinuria, hypertension) by Goodlin who contends that it had been recorded in the obstetric literature for about 100 years. Weinstein first considered this condition to be a unique variant of severe preeclampsia, hence the term 'HELLP syndrome' with reference to laboratory abnormalities (Geary, 1997). Interestingly, some authors considered HELLP syndrome as misdiagnosed preeclampsia (McKenna, Dover & Brame, 1983), while others considered it as mild disseminated intravascular coagulation that was missed because of technical inadequacy (Greer, Cameron & Walker, 1985).

The terminology and diagnostic criteria used to describe the syndrome have been confusing and inconsistent in the past (Geary, 1997). With regards to hemolysis, the diagnosis was

largely based on the presence of an abnormal peripheral smear, or an elevated reticulocyte count. Other markers of hemolysis include lactate dehydrogenase, bilirubin, urobilinogen, and free haemoglobin. In most severe cases, disseminated intravascular coagulation (DIC) will co-exist with haemolytic anaemia.

There is also no consensus regarding exactly which liver function test abnormalities should be used to diagnose the syndrome, but the majority of papers refer to elevated amino-transferase levels. It has also been shown that liver function test abnormalities generally do not coincide with the degree of liver damage. However, in cases manifesting extreme elevation of aspartate amino-transferase and lactate dehydrogenase levels, there is a high risk of maternal mortality.

The conventionally accepted definition of thrombocytopenia is a platelet count of less than 150 000 per microlitre. More recently this has been divided into a triple class system with class I HELLP syndrome referring to a maternal platelet count of less than 50 000/ $\mu$ L, class II to a platelet count of more than 50 000 to less than 100 000/ $\mu$ L and class III to a platelet count more than 100 000 to less than 150 000/ $\mu$ L. To date, the pathogenesis of HELLP syndrome remains a mystery. It has however been suggested that disorders including HELLP syndrome, thrombotic thrombocytopenic purpura, the haemolytic uraemic syndrome and acute renal failure may all be part of a spectrum of the same disease process. What is important to note, is while the pathogenesis may be similar, the diseases are not the same. The common link appears to be endothelial cell injury with subsequent vasospasm, platelet activation, an abnormal platelet prostacyclin-thromboxane ratio and decreased release of endothelium-derived relaxing factor (Geary, 1997).

The vague nature of the presenting complaints can make the diagnosis of HELLP syndrome frustrating for physicians (Kottarathil, Connolly & Walshe, 2001; O'Hara, 1999). Approximately 90% of patients present with generalised malaise, 65% with epigastric pain, 30% with nausea and vomiting and 31% with headache. HELLP syndrome may also present with convulsions, jaundice, gastrointestinal bleeding, haematuria, bleeding from the gums and pain in the renal angle, chest or shoulder. Because early diagnosis of this syndrome is critical, any pregnant woman who presents with malaise or viral-type illness in the third trimester should be evaluated with a complete blood cell count and liver function tests.

When HELLP syndrome is diagnosed, the priority is to assess and stabilise the woman's condition, particularly coagulation dysfunction. Thereafter, foetal well-being should be established by ultrasound biophysical profile, umbilical artery Doppler and cardiocography. Finally, a decision needs to be made whether immediate delivery is indicated (Geary, 1997).

Geary (1997) sums up his discussion and notes that while HELLP syndrome is rare its consequences can be devastating to mother and neonate. Since its presentation is variable, diagnosis is often delayed. Treatment depends on a number of factors, primarily the severity of the condition and the gestational age of the foetus. O'Hara Padden (1999) suggests that women who have had HELLP syndrome should be counselled that they have a 19% to 27% risk of developing the syndrome in subsequent pregnancies. Patients with Class1 HELLP syndrome have the highest risk of recurrence. In addition, these women also have a 43% risk of developing preeclampsia in another pregnancy.

Having outlined some of the clinical features and issues related to HELLP syndrome, it becomes clear that the consequences to both mother and baby can be far-reaching and dire in some instances. While the medical aspects pertaining to the disorder have been extensively written about, very little systematic research has been conducted on the emotional and psychological sequelae of HELLP syndrome, an area which my thesis aims to address. The combination of suffering a serious illness like HELLP syndrome with an unpredictable pregnancy, and an unexpected caesarean section or delivery (often of a premature child), is a heavy burden to bear both physically and psychologically (Van Pampus, Wolf, Weijmar Schultz, Neelman & Aarnoudse, 2004). The above information highlights the context of the fragile emotional status so that it can be appreciated in the care of the mother experiencing HELLP syndrome through the eyes of the patient in order to understand the impact of this disorder on the expectant mother.

In order to set the stage for understanding the emotional and psychological aspects of a high-risk pregnancy, it is important to examine and acknowledge the myriad of emotions that the expectant mother experiences in her pregnancy. Key to this understanding is the relationship between a pregnant woman and her foetus. Schmied and Lupton (2001) contend that the experience of pregnancy accompanied by all the physical and emotional changes invariably raises questions for a woman about her sense of embodiment and identity. Early research concerning the relationship between a pregnant woman and her unborn baby, tended to

concentrate on the woman's attachment to her child as well as on the critical place of such attachment in the development of maternal behaviours and attitudes following the birth of the baby (Leifer, 1977, 1980).

### **3.9 Psychological aspects of pregnancy and childbirth**

Psychoanalytic work from the 1940s to the 1960s represented the relationship between the mother and foetus as symbiotic (Benedek, 1952; Bibring, 1959, 1961; Deutsch, 1944). It was suggested that the interdependence of mother and foetus was demonstrated by the dependence of the foetus on the mother as a host, as well as the mothers' narcissistic love for herself and the ensuing belief that the baby was a part of her own body. Bibring (1961) described the two-in-one phenomenon experienced by a woman in the early stages of pregnancy and then went on to discuss the resultant change in her perception of the embodied infant as she became more aware of the foetus's movements and hence recognised it as something other than her own body. In this view, in a woman's mental preparation for labour and birth, the infant was increasingly viewed as if it were another individuated object. Similarly Rubin (1977; 1984) using a stage approach, identified a process in which women become aware of their infants whilst pregnant and begin to identify it as a separate entity. Rubin provided a cognitive map describing the 'I' in relation to the 'you', the infant, and claimed that there is a continual reframing of the relationship between mother and child both during pregnancy as well as in the neonatal period.

In her 1984 writings, Rubin emphasised a woman's sense of unity and oneness during the first two trimesters of pregnancy. In addition she asserted that during this period it is challenging for a woman to ascertain what is self and what is baby, since what happens to the self also happens to the baby. At this stage there appears to be no distinguishable physical boundaries between mother and foetus. During the last trimester Rubin (1977) contended that the woman develops a sense of boundary between herself and her infant, a more comprehensive understanding of the 'I' and 'you'. According to her theory it is the foetus that serves as the impetus for 'binding-in' through its movements, which occur at around 18-20 weeks' gestation. This process termed 'polarisation' occurs as the separate identities of mother and child are established. For Rubin therefore, the integration and expansion of the idea of the child, and of the self as a mother, is a progressive investment of self in thought and actions. As the pregnancy progresses the foetus communicates via its movements and acquires the ontological status of personhood, an object that gives meaning and significance

to the woman becoming a mother (Schiemdt & Lupton, 2001). At birth or shortly thereafter the mother conceptualises the child as a fully separate being from her own body/self.

Lumley (1980) and Stainton (1985) continued this work to develop what they proposed were the stages that women go through or need to resolve during pregnancy. This work culminated in the identification of four phases in women's developing awareness of the foetus: integrating the foetus into the body and self-image, differentiation of the foetus from the self, gaining a sense of the child and finally attachment to the foetus. In both Rubin's and these researchers' work, the need for a woman to move from seeing the foetus as part of herself, to identifying herself separate sometime in the second trimester, to finally having a sense of the foetus as a real person is highlighted in these writings.

Difficulty with these conceptions arose when some theorists pathologised what they deemed to be an inadequate individuation of women from their infants. For example Bibring (1961) and Leifer (1977) argued that the successful formation of a relationship with the foetus in utero was predictive of maternal behaviours and attitudes following birth. To confirm this understanding, Cranley (1981) developed the Maternal-Fetal Attachment Scale which has subsequently been used extensively in research to illustrate the relationship between maternal-foetal attachment and postnatal maternal behaviours. Adjustment to motherhood was investigated by many researchers utilising an array of operationalisations and measures. These included concepts like role conflict, marital satisfaction, postnatal depression, maternal attitudes and maternal competence (see for example, Antonucci & Mikus, 1988; Fleming, Flett, Ruble & Shaul, 1988; Fedele, Fleming, Flett, Ruble & Wagner, 1990). The difficulty with this type of research is that whatever the dimension of motherhood that is being purported to be measured, may not necessarily measure the same dimension or the same thing at all. Therefore Sandelowski and Black (1994) indicate that these studies have yielded inconsistent results and have therefore not supported the theoretical understandings of maternal-foetal attachment.

Schiemdt and Lupton (2001) contend that viewing the relationship between mother and foetus in this particular way is linear and static as it fails to account for any ambiguities or the constantly changing nature of the maternal-foetal relationship, nor for the myriad of ways that women may relate to their foetuses. The literature would seem to suggest that women who have not separated in this particular way are suffering from an inappropriate attachment and merging of their identity with their infants. Schiemdt and Lupton therefore argue that such a

theory implicitly embraces a view of the human subject which privileges notions of autonomy and the individuated body/self, with a distinct conceptual boundary between one's body/self and that of others.

This concept of the ideal subject is masculinist in nature as it aligns its ideas with the premise that men's bodies are intrinsically more controlled, autonomous and contained than those of women, whose bodies are culturally conceptualised as unruly, more fluid and permeable and the boundaries of their bodies/selves tending to be more diffuse (Ussher, 1999; Grosz, 1994). Lupton (1999) therefore contends that the maternal body in this cultural milieu has traditionally invoked anxiety and trepidation because of its transitional status as two bodies in one, its permeability of boundaries between self and other. Schiemd and Lupton (2001) therefore hypothesise that it may be due to this anxiety that the dominant discourses in medical literature insist on the significance of the psychodynamic individuation between women and the foetus by the time of birth, and in this way attempt to restore the privileged integrity of autonomy to women's bodies/selves.

Looking at the issue of individuation, Stainton (1985) concluded that women do establish a sensitivity toward knowledge of their infants as separate individuals. Furthermore, it was reported that women worked continuously at resolving this ambiguous relationship between themselves and their infants in an attempt to achieve a separate identity prior to the birth. In addition, Sandelowski and Black (1994) identified the importance of ultrasonography in assisting North American and men in knowing their foetuses as separate beings. Schiemd and Lupton (2001) in their study found that for most women the experience of pregnancy and the relationship with their unborn baby was characterised by ambiguity and uncertainty. They observed that despite all the visible evidence of their swollen abdomens, bodily changes and seeing and experiencing the movements of the child in utero, they still struggled to come to terms with the fact there was a separate body inside their own, which would emerge and have its own independent embodiment and personhood.

What is important to note from Schiemd and Lupton's study (2001) is that there were very few women who actually described their relationship with their foetuses in a series of developmental stages, as Rubin's theory suggests. In fact they described that relationship in terms of accepting the 'reality' of the foetus as a separate body/self as something that vacillated throughout the pregnancy. These findings support those of Sandelowski and Black (1994) who articulated that for both women and men it was a perpetual to and fro throughout

the pregnancy from the time of the child in the head to the child in the womb to the child on screen and to the child they anticipated in their arms.

Feminist scholars Young (1990) and Kristeva (1982; 1986) conceptualised the pregnant subject as split and decentred. Young (1990) argued that “the pregnant woman experiences her body as simultaneously herself and not herself...inner movements belong to another being, they are also sensed as belonging to herself” (p.160). She continues: “it is myself within the mode of not being myself” (p.163). This is an indication that Young is arguing that the foetus is both inside and outside the pregnant woman’s body thus obscuring the inner and the outer. These writers also assert that this ambiguous relationship is not restricted to the first trimester as Rubin argues. In fact, they contend that this sense of the two bodies in one persists throughout the gestational period. Young (1990, p.163) expresses this in the following way: “Pregnancy challenges the integration of bodily experience by rendering fluid the boundary between what is within myself and what is, outside, separate. I experience my insides as the space of another, yet my own body.”

Empirical research examining the psychological aspects of pregnancy in both nursing and psychology, have focused on a myriad of issues relating to pregnancy. For example, studies have examined role conflict, marital satisfaction, postnatal depression, maternal attitudes, self-confidence, attachment to the infant and perceptions of the infant (Antonucci & Mikus, 1988; Fleming, Flett, Ruble & Shaul, 1988; Leifer, 1977; Levy-Shiff, Lerman, Har-Even & Hod, 2002; Oates & Heinicke, 1985). Unfortunately these studies assume that women are a homogenous group with the same, needs, desires and experiences and therefore attempt to suggest ways that will improve women’s experiences. What these studies therefore mask are the differences between women related to race, class and socio-economic position (Annandale & Clark, 1996). In reviewing some of this work, it is important to remember that most of these earlier studies have been based on Western white middle-class women.

Some of the studies which have examined issues of class and race have found that women have different needs, desires and priorities regarding pregnancy and childbirth. The differences in medical intervention were notable. McIntosh (1989) found that working-class women generally displayed a more positive attitude towards medical intervention than did middle-class women. Furthermore the literature on pregnancy seems to suggest that more affluent women demonstrated an activist orientation towards their first pregnancy, while working-class women were described as ‘passive or fatalist’ in their orientation (Bowes

&Domokos, 1996; Martin, 1987; Zadoroznyj, 1990. Lazarus (1997) compared three groups of women: those who received prenatal care from doctors in private practice; women who were receiving care at a public facility; and those who were health professionals themselves or the spouses of health professionals. This study highlighted that knowledge about pregnancy and childbirth was linked to social class and that issues of control were differentially important to women from different classes. Choices were more limited for poor women who generally lacked support and adequate information and they cited continuity of care as far more important than personal control. However, it was found that the degree of control exercised by middle-class women was also restricted. Lazarus (1997) reported that all women irrespective of class wanted medical information to be shared with them, and that being treated with dignity and respect was deemed crucial as well as receiving emotional support. Pregnancy, childbirth and race research seems to have been even more scant than social class research, even though race and class are inextricably linked. The studies which have been conducted have examined issues like medical intervention during birth. In the United States, Martin (1987) claimed that young black women are most at risk of having high-tech medical interventions performed on them, whereas other studies suggest that middle-class women receive more medical intervention, particularly caesarean sections. South African studies have reported that white and coloured women have higher rates of medical intervention and caesarean sections (Chalmers, 1990; Matshidze & Richter, 1998).

In the South African context, pregnancy and childbirth research is very sparse. Studies have focused on issues such as social support (Nikodem, Nolte, Wolman, Gulmezoglu & Hofmeyer, 1998; Sengane, 1996); childbirth experiences of 'unmarried mothers' (Swart, 1993); effects of antenatal care on birth experiences (De Freitas, 1983; Solomon, 1996) and postnatal depression (Hargovan, 1994; Moses-Europa, 2002). While research pertaining to the psychological aspects of pregnancy in general is scarce, research on high-risk pregnancy is virtually non-existent.

### **3.10. Psychological aspects of 'high-risk' pregnancies**

While quite an extensive body of knowledge exists on the medical aspects of high-risk pregnancies, the information on the psychological aspects remains relatively sparse (Phillip & Carr, 2001). Thomas (2004) contends that literature in the social sciences has paid negligible attention to the areas of major illness during pregnancy or to postnatal physical health. It is

also important to be aware that most of the studies conducted have been done internationally, and virtually no published research has been conducted in the South African context.

When reviewing the literature on high-risk pregnancy it became evident that many of the studies conducted were rooted in the nursing tradition. I suppose this is understandable as nurses are the people who ultimately care for these women. What was also notable was how many of these studies used the early work of Reva Rubin (1976; 1977; 1984) to examine the trajectories of women at risk during their pregnancies. Again it is important to emphasise that the critiques lodged about the work of authors like Leifer (1977); Rubin (1975) and Stainton (1985; 1992) also apply to high-risk pregnancies. The research conducted in the area of high-risk pregnancy focused on the developmental tasks identified by Rubin, stress and anxiety associated with this situation (Clauson, 1996), mediators of stress (Heaman, 1998; Kemp & Hatmaker, 1989), sources of stress, self-esteem of women faced with high-risk pregnancies, hospitalisation and bed-rest (Leichtenritt, Blumenthal, Elyassi & Rotmensch, 2005; White & Ritchie, 1984), health status of this grouping of women, family functioning in this context (Kemp & Page, 1984; Stainton, 1995), and on maternal and parental needs during this experience, high-risk new-borns and their families (McCain & Dietrick, 1994). As mentioned previously during the 1990s research highlighting women's subjective experiences mushroomed (Polemno, 1997). Many of these studies which will be reviewed drew on phenomenological frameworks which highlighted the experiential, lived experiences of women who were experiencing or who had experienced a high-risk pregnancy. Some of the later work I reviewed starting looking at discourses of risk itself and the disciplinary ramifications of these discourses. What was notably absent from these studies were feminist voices. This sentiment was echoed by Layne (1997) when she examined the literature on miscarriage.

I agree with Kidner (2000) who contends that high-risk pregnancies are shrouded in a veil of uncertainty and unpredictability. These two themes are pervasive in the literature on high-risk (for example see Clauson, 1996; Simmons & Goldberg, 2011; Stainton *et al.*, 1992). Stainton *et al.*, (1992) and Stainton and Harvey (1995) correctly argue that unpredictability is present in every pregnancy, but this remains in the background. In a high-risk pregnancy unpredictability shifts to the foreground. However uncertainty and unpredictability mean different things for different women. In their study on understanding uncertain motherhood Stainton *et al.*, (1995) contend that for the women in their study, being uncertain in a high-

risk perinatal situation meant uncertainty in becoming a mother to their babies. This uncertainty, they contend, is even more intense when a previous loss/es had been experienced in any stage of their previous pregnancies. These sentiments were also expressed by Cote-Arsenault & Marshall (2000) who reported that many women fear a recurrence of loss and hence their subsequent pregnancies are anxiety-filled. In Cote-Arsenault and Morrison-Breedy's study (2001), women's stories portrayed perinatal loss as a life-altering event which sometimes continues beyond the childbearing years. However for the women in Stainton *et al's* study, the focus was not only on perinatal outcome, it was on becoming – a process according taking place in their core self. Furthermore, for these women the uncertain result was the context in which becoming a mother to this infant was experienced. Moreover for them the medical condition provided the context for the experience, but was not the experience itself (Stainton *et al.*, 1995).

The above study thus provides the background for attempting to understand the psychological/emotional aspects which I believe pertain to many high-risk pregnancies. In many pronatalist societies where motherhood is revered and having one's own biological child is almost a necessity, women feel extremely pressured to become mothers. Meyers (2001) contends that the majority of women are absolutely sure that having a child is one of the most important things in life and that not having a child would be catastrophic. Furthermore, the way some women in Stainton *et al.*'s (1995) study described the process taking place within their core selves entrenches the essentialised and naturalised notions of motherhood. It also reinforces the idea of women's biology determining women's destiny. Thus it could be argued that for some women when this perceived 'destiny' is threatened as in the case of a high-risk pregnancy, it culminates in very challenging situations for them. This is exactly what feminists have railed against; the discourse that motherhood equals womanhood and the pressures on women to prove their femininity through 'successful motherhood' arguably is unattainable for many women.

In unpacking the problem of understanding the phenomenon of high-risk pregnancy Stainton *et al.*, (1995) describe some of the difficulties women experience. For example, women who are hospitalised are referred to as 'patients' which inadvertently implies a sick role and therefore positions women as a patients. In many high-risk pregnancies women reported that they did not necessarily feel ill and this is extremely difficult for women to come to terms with (Gupton, Heaman & Ashcroft, 1997). Kemp and Page (1987) found that tolerance of the

'sick' role may mean that women anticipate a negative outcome. Such beliefs in turn may lead to helplessness, depression and decreased compliance for some women. In addition the science of high-risk care has developed from technologically based possibilities inherent in the physical manipulations of bodily processes with little or no attention to the psychosocial responses or experiences of the women involved. Science and medicine have fragmented the body into parts ignoring all other aspects of the self. Emily Martin (1987) discusses the way in which women's bodies have been fragmented and the body likened to a machine with its component parts. In sum when trying to understand the psycho-social experiences of women with high-risk pregnancies, it is imperative to understand the medical/scientific context in which this transpires.

As mentioned above, uncertainty underpins the high-risk situation for many women. Stainton *et al.*, (1995) described uncertainty as a concept, defining a concept as a generalised idea. For these authors, uncertainty contains one of the following elements: vagueness, ambiguity, lack of clarity, unpredictability, inconsistency, multiple meanings and lack of information. Their findings therefore reveal that the high-risk situation creates particular dimensions of the experience of perinatal uncertainty that were reflected in their participants' stories. These dimensions include: an elongation of time, feelings of fear, loss of control and identity, being alone with the responsibility, changed family relationships and interactions, fatigue, grief and loss, needing to be known and understood, and women experiencing responses of others as not in tune with their own needs. All of these dimensions have been confirmed in various other studies (Corbett-Owen, 1999); Cote-Arsenault & Morrison-Breedy, 2001; Dulude, Wright & Belanger, 2000); Gupton *et al.*, 1997, Heaman, 1998; Maloni, 1998; Maloni & Kutil, 2000; Martin-Arafeh, Watson & McMurty Baird, 1999, Stainton, 1992; Wohlreich, 1986).

Uncertainty in high-risk pregnancy also pertains to the label itself. Women and healthcare providers attach different meanings to the label high-risk. MacKinnon and McIntyre (2006) and Simmons and Goldberg (2001) assert that the term 'risk' in obstetric medicine is conceptualised as a technical term indicating the probability of a poor obstetrical outcome. They further contend that the medical use of the term is linked to scientific understandings and progressive science. In other words, risk is understood as something measurable, predictable and manageable. Simmons and Goldberg (2011) note that when a pregnancy is labelled 'high-risk' the care provider changes from a primary healthcare provider to an

obstetrician or maternal-foetal specialist with increased monitoring which includes increasing visits and ultrasounds. This increased medicalisation and use of technology implies that risks can be controlled and managed.

In biomedicine, the focus is centred on diagnosis and treatment as well as on the search for underlying biological or pathological causes. As in the case of all illness and disease, diagnosis and treatment is as a consequence of rational decision making by physicians during their training in medicine. This process in sociological and anthropological literature is defined as biomedical rationality (MacKinnon & McIntyre, 2006). Biomedical rationality entails the mental transformation of people into patients and eventually into cases – the objects of medical care. MacKinnon and McIntyre (2006) argue that biomedical rationality is more effective in the case of medical emergencies and single-cause acute illnesses, but less useful with chronic illness or disability. In addition, biomedical rationality completely devalues the self-healing abilities of individuals and excludes the subjective experiences of health and illness.

MacKinnon and McIntyre (2006) contend that biomedical rationality is inextricably linked with discourses of risk, responsibility and blame. People are therefore held morally accountable for lifestyle choices that result in illness and disease. Cartwright and Thomas (2001) stated that the discourse of risk inadvertently also constructs women and families as responsible for the outcomes of childbearing. This is very evident in pregnancy texts disseminated to women that support similar understandings of pregnancy and its corollary risks (MacKinnon and McIntyre, 2006). The popular study by Marshall and Woollett (2000) attest to the way in which the pregnant body is constructed as different and alienated from the woman's previous body knowledge and pregnancy, as distinct from the woman's history and lived experiences. Marshall and Woollett (2000) recount that the texts they examined outline the risks and dangers confronting women as numerous, but pay scant attention to the risks posed by medical screening and intervention. They conclude that these texts "often fail to engage with the diversity in women's experiences in reproduction and the varied circumstances of women's lives" (p 366), and thus reproduce biomedical understandings of pregnancy.

As mentioned earlier the label of risk holds a multiplicity of meanings for the women in these positions. Simmons and Goldberg (2011) argue that diagnosing women with a high-risk pregnancy results in additional stress for them. Perceptions of greater than average stress to

women and their babies subsequently results in increased levels of uncertainty, higher psychological distress and diminished well-being. In the final analysis the presence of anxiety and stress in pregnancy has been associated with adverse obstetric, foetal and neonatal outcomes (Yali & Lobel, 1999). It is therefore a vicious cycle as the label high-risk leads to stress and anxiety, which in turn influences outcomes of the pregnancy, and this results in added risks to the pregnancy. In trying to understand why and how labelling impacts on women, it is important to realise that in these situations there are tangible risks to the mother and baby which require increased vigilance by healthcare providers.

Simmons and Goldberg (2011) in their study report in high-risk situations, that healthcare providers are considered the 'experts' on women's pregnancies rather than the women themselves. This can undermine the relationship that a woman has with her own body and that of her foetus (Young, 1990). However, in Simmons and Goldberg's study this was not the case. Women in this study did not express any concerns about hierarchical relationships with their healthcare providers. In fact, all participants expressed positive outcomes for both the healthcare providers and the technology associated with this type of care. The researchers in this study speculate that the reason for this may be that they did experience positive interactions with health personnel, or their responses may simply have reflected their absolute vulnerability at the time. What was primary to them was ensuring safe passage for themselves and their infants. If they were critical of the care they received, they might have felt that they were tempting fate itself (Simmons & Goldberg, 2011).

The technological aspect of care in a high-risk pregnancy also assisted women in allying and containing their fears. In Goldberg and Simmons' study (2011) some women reported that the ultrasound enabled them to visually confirm their infant's well-being. Cote Arsenault (2001) found antepartum monitoring, such as ultrasound, foetal monitoring and increased visits to be reassuring to women either experiencing a high-risk pregnancy or pregnancy following perinatal loss.

Popular discourses argue that the relationship between a pregnant woman and her unborn child is unique. Simmons and Goldberg (2010) speculate that it may be this uniqueness that culminates in women feeling solely responsible for everything that happens to the infant. This then results in women questioning everything they do. However MacKinnon and McIntyre (2006) argue that biomedical rationality individualises risk which then is placed squarely on the shoulders of women. In their study which explored the influence of risk

discourses on women's experiences of preterm labour, they found that risk discourses exert social control over pregnant women and result in fear, guilt, feelings of being judged or punished, and an overwhelming sense of personal responsibility for preventing pre-term birth. MacKinnon and McIntyre (2006) further contend that the identification of risk factors creates spaces for physicians and nurses to give medical advice to pregnant women. They found nurses to be actively engaged in teaching women to be conscientious with self-surveillance and they were found to chastise women whose behaviours did not mirror the biomedical understanding of pregnancy risks.

Another dimension of uncertainty in the high-risk situation pertains to the outcome of the pregnancy. While perinatal loss is not only a possibility, but also often a reality in high-risk situations, there is silence around this issue. Layne (1997) asserts that one of the most conspicuous signs of the culturally sanctioned non-existence of these events is the fact that there are no greeting cards for such occasions. This cultural denial has a profound effect on women who experience such a loss. In addition, the silences surrounding pregnancy loss are not only located at the level of popular culture, but also in the medical arena (Corbett-Owen, 1999; Layne, 1997), in civil records (Layne, 1997) as well as with some women who themselves are reluctant to disclose their loss. Keane (2009) agrees with Layne (1997) by arguing that pregnancy loss and stillbirth is a common occurrence, but its relevance and the suffering and grief it results in have largely been bypassed by medical discourse and public culture. Keane (2009) contends that although feminism has been an ardent critic of medicine in relation to reproductive health, and has been active in attempts to make the hidden known, it has been tight-lipped about miscarriage and stillbirth.

Layne (2003) provides compelling arguments for the feminist silence surrounding pregnancy loss which centres on the relationship between abortion debates and foetal personhood. In commemorating their miscarriages via poetry with titles such as "I'm a Mother too", and in insisting that they have lost a 'real baby', feminist scholars have been reticent to acknowledge that embryos and foetuses are equivalent to babies and children. Layne expresses it in this way: "the fear...is that if one were to acknowledge that there was something of value lost, something worth grieving in a miscarriage, one would automatically accede the inherent personhood of embryo's and foetuses" (2003, p.240). Therefore Layne asserts that feminist are now faced with a tension between the need to support women's reproductive rights and the desire to acknowledge women's suffering. Layne thus implores

feminists to overcome their fear of foetal personhood in order to create a woman-centred and sensitive discourse of pregnancy loss.

Similarly anthropologist Lynn Morgan (1996) embarked upon a critique of feminism for refusing to acknowledge the lived experience of women who value foetal life. Morgan argues for logical and self-reflexive ethics of foetal life which acknowledge the constructed reality of foetal personhood while staying critically attuned to the social and political contexts that produce certain forms of personhood and deny others. In her study of foetal personhood and representations of the absent child in pregnancy loss memorialisation, Keane (2009) examined two genres of imagery used in pregnancy loss websites to visually represent the 'realness' of the lost child: angelic idealism and techno-medical representation. She concludes that neither genre could completely overcome the 'realness problem' of pregnancy loss. She observes that angel imagery depicts the sense of a child whose existence continues in another supernatural dimension, but its generalised and fantasised nature is inconsistent with the individual specificity which symbolises personhood. On the other hand, ultrasound images provide indexical specificity and evidence of existence of the foetus as an observable biological and material entity. However, the problem with medical discourse being represented by ultrasound, is linked to a biological rather than social/relational model of personhood, and thus it classifies the lost infant as non-existent after the death of the foetus (Keane, 2009). Keane therefore suggests that grieving parents who memorialise their lost children are restricted by the demands of intelligibility in a culture that understands 'real' personhood as ethno-biological rather than relational. Thus while grieving parents struggle to communicate the 'realness' of the lost child, memorialisation does convey the intensity of maternal grief and the intensity of the desire for a child. In sum Keane (2009) contends that whether representations of pregnancy loss are produced by medical experts, health activists, scholars or mourning mothers, they will continually mirror and represent particular culturally sanctioned norms of motherhood, womanhood, childhood and personhood.

Having explored the uncertainty and real possibility of loss in a high-risk situation, the possibility of having a premature baby in the neonatal intensive care unit (NICU) is also important particularly with HELLP syndrome pregnancies. In these situations mothers often expressed distress, disappointment, sadness, depression, hostility, anger, helplessness, grief and loss of self-esteem when recalling time spent in the NICU with their infants (Wereszczak, Miles & Holditch-Davis, 1997). Together with De Mier, Hynan, Harris and

Manniello (1996), these authors found that many mothers had intense memories and feelings of those emotions nine months after the baby's discharge from the NICU. Half of the mothers expressed the stress of contemplating the death of their infant. These results therefore corroborate the theory that high-risk mothers have high states of vulnerability, anxiety and stress.

Healthcare in speciality areas such as the NICU requires an intertwining of caring through technology and caring through touch (Kidner, 2000). Hegedus, Madden and Neuberg (1997) discerned that nurses understood care as listening and fostering relationships with parents, whereas parents perceived care as actually physically touching and monitoring their infant. This study therefore divulged the differences between nurses' expectations and parental needs. Stainton (1992) in her project found that the mismatches in mothers' and caregivers' interpretations of care arose from various sources of caring, knowledge and meaning. Regarding the former, caregivers focused on indicators of change that signalled failure, while mothers focused on those signals that indicated progress. As far as sources of knowledge were concerned, dissonance arose from mothers wanting to share responsibility for care and to be acknowledged as a knowing parent. With regard to sources of meaning, Stainton (1992) and Black, Holditch-Davis and Miles (2009) found that the most intense event where mismatches arose, related (understandably) to the actual or potential death of the infant.

Lupton and Fenwick (2001) in their study examined the ways in which mothers with hospitalised infants construct and practice motherhood. The findings revealed the similarities between mothers and nurses in terms of what constitutes 'good mothering' practices in the neonatal nursery, but they also highlighted the vast differences in these constructions. For mothers the importance of physical contact and breast feeding their infants was emphasised, whereas the nursing staff valued the presence of mothers in the nursery as well as their willingness to learn about their infant's condition and treatment. What emerged from the observations were the power struggles between nurses and mothers which influenced how mothers constructed and practised motherhood. The mothers in this study therefore attempted to construct themselves as 'real mothers' and in time attempted to position themselves as 'experts' concerning their infants. By contrast, the nurses sought to position themselves as teachers and monitors of parents, protectors of the infants and experts by virtue of their clinical training and experience. Disparities in defining the situation thus culminated in frustration, resentment and anger on the part of the mothers and disciplinary and

surveillance actions on the part of the nurses. These power dynamics as Foucauldian scholarship highlight are seldom uni-directional and always fluctuate (Lupton & Fenwick, 2001).

What can be deduced from the above is that the high-risk pregnant experience is embedded in a context of uncertainty and unpredictability which poses many complex challenges to women. The literature above provides some input regarding the key elements in these situations. Not only are the medical aspects important, but so are the maternal perceptions of these factors as well as women's own subjective experiences. What should also be apparent is the lack of focus in some of these discussions, on the HELLP syndrome experience itself. The reason for this may be that it is quite a rare disorder and has not enjoyed much attention regarding the psycho-social aspects, yet what is noteworthy are its devastating consequences. Therefore in reviewing the literature on high-risk pregnancies, one is left wondering how much of what has been established applies to women who have had HELLP syndrome. As previously mentioned, only one study examining the emotional experiences of women could be accessed (Kidner, 2000).

### **3.11. HELLP syndrome experiences**

Kidner (2000) in her study utilised a grounded theory qualitative research design to explore the range of experiences of women who were diagnosed with HELLP syndrome. Three interviews per participant were conducted using semi-structured interviews. The follow-up interviews were used for further clarification and refinement of themes. Nine women participated in this study. The data was analysed using a constant comparative process.

What this study revealed was that HELLP syndrome represented a unique maternal experience for the women that are distinctly different from the experiences of those having other types of high-risk pregnancies reported in the literature (Kidner, 2000). In this sample of women, two women had near-death experiences and three women had newborn deaths. The reported sequelae related to HELLP syndrome included liver rupture, placental abruption, disseminated intravascular coagulopathy, amaurosis, post-partum infection and sepsis.

The findings of the data resulted in 23 themes that culminated in the designing of a model depicting the maternal experience of HELLP syndrome. The common themes expressed were labelled as premonition, pain, betrayal, a whirlwind and loss. The common emotions

were fear, frustration, anger and guilt. Binding the entire experiences together were overwhelming feelings of 'no control' and 'not knowing' (Kidner, 2000).

For the women in Kidner's study, the HELLP syndrome diagnosis led to experiences that have much in common. The experience commenced with a premonition that something was amiss. The quest to find reasons for the symptoms led to a perceived betrayal from trusted others. Ultimately the mother's own body was perceived to have failed to meet her expectations of pregnancy and this in turn resulted in feelings that her pregnant body betrayed her. The actual diagnosis precipitated a whirlwind of activity as attempts were made to save the lives of the mother and the baby. The maternal experience of HELLP syndrome is saturated with a fear of death that does not dissipate with recovery, but remains as a strong determining aspect in the decision whether to attempt future pregnancies. This fear highlights the profound feelings of loss of the 'normal' maternal experience and future pregnancies. The emotions of fear of death, frustration, anger and guilt are enhanced by the whirlwind of medical activities creating situations over which the mother feels she has 'no control' and is 'not knowing'. In concluding her study Kidner (2000) advocates for further research in this area to verify and expand these findings as well as to increase the understanding of the HELLP syndrome experience.

In the final analysis when reviewing the issue of risk, the thread of material and discursive seems to weave its way through, leaving one with the notion that risk cannot be understood only as an objectivity entity, but that its subjective components must also be acknowledged. The way risk is understood at a macro/societal level influences the way it is acknowledged, experienced and practised at a micro-level. In health and medicine, discourses of risk are pervasive and extremely influential. Karen MacKinnon and Majorie McIntyre (2006) cite the work of Cartwright and Thomas (2001) who suggest that childbirth has always been dangerous but when it moved into the hospital setting, "the danger was transformed into biomedically constructed and sanctioned notions of risk" (p218). Furthermore, this new biomedical understanding of risk necessitates that all women be subjected to monitoring by professionals (even in normal pregnancies) and implies that risks can be controlled by prescribed medical intervention.

Discourses surrounding obstetrics have developed in tandem with medical obstetrics. As Foucault (1997) argues, discourses not only constitute new objects such as obstetrical risk, but they also produce subjects. Thus when pregnancy and childbearing are referred to as

risky, both women and healthcare providers are constituted in various ways. Murphy-Lawless (1998, p190) contends that risk exposes a world of relations in which childbearing women are patients:

*There has been and continues to be confusion within obstetrics about risk and its meanings. Often obstetrics has stated with great authority that risk of serious illness and death can be defined precisely, a position that by definition should also entail pinpointing those women not at risk. But just as often and sometimes simultaneously to this first position, obstetrics states that every woman is at risk, an argument which is advanced with the rider that all women must give birth within specialist obstetrics units because of the unpredictability of risk. What is more important about these incongruous and disparate lines of argument is the notion of risk itself and the extent to which this has saturated the thinking around childbirth.*

Risk has therefore been constituted and associated with the need for hospitalisation and obstetrical intervention. New and advanced technologies and interventions have come to signify reduced risks and decreased mortality and morbidity for both the mother and the infant. However, Lee (2003) boldly proclaims that high-risk pregnancy should rather be seen as a consequence, not as a disease, of medical progress. As a Professor of Medicine, Paediatrics and Obstetrics he admits that medical science's view of pregnancy is old-fashioned, even naive – shaped a century ago when the vast number of pregnancies occurred in healthy young adult women and reproductive disaster was the perceived consequence of carelessness and sin (Lee, 2003). Women with serious disease did not survive, were unable to conceive, or were advised not to fall pregnant. Illegal abortions were the order of the day and were treacherous. Maternal mortality and foetal 'wastage' as he calls it were regular occurrences, but were considered an expected misfortune (Lee, 2003). The past century however, witnessed the passionate and relentless pursuit of the safety of the mother and child, liberating women from the perceived cruelty of infertility and diminishing the risks of obstetric calamity. He continues by describing how he raised eyebrows and ire when he asked, "How could such a normal biological event like pregnancy be a disease – an abnormal unhealthy, injurious event?" (p. 53). The answer (he says), is of course located in who gets pregnant. The Centres for Disease Controls (CDC) review in February 2003 showed that in the United States, maternal mortality increases with increasing age and is dramatically increased at all age levels for women of colour or race which is undoubtedly linked to

poverty (Lee, 2003). Lee thus emphatically argues that maternal mortality remains the single most pertinent indicator of development that shows the widest disparities between countries and regions. Poverty is therefore an important determinant of maternal mortality, making it an indicator of inequity. In sum, when trying to understand high-risk pregnancy I would like to argue that it cannot be viewed only in terms of objective factors like age but must also be examined in the context of socio-economic and social conditions.

### **3.12. Conclusion**

In this chapter I have argued that the concept of risk in pregnancy has been utilised to include all pregnancies, which has justified the continuing use of medical interventions. With the construct risk being pervasive in health and medical care-giving it has come to operate as a structuring dynamic that governs healthcare in general and positions pregnant women in very specific ways. With the official introduction of the term ‘high risk’ pregnancy, formalised systems were put in place to calculate risks in pregnancy as well as to determine the ‘causal’ factors that could potentially impact the outcome of pregnancy.

Thus while risk has been conceptualised to include all pregnancies, my thesis focuses on risk in the sense of medical complications where there are tangible risks to both the mother and the baby. As mentioned previously, a large body of scholarship has focused on critiquing the medicalisation of pregnancy. What seems to be lacking in this corpus of knowledge is a critical examination of pregnancies where there are serious threats to the maternal-foetal dyad. More particularly, this area of investigation seems to be invisible in feminist work. This then highlights the need for a study of this nature, where both the everyday experiences of women as well as the discursive constructions of these risks can be given a space for contemplation. In addition, it could open up spaces for examining experiences that may be so disparate in an attempt to move away from the understanding that the only experiences that count are those who are white, middle-class, affluent and heterosexual.

## CHAPTER 4: MOTHERHOOD

*a house without a child is like a garden without a flower, or like a cage without a bird. The love of offspring is one of the strongest instincts implanted in women; there is nothing that will compensate for the want of children. A wife yearns for them; they are as necessary to her happiness as the food she eats and the air she breathes (A doctor, 1911 in Oakley, 1979).*

*Artificial reproduction is not inherently dehumanizing. At the very least, development of the option should make possible an honest re-examination of the ancient value of motherhood... until the decision not to have children or to have them by artificial means is as legitimate as traditional childbearing, women are as good as forced into their female roles (A feminist, 1972 in Oakley, 1979).*

This chapter attempts to unpack the issue of motherhood, given the primacy it occupies in society as well as in many women's lives. As previously mentioned, women with high-risk pregnancies relayed that the uncertainty they experienced related largely to their uncertainty in becoming a mother to their infants (Stainton *et al.*, 1995). Thus motherhood and the way it is constructed become crucial in trying to understand how women make sense of the HELLP syndrome experience, which is the third aim of my study. This chapter will therefore commence with a brief introduction to motherhood, examine the ideologies that underpin motherhood, outline the different feminist understandings of motherhood and highlight a poststructuralist understanding of motherhood which is the focus of my study.

Paula Nicholson (1999) argues that it is the role of motherhood that epitomises femininity. While it is true that women, and only women, have the capacity to bear children, this biological capacity is forevermore translated into psychological and social conventions that prescribe how women's lives should be lived. In patriarchal cultures, motherhood is the vehicle through which women's social value and their oppression, is experienced. Whether or not women become mothers or choose to become mothers, motherhood remains central to all women's lives. In addition, the socially constituted practices which characterise mothering, concurrently define women (Nicholson, 1992).

A woman's decision to become or not become a mother probably has the most profound impact on her life. Choices about childbearing and motherhood are emotionally laden and socially pivotal given their links with sexuality and gender identity. Becoming a mother affects one's attitude towards oneself; it determines others' judgments and very importantly, it

positions women with respect to a fundamental social structure and moral situation, namely, the family (Meyers, 2001). The family as a legal institution plays an important role in endorsing or censuring childbearing decisions. As a perceived haven of affection and sustenance, it delegates distinct tasks and responsibilities to various family members. By virtue of decisions mothers make, they assume a durable moral identity and either incur or renounce various care-giving obligations. In addition, since the family exists in relation to other social systems, motherhood decisions impact on women's extra-domestic ambitions. In other words, maternity often inhibits women's employment opportunities as the economy is structured to advantage employees who are free of care-giving responsibilities. In the final analysis, "a woman's motherhood decision is critical to her personal well-being, definitive of her social persona, and predictive of her economic horizons" (Meyers, 2001, p2).

Carol Long (2009) in her book *Contradicting Maternity* draws on a novel written by Buchi Emecheta and tells the story of an African woman whose chief desire was to be a respected mother. However, her experiences continually demonstrated the bewildering gap between social ideals of motherhood and her everyday realities. The story describes how hard she worked to give all of herself to her children, but found herself constantly facing hardship and blame, with the prize of motherhood always deferred and thus never accomplished. Long (2009) writes that the irony of the story is that this woman, Nnu Ego, managed to experience the joys of motherhood, but failed to live up to expected cultural myths and never imagined that the selflessness of giving all to her children would be so costly and where benefits were virtually non-existent.

In keeping with the material-discursive understanding of reality, how do we write and read motherhood? How do I pay tribute to both these dimensions in writing about motherhood without falling prey to a reductionist account that privileges the experiences above the institutional aspects ingrained in this phenomenon or vice versa? In addition, how do I reflect upon motherhood in my attempts to understand how women make sense of their high-risk HELLP syndrome pregnancies when motherhood for them is at risk and could potentially be lost particularly in pronatalist and patriarchal societies?

Feminist writers have been faithful in their commitment to the notion that individual experience and cultural discourses are interrelated rather than distinct – an idea that has been translated into the slogan 'the personal is political' (Spender, 1985 in Foster, 2005). Moreover, feminist perspectives have been useful in expanding our understanding of the

relationship between experience and culture by shifting our gaze of inquiry from identifying how private/individual and public/cultural dimensions interact to questioning why they intersect in specific ways. More particularly, feminist writers question and critique the assumed and invisible conflation of gender roles, social roles and political power (Foster, 2005) as feminism highlights the recursive tensions between public and private domains wherein public discourses affect private experiences, and private experiences in turn either enter public discourse or are silenced as marginal or minority concerns (Foster, 2005).

Motherhood encapsulates both personal and political dimensions. Motherhood is a component of identity and is also expressed as a specific relationship that is lived in the context of a family and community. However, motherhood is also a social institution loaded with cultural and political meanings (Arendall, 2000; Rich, 1976). Therefore when women are pregnant and their pregnancies are at risk, their desire to have the baby must be understood in the cultural and relational contexts in which this desire arises (Foster, 2005).

Academically, socially and personally, motherhood is often assembled as a function rather than as an experience (Long, 2009) and in disciplines like psychology mothers are held accountable for producing and reproducing healthy offspring (Kruger, 2006). What has been absent from these understandings is the mother as subject. While the last few decades have witnessed a shift in this regard, Kruger (2006) asserts that all psychological research with mothers needs to be cognisant of the powerful ideologies underpinning the institution and hence the experience of motherhood. Many other writers have conceded that the role of mothers in society is saturated with ideological meaning and cultural significance (Braverman, 1989; Glenn, 1994; Kruger, 2006). Consequently, these conventional and persistent dogmas have obscured both complexity and diversity in culture and across historical moments, as well as the individual experiences of motherhood. Thus it is important to examine the ideological underpinnings of motherhood.

#### **4.1. Ideologies underpinning motherhood**

Motherhood seems to be a concept central to the ways in which women perceive themselves as well as how they are defined by others particularly in pronatalist societies. Yet some writers highlight the notion that the era of new reproductive technologies has the capacity to subvert the category mother (Lawler, 2000). However, whatever the potential for alternate constructions of mother/motherhood, hegemonic ideologies persist, powerfully premised on assumptions of biological determinism and the unavoidable destiny of women to become

mothers. Key to these ideologies is the idea that mothering is instinctive and therefore universally experienced and constant (Miller, 2005).

Barbara Katz Rothman (1993) argues that our thinking around motherhood is seriously tainted as we find ourselves surrounded by contradictions. However, in an attempt to understand these contradictions we need to step back. The process of stepping back is likened to the disentangling of a fabric so that one eventually gets to the underlying threads that weave together the tapestry of motherhood. Three deeply rooted ideologies underpin the Western construction of motherhood: an ideology of patriarchy, an ideology of technology and an ideology of capitalism. The term 'ideology' as used in this context refers to a "conceptual system by which a group makes sense and thinks about the world" (Glen, Chang & Forcey, 1994, p.9). In other words ideology organises our thinking about the world and therefore permits us to see things, but can also blind us to our lived realities. The ideologies of patriarchy, technology and capitalism supply us with a vision of motherhood, yet simultaneously obscure this view, and provide us with a language for some things while they silence others (Rothman, 1993).

Patriarchal ideology calls attention to the seed as the foundation for paternity claims. At the outset, the concept of the seed was used to privilege the biological father, but later was extended to biological mothers as donors of the egg. Thus in legal cases, relationships based on seed are privileged over relationships established through nurturance and commitment. The second ideology underpinning motherhood – the capitalist ideology that encourages the extension of ownership or property relation –, acknowledges women's ownership of their own bodies, but fails to recognise their rights or powers as mothers. While Rothman (1993) accepts that the word 'property' is not used when referring to human relations, she asserts that the term 'rights' is used and kept implicit. Central to this mode of thinking is that women are subject to attempts to control their behaviour during pregnancy, on the basis that their bodies may hold babies which belong to other people (as in surrogacy) or in which the state may claim an interest. Finally, the ideology of technology espouses a mind-body dualism which positions pregnant women as unskilled workers, machines, or simply containers for genetic material. In this understanding women's bodies may be utilised to supply the menial physical task of bearing and raising children, while moral authority and control over children's lives continue to be bestowed upon men (or women) who have not partaken in any of this labour (Glenn, 1994; Rothman, 1993).

Rothman (1993) continues her argument by highlighting the deep-seated fears that we have with regard to deconstructing the ideology of motherhood. We fear to unpick this very complex fabric, for the tug at the individual loose strands will amount to us plummeting into some dark void. She provides examples of how confronting any part of the system, results in other parts potentially hampering our way. For example, when we confront technological ideology, fears of the proverbial baby being thrown out with the bathwater is invoked, or fear of impending death lingering at every birth or women confined and held hostage to some insane biology. When we challenge patriarchal understandings of genetic-based parenthood, we hear the echoes of the fears of women of privilege who have established some civil liberties of patriarchy for themselves, often at the expense of other women, especially those of colour.

As mentioned, while the possibility for creating alternate constructions of mother/motherhood remains, these hegemonic ideologies remain a powerful force in shaping expectations. Miller (2005) succinctly affirms that the ideologies framing and moulding motherhood are insidious, dynamic and linked to power. Yet these ideologies fail to acknowledge that women are able to exercise some agency over their situations as they completely supersede individual experience, and they continue to perpetuate idealised notions of motherhood, and consequently lack the capacity to account for the diversity experienced in mothering. However, despite the impossibility of these ideologies, women continue to become mothers and to subscribe to idealised versions of motherhood. In fact women continue to become mothers with very unrealistic expectations (Oakley, 1984).

Based on the ideologies of patriarchy, capitalism and technology, a mandate for mothering has been established which espouses that mothering involves child-rearing methods that are child-centred, expert-guided, labour-intensive, emotionally consuming and financially costly (Hays, 1996). The mother constructed from this mandate is delineated as “ever-bountiful, ever-giving, and self-sacrificing” (Basin, Honey & Kaplan, 1994, p.2). The mother depicted in terms of this mandate is objectified as the individual who is devoted to the care of her children and others, and is “not a subject with her own needs and interests” (Basin *et al.*, 1994, p.2). Moreover, intensive mothering is embedded within idealised notions of the white, middle-class, nuclear family. In this understanding intensive mothering assumes and reinforces the traditional gender-based division of labour. (Hartsock, 1997).

Arendall (1999; 2000) correctly asserts that despite diverse arrangements and cultural practices, the intensive mothering ideology persists. The standard of mothering embedded in this hegemonic discourse, (the mother absorbed in nurturing activities in her biological nuclear family unit), contributes to a variety of deviancy discourse, directed, albeit differentially, at mothers who for various reasons do not comply with the script of full-time motherhood. These deviancy discourses of motherhood vary by race and class. Single mothers, adolescent mothers and welfare mothers are commonly subjects of deviancy discourses (Fineman, 1995; Macleod & Durheim, 2002). White married mothers who are employed have also been viewed as deviant by virtue of their employment (Stacey, 1996). In determining who is deviant and who is not, societal attitudes have been high-handed and uneven, revealing the gaps in the hegemonic ideology of mothering. For example, on one hand deviancy discourses highlight mothers of colour who are unmarried and not in paid employment but dependent on welfare for support; and middle-class white mothers who are employed on the other hand. In the final analysis, setting up intensive mothering in a particular way gives rise to the good mother, and allows those who do not conform or are unable to meet these standards and expectations to be positioned as deviant.

Having examined some the ideologies of motherhood and the motherhood mandate (intensive motherhood) it is evident that motherhood is a social construct for which the meaning is established through the everyday relational context of discourse, rather than through some internal, essentialist identity (Oelsen, 2000). This is the understanding that I argue for in my thesis; however there are many splits in feminist thinking regarding motherhood. Feminist interest in this category stemmed from the realisation of motherhood as a site of patriarchal regulation and control (Marshall & Woollett, 2000). The ensuing section will explore some of these differing views and culminate in the understanding of motherhood for my project.

#### **4.2. Feminism and motherhood**

Maternity has been a real thorn in the flesh for feminism for some time. Opinion seems to be split regarding the importance ascribed to maternity and motherhood. Some are of the opinion that there has been a recent turn to maternity where a number of feminists have sought to address, theorise and give voice to maternity, while others argue that maternity has always been central to feminism from its beginnings. However, it is widely accepted that much of second-wave feminism displayed very negative attitudes towards maternity and this was encapsulated through the writings of influential feminists like Betty Friedan (1963) and

Shulamith Firestone (1970). However, there seem to have been shifts, as more feminists have begun to engage with these issues. For feminists to ignore the issue of motherhood would be foolhardy as Rich (1976) clearly articulates that the institution of motherhood affects all women whether they become biological mothers or not.

I think almost all authors writing under the banner of feminism acknowledge their anxiety in trying to explicate the unfolding of motherhood in feminist theory (Snitow, 1992, Tong, 2007; Walker, 1995). Various authors have also utilised a variety of ways to explain this evolution. Despite the means however, what is important is to gain insight into the changing understandings of the maternal and motherhood.

Arendall (1999) and Walker (1995) contend that mothering and motherhood are the subjects of a rapidly growing body of scholarship and knowledge. However, it was feminists who succeeded in problematising motherhood. Walker (1995) asserts that white, Western feminists have vacillated between attacks on motherhood as a patriarchal construct and affirmations of it as a valuable identity and responsibility that must be protected against male control and masculinist values. Black and third-world feminists have criticised what they regard as the ethnocentrism of much of this debate, while more recently, poststructuralists have subjected the unitary concept of motherhood to a radical deconstruction (Guerrina, 2001).

If one examined feminist thought of motherhood during the early 1960s the work of Friedan and Firestone stand as bastions of women's voices. Motherhood was viewed as one of the primary sources of women's oppression in Western European society. Social representations of motherhood were used as a source as well as an excuse for the gendered division of labour. With regard to women's reproductive bodies and maternity in particular, Beauvoir's writings are extremely negative as she was very ambivalent about mothers, motherhood and pregnancy. Moi (1999) writes that in *The Second Sex* portrayals of a destructive mother imago are rampant. While challenging dualisms on one level, she seems to fall into this very trap by assuming that experiences of pregnancy, childbirth and breastfeeding are rooted in immanence and therefore transcendence cannot be attained. In sum, transcendence for women becomes challenging because of pregnancy and childbearing. According to Beauvoir, the split subjectivity of maternity is neither positive nor empowering, since it is a hindrance to women's freedom (Chadwick, 2006). On the other hand, Shulamith Firestone in the 1970s described pregnancy as 'barbaric' and wrote that 'childbirth hurts' and believed

that liberation strategies should be based on liberation from our bodies , both in fact and in definition (Spelman, 1982).

This era was epitomised by ideas which seemed to voice the opinion that childbearing and motherhood should be rejected. The book *Our Bodies/Ourself*s highlights the hidden dynamics of our alienation from that earlier time. Snitow (1992) says it is only after prolonged reading that the reassurance is offered that, as women, we can be fulfilled and whole without children. This kind of reasoning, she contends, led to a critical self-questioning about motherhood which up until then had been taken for granted (Snitow, 1992). The backlash of this was that many housewives misread these notions as a direct attack on them.

The mid to late 1970s ushered in a period where feminist work of exploring motherhood took off and many feminist books were scripted, both about the daily experience of being a mother and about the far-reaching implications. In 1976 Adrienne Rich wrote her book *Of Woman Born* in which she argues that male control of women's reproduction and women's mothering is the foundational point of patriarchy (Rich, 1976). Furthermore, she asserts that in order to challenge the institution of motherhood one needs a complete understanding of woman's body – of which motherhood is only one dimension. In addition, she calls for women to take back their bodies, which in turn she believed would result in major transformation in society. In the final analysis Rich's account reproduces essential motherhood as the female body once again appears to be conceivable only as a reproductive body (DiQuinzio, 1999). This spinoff is that Rich's theorising was situated in the sex/gender distinction, or more broadly within 'second wave' feminism (Chadwick, 2006).

At the same time French feminism through the works of Helene Cixious and Julia Kristeva started to emerge and became very influential throughout the academy. Moi (1986) asserts that Kristeva has become one of the leading poststructuralist thinkers of the twentieth century, and offers one of the most sophisticated attempts to theorise subjectivity, bodies and language simultaneously. Pivotal to Kristeva's work is the view that no subjectivity exists prior to or outside language. However, 'language' in her understanding does not refer to a separate system of words or meanings, but denotes a signifying process in which both bodily energies (drives) and social constraints are transfused into language and in which the 'speaking subject' both 'makes and unmakes himself' (McAfee, 2004, p 14). For Kristeva a stable, unified essence does not exist prior to any process of signification. The Kristevan subject is therefore a 'subject in process' (Boulous-Walker, 1998).

During that time Nancy Chodorow (1978), also published *The Reproduction of Mothering*. Chodorow argued that women's mothering is central to the sexual division of labour. Women's mothering role profoundly affects women's lives, ideologies about women, sexual inequality and the reproduction of particular forms of labour power. Snitow (1992) therefore claimed that the intellectual work of feminism had its renaissance during those years. Chodorow (1978) and Ruddick (1980) challenged the idea that women were born mothers. According to Snitow (1992), the 1980s to the 1990s symbolised a time when feminists examined what women do when they mother. Sara Ruddick in her article 'maternal thinking' provided a rich description of what she called 'maternal practice' and 'maternal thinking'. Snitow (1992) argued that 'maternal thinking' is the most comprehensive response since Adrienne Rich to the issue on speaking the life of the mother. Ruddick (1980) believed that mothers adopt a nurturing identity as a consequence of the care-giving work they do, rather than as a result of identification via attachment. As mothers interact with their children, they establish deep emotional bonds that influence maternal and connected ways of thinking. This period according to Snitow (1992), particularly in America, was a period of frustration, retrenchment, defeat and sorrow. For example, she quotes the example of a woman who lost a custody battle when she contracted her baby away before the birth. From this episode Phyllis Chesler's *Sacred Bond* was written – the very title Snitow (1992) declared inconceivable a decade earlier.

During the mid-1980s many women started writing about work, careers and motherhood (Gerson, 1985). Also books on abortion were more frequently seen in the public arena. Coupled with the intellectual activity which took place were the activist efforts where women emphasised the right to wait, the right to space one's children, the right to have each child wanted (Snitow, 1992). In addition, divorce rates were escalating and women's participation in the workplace was increasing – resulting in struggles around day care, child support, fair enough custody arrangements and no reliable support from men. At the same time many feminists were writing about the importance of their babies and how nothing else seemed comparable to those experiences. Snitow (1992) attributed this period to the fact that she believed women were heartbroken. She laments that since 1980, with whatever its excesses or limitation, feels long gone. The continued project of elaborating the culture of motherhood at this stage omitted the negative side of the mother's story – her oppression, anger, regrets and disappointments. This period therefore seemed to symbolise a stage where the heroism of women pertained to raising children alone, being poor, or normally both were praised.

Nurturance as an ethic seemed to be embraced, and the hope was always there that men would share this ethic. Complaints which were expressed sounded almost outrageous, even to feminists themselves.

The 1990s ushered in a period of poststructuralist analysis with the intention of expanding feminist investigations concerning motherhood (Guerrina, 2001). In these understandings mothering and motherhood are construed as the outcomes of dynamic social interactions and relationships (Arendall, 1999; 2000; Guerrina, 2001). Instead of mothering definitions and practices being viewed as natural, universal and unchanging (Glenn, 1994) they are understood to be contextually, historically located and variable.

#### **4.2.1. Feminist poststructuralism and motherhood**

Poststructural feminism conceptualises gender, gender roles and gender divisions of labour as the products of their social, economic and political frameworks. Therefore motherhood and maternity are viewed in a similar fashion: as the product of the same social structures that define the concept 'woman' resulting in meanings of motherhood and maternity being multiple, variable and changing. This understanding of motherhood compels feminists who subscribe to this worldview to shift their focus to the critical analysis of values surrounding the social and biological functions of reproduction which construct the concept of 'woman' (Guerrina, 2001).

Guerrina (2001) claims that if we accept that the concept of 'woman' is a contested site of meaning, then the logical outflow of this position is that the association between the social and the biological function of reproduction which is embedded in the concept of motherhood, must also be contested. Motherhood and maternity are then the result of gender relations, rather than a universal and unifying experience for women (Apple & Gordon, 1997). While some women experience some biological similarities throughout pregnancy and maternity, it would be foolhardy to believe that these commonalities define the essence of motherhood either in the private or public sphere.

In addition poststructuralist analysis questions the assumption that social structures have an equal impact on all women and mothers in diverse contexts. Instead, poststructural feminists argue that differences due to class, race, sexual orientation, ethnic background and so forth, shape women's interpretations of their experiences. Basing their analysis of the deconstruction of oppressive forces in society, poststructuralist feminists introduce the fusion

of the private and the public spheres, hence making all mothers of all types the subject of comprehensive debate (Ross, 1995).

In framing motherhood as dynamic and shaped by prevailing social structures and context, the assumption is that motherhood is an ongoing process that is negotiated and re-negotiated by both mothers and their support systems (Henderson, Harmon & Houser, 2010). Recent literature exposes how mothers' support systems including 'fellow moms' serve as powerful sources of pressure. For example Jackson and Mannix (2004) discuss mother-blame as ever present and impacting powerfully on their feelings of adequacy and self-worth in formal healthcare structures. However, Henderson *et al.*, (2010) contend that this social pressure is far more pervasive and is exercised by fellow moms. The concept they utilise to explain this phenomenon is 'new momism'. Thus their analysis of new momism invokes a Foucauldian understanding of motherhood.

#### **4.2.2. Foucault and motherhood**

The concepts of the panoptic and surveillance, Douglas and Michaels (2004) argue, could be utilised in understanding new momism. It is something taken so for granted that many women do not question any longer that mothers are constantly subjected to the pressure of being monitored by others in both formal and informal settings. In the formal sphere, professionals in education, medicine and the psy-professions serve as agents of social control. These sources highlighted are formal in the sense that they have 'legitimacy' as objective sources of information on how parents should rear their children. These texts are distributed uniformly to all parents and are readily accessible via the media (Henderson *et al.*, 2010). The pressure to conform and be perfect usually emanates from a combination of sources like teachers, or the healthcare system in the form of pediatricians. For example, pediatricians evaluate development according to certain norms and standards which they use to assess children's development. Children are ranked in terms of their physical growth, and are grouped into percentiles with regard to how they compare physically to other children their age. If a child weighs significantly less, parents are instructed what to do to correct the situation. While these measures may not be perceived to be harsh, they nonetheless alert parents to be on their guard, instilling the idea that they are constantly being watched by an external authoritative figure (Henderson *et al.*, 2010). Henderson *et al.*, suggest that, as in Foucault's exposition of prisoners where they internalise the gaze of the warden, so parents internalise the gaze of authoritative figures.

Because of these formalised seemingly objective standards for mothering, coupled with fear-based messages from the media, mothers begin to behave as if on constant guard. In short, the surveillance is internalised and mothers begin to be critical of not only themselves but of other mothers as well (Henderson *et al.*, 2010). In addition, their judgments are based on formal guidelines for parenting behaviours and child development, but often they are arbitrarily based on fear and ‘mother know best’ practice (Henderson *et al.*, 2010, p. 236).

Motherhood understood in this way therefore takes on understandings of power which according to Foucault are everywhere, yet nowhere; as well as mechanisms of surveillance which are internalised and thus become a form of patrolling the self. Not only in raising children, but in pregnancy, these forms of power play themselves out in very particular ways where women take full responsibility for everything that happens to them and carry the weight of that responsibility. As van Pampus *et al.*, (1998) noted, the burden of a high-risk pregnancy when there are real threats to the mother and baby, is indeed a heavy weight to bear. Therefore having established that motherhood is not unitary, singular or universal, how does one begin to understand how and why mothers themselves position themselves in particular ways? Perhaps one way of facilitating this understanding is to deconstruct motherhood, as this certainly will give a sense of how some women with medically complicated pregnancies may position themselves and make sense of their experiences in becoming mothers.

### **4.3. Deconstructing motherhood**

Authors such as Arendall (2000) and Long (2009) seem to approach motherhood from both discursive and experiential perspectives. Arendall (2000) refers to the latter as the ‘phenomenology of mothering’, while Long (2009) draws on psychodynamic theorising when addressing the experiences of motherhood. However, what is important with regard to motherhood is succinctly expressed in a quote by psychoanalyst (Schwartz, 1994, p.253)

*If we could transcend our tremendous resistance to altering the traditional representations of motherhood based on our collective anger, envy, idealization, and objectification of our female mothers, then we might begin to ask some historically germane and potentially more interesting questions about being and experiencing motherhood.*

In her analysis of motherhood, Rich (1976) differentiates between the experience and the institution of motherhood – and describes the social representation of pregnancy as “a woman pregnant as a calm woman, calm in her fulfillment, or, simply a woman waiting” (Rich, 1976, p39). Binary oppositions espousing mother as Madonna and whore (Wellton, 1988), serve to position motherhood as a state of purity and as Rich argues, valorise passivity. Ideal mothering is therefore set up as infinitely loving, serenely healing and emotionally rewarding (O’ Barr, Pope & Wyer, 1990, p14). The good mother is portrayed as happy in her tasks, and expecting no rewards.

The difficulty with the ideal is that standards are set which are difficult to attain. Hegemonic constructions of motherhood accept the biological capacity of women to bear children as the zenith of female experience (Glenn, 1994) and classify the tasks and experience of motherhood in normative ways (Phoenix & Woollett, 1991b). Deconstructing motherhood encompasses a refutation of singular truths, and instead highlights the practices and definitions that are understood to be historically located and mutable.

As mentioned previously, feminist interest in this category stemmed from the realisation of motherhood as a site of patriarchal regulation and control (Marshall & Woollett, 2000). These arguments highlight how maternal idealisation orders female experience to patriarchal advantage (Long, 2009) as the status quo is maintained, motherhood is rigidly mapped out as female territory. O Barr, *et.al.*, (1990) argue that by constructing motherhood as biological, moral and timeless, patriarchal society is relieved of its duty to make “material, political and temporal arrangements to assist it” (p.3). The implication of this is that the idealisations of motherhood are both active, constructing good mothers (actively exercising power over the arena of motherhood) and passive, asserting power by delineating the responsibilities of mother in naturalised terms (Long, 2009).

A major shortcoming of theories examining patriarchal power is that they address the general ramifications of maternal idealisation for the institution of motherhood, but only touch on the consequences for maternal subjective experiences. In this regard, it is beneficial to examine not only what power does, but what it masks. In other words, what are the implications for women whose pregnancies and hence motherhood itself is at risk or may be deferred? The pervasiveness of idealisation has resulted in motherhood being an unsurpassed defining identity, and that the equality of motherhood with womanhood implies that mothers are constructed singularly, and therefore cease to be anything else (Richardson, 1993).

Walsch (2007) asserts that something only exists and is able to operate when the opposite of that quality is identified. Thus idealisations can only operate if there is a corresponding denigration (Long, 2009). Warner (1976) states that these kinds of representations are presented powerfully in Christianity through the characters of the virgin Mary and the evil temptress symbolised by Eve in the garden of Eden. These figures, Warner (1985) argues, provide fantasies of motherhood as well as commands and warnings. The denigration of mothers is also often depicted in films. For example Long (2009) draws on the *Alien* films depicting the repulsive mother whose maternal instinct destroys and devours, threatening to devour society itself, and constantly serving as a reminder how precarious mothers can be. While the idealised and denigrated mothers may be polarised in fantasy, their existence implies ambiguity and sets motherhood up as potentially both creative and destructive. These constructions of motherhood thus set up binaries. Long (2009) thus suggests that while motherhood is idealised, women themselves are often denigrated. These binaries therefore operate in two ways: first, they categorise mothers as ‘normal’ or deviant; and second, they function to discipline women through a set of technologies such as childcare manuals that constantly serve to remind mothers of the ever-possible risk of failing and therefore becoming ‘bad’ mothers.

Constructions of motherhood also encompass both an exercise of power and a process of exclusion of identity. Pope et.al (1990) therefore argues that the experience of motherhood is symbolised by ‘relegation to silence, erasure and loss of subjectivity (p.4). Glenn (1994) correctly asserts that discourses of motherhood as a labour of love serve to obscure the workings of power. Oakley further elaborates that the major loss associated with the experiences of motherhood results in a loss of identity and that dominant and individualised discourses alienate women, limiting their ability to seek alternatives or to resist hegemonic constructions of maternal ‘normality’ (Long, 2009). Given the precarious position women find themselves in, it is important to examine how women come to understand and make sense of their experiences of becoming mothers and motherhood. This understanding should then shed some light on the treacherous paths that women with high-risk pregnancies may need to traverse to negotiate what it means to become a mother. It also important to examine the context in which motherhood occurs. The ensuing section will explore motherhood in South Africa.

#### **4.4. Motherhood in South Africa**

The contexts in which mothering in South Africa occurs are inevitably bound to race, social class, age and socio-cultural position and consequently are diverse and fragmented. Walker (1995) and Long (2009) argue that probably the most defining characteristic of South African society is diversity. South Africa is informed by both past and present, is both urban and rural, is both developing and developed, rich and poor (Long, 2009). South African mothers thus draw upon a wide range of cultural practices. Both Walker (1995) and Long (2009) focus on African motherhood in their work, as these women represent the majority of the participants in their projects. However in my study, women across the colour and race spectrum participated. Hence this will be a more general discussion of motherhood in South Africa.

I agree with Long (2009) who asserts that attempting to delineate South African motherhood entails highlighting the impact of mothering ideologies, deriving from both Western and African contexts and developing in relation to both, but simultaneously maintaining very context-specific constructions of mothers. For example there are many similarities in how women understand their roles and what they aspire to irrespective of their class positions. This was clear in studies conducted by both Youngelson (2006) with women on farms and Jeannes and Shefer with white middle-class women, where they all aspired to notions of the 'good' mother and ascribed to the mandate of intensive mothering. What is evident in the literature on motherhood is that very little research has been conducted and published (Kruger, 2006). The perspectives of women themselves in this area are sparse, and the few studies that have been conducted seemed once again to perpetuate the white, middle-class stream of research (Daniels, 2004; Frizelle & Hayes, 1999; Jeannes & Shefer, 2004; Kruger, 2003; Lesch & Kruger, 2005).

Walker (1995) highlights those historical studies on motherhood that focused on the period from colonialism onwards. What some of these studies demonstrate is that cultural practices and beliefs were changed by colonialism, because of the fusion of Christian and traditional belief systems. While traditional beliefs and practices remain pivotal, the content of these belief systems were altered in relation to competing beliefs and historical change. Walker (1995) suggests that African notions of motherhood were influenced by colonialism, urbanisation and westernisation. Furthermore Walker (1995) argues that historical analysis demonstrates that Christian notions of motherhood dominated in the mid-twentieth century.

The apartheid era also bore witness to a fusion of both western and traditional formulations of motherhood. Motherhood was idealised on both sides of the apartheid struggle. On one hand, the volksmoeder ('mother of the nation') was hallowed and responsible for producing and maintaining Afrikaner culture. On the other hand, African women mobilised themselves politically around their identities as mothers (Walker, 1995). What is interesting is that motherhood was considered critical to the political struggle for both black and white women; however black women were portrayed as revolutionary, activist and strong. White women were portrayed as more passive and home-bound.

Motherhood was not only a key site of identity struggle during the apartheid era, it was also profoundly affected by it. The government at that time was ruthless in its vigilance of maintaining separate development and monitoring movement. Due to the homeland system young men were compelled to leave home to seek work, leaving women to care for the family (Duncan & Rock, 1997). Thus while traditional values continued to guide what mothers did, female-headed households increased, adding to the burdens of mothers (Pick & Obermeyer, 1996).

Despite historical changes and increasing diversity, motherhood in African communities still remains a central and defining identity. Walker (1995) comments that 'mother' and 'woman' are often used interchangeably and the word 'mother' is both a descriptor and a compliment. Lewis (1999) writes that for black South African women, the title 'mother' has little bearing on an individual's experiences, but rather becomes a validating term that embodies the essence of their social standing. Not only in black communities, but across the race and class spectrum in South Africa, motherhood is deemed important and is idealised, but also holds ramifications for the deviant. Dyer (1999) describes South African women's fears and the stigmatisation when women are unable to bear their own biological children. Thus the inability to bear and have children places women under tremendous pressure and this in all likelihood is exacerbated for women whose pregnancies are at risk. Studies in South Africa on infertility in particular have demonstrated the extremes and desperate measures women will employ to ensure that they have a child (Pedro, 2012). Having sketched the context of motherhood in South Africa I will examine how women become mothers in dynamic contexts of healthcare and social relations in general.

In her book *Making sense of Motherhood*, Tina Miller (2005) describes the time period we reside in as 'late modernity' and argues that it is characterised by swift change and

unparalleled uncertainty. Since transformations are occurring at an unprecedented rate and old customs and traditions no longer provide the stability or solidity they previously did, this has resulted in increased perceptions of risk. This heightened sense of risk makes individuals more dependent on expert bodies of knowledge and knowledge claims and it simultaneously compels individuals to explore personal and social change more reflexively. She notes that this most likely results in trust being placed in expert bodies of knowledge and in ‘experts’ themselves.

How this plays itself out with regard to reproduction, childbearing and mothering is that women who become mothers may continually pursue and prioritise what they regard as expert knowledge. The expectations of women who become mothers are continually shaped by and through systems of authoritative knowledge as they navigate the ‘risky’ and morally loaded path to ‘responsible’ motherhood. Thus, avoiding risk and being seen as responsible during pregnancy, childbirth and motherhood means continually being reliant on expert knowledge. To avoid such engagement, for example avoiding screening tests, clinic visits and expert advice, would be seen as totally irresponsible behaviour. In the final analysis, such deviant behaviour would be seen as endangering not only the mother’s health, but more importantly that of the foetus she is bearing. For women in Western cultures the transition to motherhood therefore is experienced in a context of professional, expert and self-management (Miller, 2005).

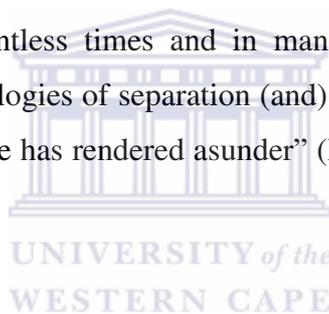
#### **4.5. Normative mothering practices**

Pregnant women in Western societies are bombarded with a range of ideas about pregnancy, childbirth and childrearing (Phoenix & Woollett, 1991). Preparing for motherhood is situated within very developed systems of preventative antenatal care, clearly rooted in the biomedical model, namely the clinic and the hospital (Miller, 2007; Oakley, 1992). For many women the hospital is considered the natural place to give birth (Treichler, 1990) and this general approval highlights both the dynamic qualities and power of authoritative knowledge (Miller, 2005; Miller, 2007).

Prior to the birth of a child, women are defined in relation to notions of ‘good’ mothering. The preparation period entails many activities including attending antenatal classes, wearing appropriate clothing, eating correctly, appropriate exercise and attending parent-craft classes (Miller, 2005). The post-birth period however is less clearly defined and developed and is located more in the clinic setting, and in accordance with essentialist ideas of mothering.

While medical regulation and supervision dominates the antenatal period, medical gaze rapidly shifts from the mother to the baby during the postnatal period. Implicit and coupled with this gaze is the processes of self-surveillance. Miller (2005) noted that during this period women evaluated themselves against others in a hazy context where ‘normal’ mothering is not clearly articulated but potently reinforces expectations.

The postnatal period heralds the end of intense supervision and a sense of joint responsibility. In addition, women are now expected to intuitively know what it means to be a mother, despite the fact that all other knowledge had to be suppressed in favour of medical knowledge. It is at this stage that things come undone for many women as the experience of becoming a mother may not match the expectations which they may have had. This chasm between dominant ways of knowing in the antenatal period, which strengthen particular notions of good mothering, and women’s own understanding, can be construed as potentially disempowering, particularly when women have been alienated from their own feelings and knowledge. Written about countless times and in many ways, “the history of Western obstetrics is the history of technologies of separation (and) it is very hard to conceptually put back together that which medicine has rendered asunder” (Rothman in Davis-Floyd & Davis, 1997. P315).



#### **4.6. Voicing subjectivity**

In the preceding sections, I examined some of the social and discursive aspects of motherhood. However, the invisibility of motherhood needs to be unpacked (Long, 2009). Terry Arendell (2000) in her decade review of motherhood points to the gaps between the ideologies of mothering and motherhood and the experiences of women. She argues that the mothering experience is saturated with dialectical tensions. For example, mothering can both empower and disempower due to the tremendous responsibility placed on women. She cites Ross (1995) when exploring mothering as potentially joyful, growth-promoting and personally fulfilling on one hand, and distressing, anxiety provoking and depressing on the other. Child-rearing therefore may usher in feelings of liberation and transformation, but also of oppression and subordination. Mothering therefore cannot be construed as a singular experience nor is it experienced in the same way by all women. As has commonly been cited, mothering carries multiple, contradictory and often shifting meanings (Long, 2009).

In an attempt to foreground women’s voices and experiences, the women’s liberation movement of the 1960s and 1970s as well as feminist psychologists, petitioned psychology to

examine mothering from the perspective of mothers themselves. This mandate ushered in novel ways of exploring what mothering means to women themselves and provided fresh evidence of how women experience being mothers (Kruger, 2006). At this juncture, mothering was examined as a role or an identity that profoundly shapes and effects women's lives in very specific ways (Bailey, 1999; Smith; 1994; Snitow, 1992).

The 1970s in particular witnessed an explosion of research interest in women's experience of and transition to motherhood on account of feminist debates concerning the complex issue of motherhood (Snitow, 1992). This was the era in which myths surrounding motherhood were exposed, and women started to reveal the very dark side of motherhood. What seemed to compound the issue was the compartmentalised way in which motherhood was studied. Arendall (2000) argues that those who largely theorise and those who primarily engage in empirical work remain very separate, with mutual conversation virtually non-existent. A similar kind of tension seems to exist in 'feminist' versus 'non-feminist' work where researchers are simply interested in examining the transition to motherhood without exploring its political ramifications.

As previously mentioned, early research on the transition to motherhood was underpinned by the assumption that pregnancy and motherhood represents a series of developmental tasks (implicitly 'feminine' tasks) which imply that women either succeed or fail at adjusting to the demands of motherhood (and by implication, womanhood and 'femininity'). For example, Reva Rubin (1976) examined the maternal tasks in pregnancy. Another study conducted by Leifer (1977) revealed that certain characteristics detected during pregnancy seemed to be predictive of subsequent adjustment and adaptation to motherhood. Thus, early attachment to the foetus during pregnancy was highly correlated with the development of more intense maternal feelings and emotional attachment to the baby afterbirth. In addition, there seemed to be a strong association between maternal abilities during pregnancy and feelings of competency in mothering abilities by the second month postpartum. What Leifer's study therefore seemed to highlight was the importance of understanding that the experience and process of pregnancy was an important component in the transition to motherhood (a component often overlooked by many studies).

Also related to studying the transition to motherhood, a group of nursing professionals studied and documented women's adjustment to motherhood through 'maternal role attainment'. The leading scholars in this field were Rubin (1967a; 1967b) and Mercer (1985;

1986). For Rubin a number of cognitive-behavioural tasks programmed to occur during pregnancy are regarded as critical in the development of maternal role attainment. Mercer on the other hand, defined maternal role attachment as attachment, competency, and pleasure and gratification in the mothering role. The work of these scholars then set the stage for a number of researchers wanting to explore how various factors either facilitate or hinder maternal role adjustment (see Majewski, 1986, Walker, Crain & Thompson, 1986a, 1986b; Fowles, 1996, 1998a).

Other studies examining women's adjustment to motherhood examined marital satisfaction (Belsky, 1985, Belsky & Pensky, 1988), postnatal depression (Nicholson, 1998, 1999a), maternal attitudes, maternal competence, attachment to the infant and perceptions of the infant (for example, see Leifer, 1977; Fleming, Flett, Ruble & Shaul, 1988; Levy-Shiff et al., 2002). As with all quantitative measures, studies claiming to measure almost any dimension of mothering, always run the risk of not necessarily measuring the same construct. This makes comparisons difficult and it is equally difficult to develop a clear understanding of what it means for women to adjust to motherhood. A further contention with this line of research is that women's subjective voices, struggles, negotiations and resistances are potentially lost.

Smith (1992) argues that what is lost in this process is the prospect of discovering how any particular woman is responding to the experience of pregnancy and becoming a mother. Therefore in these types of studies, the woman is 'disembodied' or 'de-individualised' appearing only as part of a statistical average (p176).

Taking women's subjectivity seriously is one of the key features of feminist research, particularly in the area of motherhood. The pioneering work of Ann Oakley (1979; 1980), continues to occupy centre stage in the field as it was very successful in integrating an analysis of birth and the transition to motherhood. Central to her work (and later feminist work) is that the passageway to motherhood is challenging and problematic for the majority of women, not because of any inherent dysfunction, but because of the ideology of intensive mothering (Lee, 1997; Nicolson, 1998; 1999a; Rich, 1976). In alignment with feminist thinking, feminist work in this domain has prioritised women's own accounts. This corpus of knowledge has endeavoured to explore the dynamics, contradictions and inter-discourse between the lived experiences of mothering and the ideology of motherhood, through the use

of qualitative methods largely drawing on individual interviews. Based on this work writers like Nicolson (1999b) asserted that mothering is not automatic and has to be learnt. Therefore becoming a mother in Western society is experienced as an overwhelming redefinition of identity and involves complex issues of loss (financial, bodily and practical control, time and independence), isolation, realising the stark realities of motherhood which encompasses complete responsibility for a helpless infant, processing these realities and learning to cope (Lewis & Nicolson, 1998; Fox, 2001; Bailey, 2000).

The pertinent issue surfacing across this feminist literature is that becoming a mother involves profound changes to the selves and identities of women. What remains contested is the form and intensity of these changes and not many researchers have prioritised the issue of change in their investigation and analyses. Two researchers who have, however, explored these issues are Lucy Bailey (1999; 2000; 2001) and Jonathan Smith (1994). Bailey explored the transition to motherhood within the parameters of self-identity change and focused on the discursive construction of self, motherhood and gendered corporeality. In her 1999 study Bailey found a newly gendered identity is experienced as the pregnancy progressed accompanied by a distinct opportunity for discursive change. Women in her study viewed pregnancy as an absolute confirmation of 'womanness' and all felt that it improved their sense of self-worth. What was also deemed as positive by women was the fact that they felt exempt from feminine norms of slenderness (Bailey, 2001). The ambiguity that the women felt during this time related to their perception that they were erased as sexual beings and alienated from the sexual aspects of womanness. What was interesting in this study was that women did not construct their identities as changed, but rather as refracted. Bailey (1999) asserts that the changes women experienced did not constitute a new sense of self, or result in a fragmentation of multiple selves, but they seemed to constitute different elements of a refracted self. She describes this as analogous to the previously hidden spectrum of the rainbow of which women were now made conscious of (Bailey, 1999).

Jonathan Smith (1992; 1994, 1999) also explored the transition to motherhood from the perspective of identity change, but he prioritised individual experiences rather than discursive constructions. What Smith (1994) focused on was the idea of self-reconstruction and compares real-time accounts to retrospective accounts of the transition to motherhood. What he found was that the retrospective accounts differed quite dramatically in that the positive aspects were exaggerated and the negative ones downplayed; there seemed to be a definite

progressive narrative alluding to self-development and improvement and thus negating earlier suggestions of decline and divergence and there seemed to be a reconstruction of order and continuity, thereby undermining change. These findings seem perfectly aligned with theoretical frameworks that assume the self to be related to narrative accounts of continuity, progression and cohesion (Gergen & Gergen, 1983).

While it is now widely accepted that becoming a mother involves profound changes to the identities of women, it has also been noted that there are huge discrepancies between women's expectations of having a child and the ultimate reality they experience. Ann Oakley's research (1979; 1980) is instrumental in this regard as she argues that it is the cultural idealisation of motherhood that sets up this discrepancy for women. The paucity of research directed at examining the relationship between expectations of birth and motherhood can largely be attributed to the difficulties in defining the constructs themselves (for example, what is meant by 'expectations') and hence impacts on the measurement and conclusions regarding these issues. A cursory glance at the literature revealed that the construct 'expectations' has been defined in different ways and rather loosely. For example, some researchers proposed the use of terms such as hope-casts or fear-casts instead of the word 'expectations' which they believed had an ambiguous and unclear meaning (Micheli & Castelfranchi, 2002). Others have used the word to refer to how women would prepare mentally in terms of anticipating what could emerge during the first few months following the birth of the infant. Thus what seems to emerge from some of the studies conducted quantitatively is the difficulty in defining some of these complex constructs and then drawing valid conclusions about women's behaviours, thoughts and emotions.

What is interesting across this body of knowledge is the lack of studies addressing issues of race and class. Most of the studies were conducted with middle-class white women, while similar studies with women from more disadvantaged backgrounds are visibly absent. This issue becomes important particularly in the South African context where issues of race and class are central to understanding and making sense of women's lives. In the same breath it is important to note that in the South African context, studies on motherhood in general are few and far between. Examples of some of this work include postpartum depression and its relationship to maternal adjustment (Hargovan, 1994; Lacock, 1992; Sheldon, 1992); teenage pregnancy and motherhood (Carolissen, 1993; Erasmus, 1990; Macleod, 1999b; Makhetha, 1996; Moses-Europa, 2006; Preston-Whyte & Allen, 1992; Preston Whyte & Zondi, 1992);

and discourses of motruger, 2006; Youngelson, 2006). With regard to the experience of high-risk pregnancies and motherhood, virtually no previous studies could be accessed. This topic seems absent and non-existent in the South African context.

Thus far the literature reviewed has focused on the discursive construction of motherhood and experiences of motherhood when women have had healthy uncomplicated pregnancies with healthy full-term babies. However, not all pregnancies turn out 'normal' and not all babies are born fullterm. As previously mentioned, many women end up with high-risk pregnancies and consequently with pre-term babies. In the case of premature births and infant hospitalisation, women are compelled to practise motherhood in a context in which there are significant constraints in terms of how they interact with their newborn. When women are hospitalised due to problems in their pregnancies, or their infants are hospitalised, it has major implications for how women see themselves as mothers and how they construct and identify with notions of the 'good mother' (Lupton & Fenwick, 2001).

In a study conducted by Wereszak, *et al.*, (1997) mothers of prematurely born infants were invited to participate in a study where they had to retrospectively recall their responses to their infants' hospitalisation in the neonatal intensive care unit (NICU). Forty-four mothers were interviewed as part of the longitudinal study. Three years after the birth of their infants, mothers vividly recalled memories of stress pertaining to the appearance of their neonates, the pain and procedures the infants had to endure, changes in their role as parents, and severe stress related to the severity of the illness as well as uncertainty about the outcomes. Thus hospitalisation of premature babies definitely takes its toll upon mothers.

Lupton and Fenwick (2001) embarked on a similar study, but focused more on the practice and construction of motherhood in this context. The findings of this study revealed the similarities as well differences between mothers and nursing staff about what constitutes a 'good mother' in the context of the NICU. As previously noted, there were fundamental differences between mothers and nursing staff regarding what is considered to be beneficial for their infants. Power struggles between the nurses and mothers were visible and this had implications for how the mothers constructed and practiced motherhood. Establishing connections with their infants and normalising the situation for themselves seemed to provide a sense that they were 'real' mothers. Over time, many of these mothers positioned themselves as 'experts' on their infants. Nurses on the other hand attempted to position themselves as 'teachers and monitors' of the mothers, 'protectors of the infants and 'experts'

by virtue of their training. Lupton and Fenwick (2001) observed how the differential way in which the situation was defined resulted in absolute frustration, resentment and anger on the part of mothers and disciplinary and surveillance actions (both covert and overt) on the part of many nurses.

This study highlights some of the difficulties that mothers with medically complicated pregnancies experience in becoming a mother to their infants. The medical context, with its hierarchical structures and asymmetrical power dynamics make it a challenging environment for mothers. However, Foucauldian scholarship has revealed that power dynamics are seldom uni-directional. This was certainly observed in Lupton and Fenwick's 2001 study where many of the mothers made subtle or overt attempts to exert greater control and to resist the nurses' attempts to control the situation.

Having reviewed the literature on high-risk pregnancy and motherhood it is evident that those situations present many challenges for women. The uncertainty which the situation holds for many mothers creates tremendous anxiety and often results in frustration, anger and resentment. While most of the literature presented pertains to high-risk pregnancies in general, only one study published focused on HELLP syndrome pregnancies. Based on the literature it seems apparent that there are many similarities in women's experiences of their HELLP syndrome pregnancies; but what stood out was the pervasiveness of the fear of death and dying and understandably so because it is a condition potentially fatal to mother and baby.

Researching HELLP syndrome and the meaning-making process contains its own challenges in terms of the complexity of the illness, pregnancy and motherhood. As outlined, these issues hold a multiplicity of meanings for women particularly because of the diverse social positions women occupy. As I have argued the category 'woman' has to be understood as multiple, fragmented and non-unitary. Unpacking this in a feminist-postmodern epistemology drawing on qualitative methods allows for theorising these complexities. However while there is no unitary, singular feminist method or methodology (Banister, Burman, Parker & Tindall, 1994), feminist researchers have been influential in challenging positivist masculinist research agendas. Therefore while there are many differing viewpoints regarding what qualifies as 'feminist research', the commitment to interrogating the social and subjective locations in which research is embedded remains common to many feminist research directives (Lather, 1993, Stanley & Wise, 1990; 1993). In the final analysis feminist

researchers are encouraged to recognise the researched as subjects and not merely objects, submit themselves to equal scrutiny required of the research process, and acknowledge that their research is not a representation of some reality but a motivated construction available for further scrutiny and analysis (Stanley & Wise, 1993). Based on the above comments, I will attempt to plot the process as it unfolded in this project.



## CHAPTER 5: METHODOLOGY

This chapter represents an account of my journey in and through the research process. These accounts are often relayed as singular, linear and very neatly ordered. My experience demonstrates the contrary. The process of research as I have come to understand it is filled with uncertainties, ambiguities and unknowns, particularly in the area of qualitative research. I was not only taken into very unfamiliar physical locations, but also had to traverse uncharted waters within myself. This journey was as much about my participants as it was about me. This chapter therefore details a process of my travels into the complex, difficult and often chaotic area of high-risk pregnancy.

This chapter also signals the beginning of the telling of a story. Denzin and Lincoln (2000, p.3) assert that qualitative research “is a situated activity that locates the observer in the world”. Qualitative research consists of a set of interpretative material practices that serve to attempt to render the world visible. These practices are considered to impact on and hopefully contribute towards social transformation.

The question for me that emerges therefore is what does representing the story mean in my project? Is representation possible at all? In this regard the guidelines of Denzin and Lincoln (2003) and Glesne (2006) become important. Firstly, the research tale cannot be considered in isolation from the teller; secondly, it is imperative that the researcher considers the contextual and value-laden nature of language; and thirdly, it needs to be acknowledged that all textual representations are in a sense ‘fictitious’ and therefore no true ‘re-presentation’ exists (Glesne, 2006, p.193). These ideas in essence also synchronise with poststructuralist thinking, the paradigm in which my project is embedded. Therefore in telling my story I explicitly acknowledge that this is but one story told from one perspective, namely a material discursive perspective that acknowledges also my own centrality as the one who relays the story.

### **5.1. Feminist perspectives on locating knowledge**

The need to identify a unitary feminist methodology has long been abandoned (Reinhartz, 1992; Stanley & Wise, 1993). Feminists therefore claim no single standard of methodological correctness or feminist way to conduct research, nor do they consider it a necessity to do so (Banister, et al., 1994; Reinhartz, 1992). Many feminist researchers use the metaphor of a journey to express their research, or view it as an archaeological dig, that utilises various methods or tools appropriate to the task at hand (Reinhartz, 1992). In stark

contrast to the positivist scientific approach, feminist knowledge-building is an on-going process that is tentative, fluid and emergent. More often than not, feminist knowledge-building is described as emerging through conversation with texts, research subjects, or data (Reinharz, 1992).

The term 'epistemological perspective' encapsulates the research goals and orientation of a project, the aim of which is to challenge and rethink exactly what constitutes 'knowledge'. Rather than aiming to convince fellow scholars through research, many feminist researchers emphasise the challenge to and estrangement from traditional knowledge construction because of being simultaneously inside and outside one's discipline. Feminist knowledge is therefore borne out of deep scepticism about 'universal' knowledge claims, which in reality are premised on men's lives (Letherby, 2003; Tincker, 2005).

The overarching goal of feminist research is to transform conventional frameworks and the knowledge to which they contribute. Feminist inquiry is a dialectical process, which entails listening to participants and understanding how the subjective meanings they attach to their lived experiences may conform to or be at odds with meanings internalised from society in general (Tincker, 2005). Feminist scholarship is both trans-disciplinary and explicitly political. With its agenda being social change and justice it has sought to unpack unequal gender hierarchies, as well as other hierarchies of power, and their impact on the subordination of women and other disempowered people (Tinker, 2005).

Tinker (2005) concludes there are four methodological guidelines that inform feminist research perspectives: a contemplative concern regarding the research questions asked and why they are asked; the aim of designing research that is useful to women (and also to men) and is both less biased and more universal than traditional research; the centrality of questions of reflexivity and the subjectivity of the researcher; and a commitment to knowledge as emancipation. While these guidelines may not be unique to feminism, what is unique is a commitment to asking gendered questions and building knowledge from women's lives which feminists believe has the potential to transform existing knowledge frameworks. (Fonow & Cook, 1991; Harding, 1987).

Since my project is couched in a feminist poststructural epistemology, I wish to forward the argument of Ros Gill (1995) that this form of inquiry is a 'passionately interested' one. Aranda (2006) proposes that poststructuralist feminist epistemology is a distinctive approach

to research as it involves a perpetual critique of the key enlightenment assumptions of humanism, reason, truth and progress. Furthermore, this sceptical, interrogative and deconstructive approach does not endeavour to completely abandon these epitomes, but strives to review and recycle these assumptions. Therefore this form of inquiry demands that we acknowledge our epistemological and ontological positioning as well as our political values in our projects, and requires an understanding of reflexivity as a social practice rather than a property of the self (Aranda, 2006).

Poststructuralist feminist epistemology therefore has been a valuable resource to my project because of a number of distinctive features. These include the anti-foundational theoretical premise which focuses on the contingent and relational nature of all knowledge and an analytical focus which exposes power, seeks out difference and diversity, draws on the strengths but avoids the extremes of relativist explanations. These perspectives are steeped in politics, imbued with values and most importantly, open to challenge and change. Furthermore, they allow for an understanding of power, resistance, submission and change. This in turn opens up spaces to explore the power dynamics, practices and material effects of discourse, and in identifying discursive practices of dominant discourses, to understand how to resist these. In addition, poststructuralist feminist epistemologies offer a way out of polarising debates, as these either/or positions usually result in theoretical and practical stalemates. What these approaches promote is that binaries should be construed as relational and therefore in need of deconstructing and re-inscribing (Aranda, 2006).

In what follows, I attempt to sketch a portrait of what transpired during my travels. There were many stops and starts to this project and this journey manifested more circularly than linearly.

## **5.2. Beginnings**

As previously mentioned, this project was borne out of my own personal experiences with HELLP syndrome. After I had lost my daughter, and almost lost my own life, I was desperate to learn more about this rare disorder and why this happens during pregnancy. I learnt of the HELLP syndrome society that was established when a couple also lost their daughter. The HELLP syndrome society represents women across the world wanting to share their experiences. They also raise funding for research and provide information about the disorder and related material.

At the time of my first experience, relatively little was known and the information regarding the psycho-social aspects of the syndrome were virtually non-existent. What I did come across on the website were loads of stories told by survivors of HELLP syndrome. It was at that point that I knew this was going to be the topic of my PHD dissertation. After having gone through absolute trauma, I could not believe that this story could remain untold. Moreover, being an academic, I felt that my position would enable me to take this issue forward in a more formal way.

The HELLP syndrome society also put me in contact with Maria Kidner who had just completed her master's degree in nursing. As mentioned, she was the first to examine the emotional experiences of women who had suffered from HELLP syndrome. After being in contact with her via email, I decided to formalise my intentions. I also met the head of high-risk obstetrics at one of the state hospitals. He explained some of the challenges they face in tertiary care institutions, particularly with issues of language. He was extremely interested in my ideas and assisted by discussing some of the healthcare issues. What stood out for me was the difficulties doctors have in explaining something so complex to women in English, when in many cases, English may not be the mother tongue of many women. I kept contemplating what it would mean for someone to try to make sense of such trauma, when one is not literate or when the language of communication becomes such a barrier.

At the same time I was introduced to a gynaecologist specialising in high-risk pregnancies in private practice. I met with her and learnt that she saw quite a few women who had HELLP syndrome. She then promised to assist me in recruiting participants and was very encouraging concerning my study. Not long after our initial meeting, I fell pregnant with my daughter, and asked her to be the attending gynaecologist.

The stage thus seemed set for me to pursue my deep passion and almost in a sense give form to such traumatic experiences. Initially, when I conceptualised the study, I was only going to explore the emotional and psychological experiences of HELLP syndrome survivors. However, when I read Corbett-Owen's (2003) master's dissertation on pregnancy loss she described how important the medical context was, and how that encounter determined to a large degree how women made sense of their experiences. This compelled me to examine and to take seriously a context which could not be ignored. In addition to reading about the role the medical context played in the HELLP syndrome experience, I also read around issues of motherhood and the centrality of motherhood to many women, and realised that examining

the meaning-making process for women who have had HELLP syndrome must take motherhood into account. This reflection culminated in my formulation of the following aims to be explored:

- to facilitate and listen to the voices of HELLP syndrome survivors;
- to explore the emotional and psychological experiences of HELLP syndrome survivors;
- to analyse the role biomedical discourses play in women's understandings of their experiences of HELLP syndrome;
- to explore the subjective experiences of HELLP syndrome in the context of traditionally held notions of motherhood.

The next stage of the project involved thinking through developing the research questions, and how to access the participants. At that time I was teaching on the psychology honours programme in my university and was involved in supervising students for their mini-thesis. As staff members, we could involve post graduate students in our projects. I proposed my topic as a possibility and two honours students decided to conduct their study on HELLP syndrome, and they became instrumental in my projects in the fieldwork.

These aims of my study were therefore translated into the following research questions:

- What were the psychological/emotional experiences for women who were HELLP syndrome survivors?
- How did women experience the medical context in which they gave birth?
- How did women become mothers in the context of having had HELLP syndrome?

### **5.3. Recruiting Participants**

Recruiting participants for any study is always a challenge, particularly in the South African context. Many South African citizens are still illiterate and many people are not articulate especially those from disadvantaged backgrounds. However, in my study this posed an immense challenge. Reading the literature on high-risk pregnancy in general, revealed a dire need for studies to be conducted in South Africa. In addition, I discovered how little work had been done with women across the race and class spectrum. The international literature exposed the middle-class bias of many of these studies. Moreover, my discussion with the

head of obstetrics at one of the state hospitals also demonstrated how the prevalence of HELLP syndrome within lower-income groups in the greater Cape Town area may be greater than what has been reported. To recap, a study conducted in Cape Town at Grootte Schuur hospital from 1995 to 1998, found that 36 of 72 women (50%) with severe preeclampsia and renal failure had HELLP syndrome (Drakely, et al., 2002). Therefore to do justice to such a project in the South African context meant recruiting participants from both private and state hospitals.

The next part of the deliberation centred on who was to be part of the study. The first important criterion was that the person had to be diagnosed with HELLP syndrome by the attending obstetrician. Secondly I considered the time period between the experience and the interview. Based on my reading, I interviewed women who had HELLP syndrome a year prior to the interview, but not longer than five years ago. The proposed time frame took into account the fact that anything prior to a year may have been too fresh and not yet processed. Any experience that may have occurred five years previously may have become vague and the details forgotten. The third criterion related to the thorny issue of language, which is crucial in a post-modern account. The diversity in our country and the fact that there are 11 official languages, pose huge dilemmas for researchers, particularly those working in a qualitative discursive framework.

In most cases in South Africa, researchers make a conscious decision to interview participants who speak their mother tongue and choose not to interview those whose mother tongue is different to theirs. These decisions are always tricky and the possibility of who one excludes by virtue of these decisions becomes important. In my study I opted for interviewing any woman who was willing to participate irrespective of what her mother tongue was. There was an African-language speaker (my own home language is English) who participated and she was keen to share her experiences. In retrospect I was happy with my decision, as the willingness of the participants in my perspective was more important than all the language considerations. I did make the option of an interpreter being available, but all the participants felt that they were quite comfortable speaking in English or Afrikaans.

With this in mind, I set out to recruit participants from all walks of life. I did not want my sample to consist only of middle-class women. I applied to both tertiary state hospitals in the region for permission to access participants for my study. My doctoral proposal served at both ethics committees and permission was granted for the study. A medical registrar was

appointed and they went through the hospital records to access potential participants. Names and contact details were forwarded to me and telephonic contact was made. One issue worth mentioning is the difficulty I had with some of the potential participants from one of the hospitals claiming that they did not have HELLP syndrome. This left me wondering about the state of the medical records within some of the state institutions. I also advertised via word of mouth and participants who attended private hospitals responded. In terms of private hospitals I approached some gynaecologists that I knew dealt with high-risk pregnancies in their practices to speak to potential participants. Three of my participants were recruited via this method.

Once telephonic contact was made, I introduced myself, spoke about my study and invited the women to partake in my study. Interestingly, the majority of them could not give permission without the consent of their husbands. Two of the women reported that their husbands did not want them to talk about their experiences. Another participant (a Muslim woman) reported that her husband said she could participate, but not during Ramadan, which is considered a holy month in Islam.

#### **5.4. Brief particulars of women interviewed**

In writing up this section, I deliberated on what would be the best way to represent the biographical information of the women in my study. In many instances, demographic details are presented in table format and I wondered whether such a way of presenting information defaces people. I therefore decided to present the information in narrative format and to present a brief verbal description of each participant. This I believe presents the story of each person in a very respectful way.

In total I managed to recruit ten participants for my study. As mentioned, two participants declined because their husbands did not consent to the interview. Another participant could not participate because the interviews took place during Ramadan. Below follows a brief portrait of each participant. Pseudonyms have been used to safeguard the confidentiality of all participants.

#### ***Evelina***

Evelina is 37 year old, an Afrikaans-speaking woman, who is married and has two children. She had three pregnancies, one being with HELLP syndrome. She also had one first-trimester miscarriage. She is a cleaner by trade and is a practising Christian.

### ***Jean***

Jean is a 19-year-old girl who lives on a farm. She is Afrikaans-speaking. She did not complete high school and was unemployed at the time of the interview. She had one pregnancy with HELLP syndrome and has a son. Jean identified herself as a Christian.

### ***Maya***

Maya is a 29-year-old clinical psychologist. She is English-speaking. She has two children. HELLP syndrome struck with her first pregnancy at 38 weeks. She attended a private hospital and then was transferred to a state hospital. Maya did not identify herself in terms of any religious affiliation.

### ***Yvonne***

Yvonne is a 33-year-old English-speaking woman who had two pregnancies both with HELLP syndrome. She lost both her babies at 24 weeks. She was attended to at a state hospital. She is a Christian. She is an administrator.

### ***Soraya***

Soraya is a 32-year-old Muslim woman who speaks English. She is married and is a scanning clerk. She had two pregnancies, one with HELLP syndrome. She has two children. She attended a state hospital in both her pregnancies.

### ***Xoliswa***

Xoliswa is 30 years old and speaks Xhosa. She is married and is unemployed. She did not complete high school. She had three pregnancies one of which was a HELLP syndrome pregnancy. One baby died. During all three pregnancies she attended state hospitals. She is a Christian woman.

### ***Miriam***

Miriam is a 43-year-old English-speaking woman. She is Muslim and is an orthodontist and a senior lecturer at a university. She had three pregnancies, one with HELLP syndrome and lost her baby in the process. She has two children. She attended a private hospital for all her pregnancies.

### ***Kerishne***

Kerishne is a 37-year-old woman. Her mother tongue is Gujarathi and she is Hindu. She had four pregnancies of which three were HELLP syndrome pregnancies. One infant died. She attended both private and state hospitals. She has three children.

### ***Kayla***

Kayla is 38 years old and is married and is a Christian. She had five pregnancies, one being with HELLP syndrome. She had one first-trimester miscarriage. She has four children. She is Afrikaans-speaking and is the director of a company. She attended both private and state hospitals.

### ***Samantha***

Samantha is 30 years old, speaks English and is married. She had three pregnancies, one of which was a HELLP syndrome pregnancy. She has two children and had one miscarriage. She is a housewife and is a Christian.

### ***Micha***

Micha is 39 years old, speaks English and is married. She had five pregnancies, three of which ended in first-trimester miscarriages and two were HELLP syndrome pregnancies. She lost one baby with HELLP syndrome at 24 weeks and the other was prematurely born. She is a lecturer at a university. She describes herself as a Christian.

The mean age of the participants was 33.4 years. On average the women in this study had 2.7 pregnancies. Four women in the study reported that they had lost their babies, while another participant said she had a miscarriage at four months.

## **5.5. Making data: The interviews**

The interviewing process for me always constituted a double-edged sword. On one hand, it is that part of research where one steps into the 'real' world of people. On the other hand, one

has to conduct this conversation in a way that yields the information one is hoping to co-construct. Thus as a researcher I had my agenda, and the participants had their own. The question then was how to strike a balance between the two, particularly given the sensitive nature of the topic. Kidner (2000) similarly commented on how her interviews involved striking the balance between what she wanted for her study and what the participants needed for themselves. This often translated into her allowing each participant the time and space to work through the experience at their own pace until the participant felt that she could conclude the interview. This was very much how I decided to steer these conversations.

At a theoretical level, conducting interviews from a post-modern perspective also calls into question the very notion of interviewing itself (Gubrium & Holstein, 2000). Conventionally, qualitative research interviews purport to explore the complex world of experience and the processes of interpretation and the production of meanings. The underlying assumption is that experience, interpretation and meaning-making can be known. The aim therefore is to collect original stories and accounts to highlight the ways in which people come to understand, act or manage their daily lives. This is the juncture where qualitative research and post-modernism intersect with their mutual concern for the socially constituted nature of meanings and human experience as mediated through language. However, modern epistemological and ontological assumptions underpin much qualitative research. Therefore Denzin and Lincoln (2000) contend that qualitative research and corollary data-gathering methods are nothing more than technologies of representation. Thus shifting the gaze in interviewing involves not viewing participants as passive vessels. Instead, it involves active constructions and co-constructions of meanings and truths between researcher and participants (Gubrium & Holstein, 2000).

Considering the interviews conducted, I conclude and question the co-constructed nature of post-modern interviews. The issue of co-construction speaks of reciprocity and equality between participants. Yet in the interviews with most of the participants, I found myself having to probe and ask questions, as the participants were not always forthcoming and it was difficult for some to talk about their painful experiences. In addition, I agree with Chadwick (2006) who researched women's narratives on birthing that people seem to have a good sense of what an interview entails, and in the mind of many it encompasses someone asking questions and the other party providing the answers. However, during the interview with the clinical psychologist, she did most of the talking, which I must admit was a welcome

relief. What participants did talk about and ask me about at the end of the interviews was more information on HELLP syndrome itself. They wanted to understand how often it occurs, why and what the chances are of it recurring in subsequent pregnancies. So with regard to information sharing, they were quite spontaneous and open.

The interviews were conducted in a space in which the participants felt comfortable. Some of them wanted to meet at a neutral place, while others were quite comfortable in their own homes. For one interview, I had to travel to a farm situated in a very rural part of Paarl. I was struck by the poverty in which the participant resided. Another participant lived in a very affluent area and suburb and this was a stark reminder of the tremendous gaps prevalent in South African society.

A semi-structured interview schedule together with a demographic questionnaire was utilised during the interviews (See Appendix 1 and 11). This method of gathering information was well-suited to my study as it provided me with an opportunity to listen to the experiences of women from their own vantage point, using their language of choice. The research questions acted as a guide to what was discussed. Questions posed served to prompt the interviewee or to ask for clarity about what had been said. The interviewee's responses were what ultimately shaped the structure of the interviews (Esterberg, 2002).

The questions asked in my study were also guided by what Kidner (2000) experienced in her study. Initially in her pilot interview, she asked her participants to recount what had happened during their HELLP syndrome experience. She reported that this resulted in a chronological recounting of their stories. She then modified the question and asked them more reflective questions including: "What was the worst thing that happened to you during this experience, and how did you feel about this?" and "What was the best thing that transpired during this experience and how did you feel about this?". I used these questions and added other questions about the hospital context as well as what motherhood meant to them and why it was important for them to become mothers.

The interviews lasted anywhere from one to two hours. I was very moved by some of the stories relayed. I found these women very brave and courageous when retelling their stories. One of the participants thanked me for interviewing her and she told me that no-one, not even her immediate family, had ever asked her what had happened or about her experiences. She said she felt grateful for the opportunity to talk about her experience.

Follow-up interviews were held to discuss issues which I felt needed clarification and to give the participants an opportunity to add anything they wanted to their interview. In many cases, there was not much that could be added. They felt that they discussed what was important to them during the first interview. In two cases, participants chose not to take up the offer of a follow-up interview. In one instance the participant could not 'seem to find the time' and in another case, the participant said that she could not see herself talking about the issues again.

While listening to the participants in the interviews, I paid careful attention to how they were embedded in a particular situation and context (Parker, 2005). What was iterated in the interview was construed as being shaped in a set of contexts, some of which are: the actual interview, the social identities of both, the social situations from which we come as well as our classed and racial positioning. Parker (2005) suggests that ethnographic sensitivity is critical, hence I was extremely mindful of the participants' backgrounds as this shapes the content and form of the information discussed. Willig (2000) reminds us that qualitative research acknowledges that the people we study are not neutral or objective. The participants have their own agendas, ideas, worldviews and motives that shape how they respond to the questions asked, as well as how they present themselves.

### **5.5.1. Data Analysis**

The data in the study lent itself to two levels of analysis which is in keeping with the theoretical framework of my study which is material-discursive. On one hand, the emotional and psychological experiences of HELLP syndrome were explored and this definitely opened up spaces for a phenomenological analysis. Secondly, I explored how survivors of HELLP syndrome made sense of their experiences in relation to the medical context and to broader social discourses of mothering and motherhood. The discursive component of the study was analysed using a discourse analytic approach.

### **5.5.2. Phenomenological analysis**

Jennings (1986) argues that when the term 'phenomenological' is used in psychology it is used interchangeably with the word 'subjective'. Cosgrove (2000) argues that this conflation of terms is unfortunate because it undermines not only the depth and vision of phenomenology, but also its potential for being radical. A phenomenologically-gearred psychology refuses to simply accept the dualisms implicit in traditional psychology (for

example, objective/subjective) and advocates for a reversal of these dualisms. Instead, it would disrupt the subject/object divide.

More particularly, one of the most basic principles of a phenomenological approach is that consciousness/experience (as is more commonly used in psychology) is considered the appropriate subject matter in psychology. Husserl (1970; 1977) the pioneer of phenomenology, identified a crisis in psychology in that it is steeped in the natural attitude; it is guilty of naturalising consciousness or experience, and of considering experience as if it were part of the physical world and is subjected to the laws of nature. Giorgi (1985) has alerted us to the fact that psychology in a sense was compelled to appropriate the methods of the natural sciences if it was to elevate its status as a science, despite the fact that the object of study within psychology (consciousness/experience) is not a tangible object at all. Therefore as Giorgi (1985; 1990) and others have alluded to, Husserl has set the stage for establishing why a psychology based on the natural science paradigm has been unsuccessful in providing us with either an epistemological or methodological framework from which we can explore human phenomena.

Husserl's famous pronouncement 'back to the things themselves' can be understood as a requirement to comprehend a unique and critically important component of consciousness and reality. The call to get back to things themselves could be understood as a cry for any social science investigation of human phenomena to appreciate the experiential nature of reality. In other words, according to phenomenology, the social sciences need to recognise that reality is not mental or material, rather it is experiential.

Another important tenet of phenomenology according to Husserl is intentionality. Husserl therefore proposed that every lived experience contains meaning units. Psychology however, has not fully appreciated the importance of intentionality and in so doing has historically privileged quantification over description. Giorgi (1985) writes that the psychologist is left dealing with measured behaviour as data, rather than the lived behaviour of the subject. This shift in focus therefore allows researchers to examine how women experience particular phenomena, in this case, how they experience HELLP syndrome.

By taking Husserl's critique of naturalism and his theory of intentionality seriously, the phenomenological psychologist has the tools with which to develop empirically based

‘replicable’ methods of inquiry. In my study the guidelines of Giorgi (1985) were utilised in analysing the data. These four ‘essential steps’ were applied:

- The entire description was read to obtain a general sense of the whole statement.
- Once a sense of the whole was grasped, I went back to the beginning and read the text once more with the aim of discriminating meaning units from a psychological perspective and with an emphasis on the phenomenon being researched.
- Once meaning units were delineated, I went through all the meaning units and expressed the psychological insight contained in them.
- Finally, I synthesised all of the transformed meaning units into a consistent statement regarding the participant’s experience.

### **5.5.3. Discourse Analysis**

Discourse analysis has gained more stature in qualitative research in the past decade. It certainly offers the promise to challenge our thinking about aspects of the reality of health and health care practice (Cheek, 2004). Greater prominence however, has not resulted in better understanding or use of discourse analysis as an approach in qualitative research. In fact, I agree with Cheek (2004) that the waters have become more clouded than clear. This opacity can be attributed to two issues. The first relates to the confusion surrounding what exactly discourse analysis is. The second relates to the poor reporting of research purporting to use discourse analysis. What is often lacking in these studies is that they tell us very little of the underpinnings of the research, including the way discourse analysis is understood and operationalised in the study in question (Cheek, 2004).

Therefore in my study, I will attempt to avoid these pitfalls by first defining what discourse is and how it I will appropriate it in my study. There are not only various definitions of discourse, but they are diverse as well. Mills (1997) argues that discourse has almost assumed a ‘common currency in a variety of disciplines...so much so that it is frequently left undefined’ (p1). In my study I draw on the approach of Parker (1992) and Hollway (1989; 1995). Both of these scholars work within a poststructuralist framework that has a Foucauldian influence. In the area of health psychology, there are two principle ways in which a Foucauldian discourse analysis has been used. Firstly, it has been used to deconstruct expert discourses of health and illness and secondly, it has been utilised to

determine the extent to which dominant discourses are reflected in lay people's talk about health and illness (Willig, 2000). It is the latter focus that my study utilised.

In poststructuralist terms, the social world is construed as a text that comprises the interplay of several codes and perspectives. Poststructuralist theory therefore allows for the possibility to explore the multiple and often contradictory discourses in which individuals position themselves. According to Foucault (1972, p.49) discourses are not "a mere intersection of things and words". Rather, they are "practices that systematically form the objects [and subjects] of which we speak" (p.49). Taken in totality, discourses weave themselves together to produce a text (Parker, 1994). The aim of discourse analysis, therefore, is to unpack the discourses that are operative in order to expose the psychological processes that are contained in a given text. In my study this translates into analysing the texts of women who have had HELLP syndrome, and unpacking the discourses they utilised in making sense of their experiences. This mirrors Foucault's concern with understanding the ways in which discourses, or practices, produce types of 'psychology' (Parker, 1994). In other words, the way in which discourses open up spaces into which "particular types of selves" can step (Parker, 1992, p.8).

With the above considerations in mind, I have utilised the following definition of discourse in my study:

"A discourse provides a set of possible statements about a given area, and organises and gives structure to the manner in which a particular topic, object, process is to be talked about" (Kress, 1985, p.7).

Discourses thus act as platforms for discursive frameworks, which structure reality in particular ways. However, it is important to recognise that at any point in time, there exist a number of possible discursive frames for thinking, writing and speaking about aspects of reality. At any point in time, certain discourses will function to marginalise or exclude others. Therefore whichever discursive frame is afforded presence is a consequence of the effect of power relations (Cheek, 2004). According to Weedon (1987) discourses are not neutral as they in some way represent political interests and subsequently are always competing for status and power. Foucault (1984) argued that "discourse is the power which is to be seized" (p.110). Therefore in Foucault's analysis it is the operation of matrices of power that enables certain knowledge to be produced and 'known'. In medicine for

example, the human body as an object of scientific/medical scrutiny is both constructed by, and in turn, assists in the construction of scientific/medical discourse. In short, the human body is both focus and consequence of medical practice (Armstrong, 1983).

The discourse analysis in my study involved the careful and thorough reading and re-reading of all transcripts. However, I felt that the mere reading of transcripts was not sufficient as one does not really hear what participants have said. As Lisa Mazzei (2004) questions, how does one establish intimacy with the conversations of the participants in the absence of their voices? What she chose to do in her study was to listen to the tapes numerous times and to develop a process for listening to allow her to probe the layers, the complexities and the contradictions to be found. Thus during the initial stage of analysis I chose to listen to the tapes, in conjunction with reading the transcripts. This led me to being more attentive not only to the words that were spoken, but to *how* they were spoken. This also resulted in greater attention being paid to the conversation in context, noting its ebb and flow (Mazzei, 2004).

Based on the suggestions proposed by Parker (1997) and Nikander (2008), my analysis involved the following:

1. Immersion in the data through reading and re-reading transcripts in conjunction with the recorded data while listening for emphasis.
2. Deconstructing the dominant discourses in my analysis involved asking some questions per guidance from Nikander's (2008) work;
  - What are the speakers producing as relevant in their account?
  - Is the speaker doing extra discursive work?
  - Why is this particular detail being mentioned here?
  - Why do I feel that there is a silence or that some topic is being avoided or only alluded to?

The coding of transcripts involved the usage of the initial analytic questions, reference to the literature for previous coding that was used to describe similar discourses and listening to what women emphasized in their interviews as important.

3. The analysis was reflected back to some of the women to check for accuracy and the reading of the data was done jointly with a co-researcher for reflection.
4. Parker (1997, p.74) asserts that 'reflexivity of a discourse allows us to reflect on the terms that are used, to treat the discourse itself as an object, and encourages a reflection

on the term used to describe the discourse'. I engaged in a reflexive process and reflected on my role as researcher as well as what my particular set of characteristics I brought to the process. This is discussed in the section below.

In analysing the data both phenomenological and discursive methods were utilized. The aim of the study lent itself to a phenomenological analysis. However, in the second layer of analysis I utilized a more discursive framework in an attempt to understand the complexities within the sample of women interviewed. Thus the results sections consist of both types of analysis.

### **5.6. Reflexivity and Positionality**

*Some sort of reflective identification of the academic writer with the 'Other' interpreted, analyzed or written about, is so important in reestablishing critical authority in the rubble of paradigms precisely because the most powerful and paralyzing aspect of the critique of representation has been its ethical implications for the very mode of communication – discursive, impersonal writing – so basic to academic work (George Marcus, 1992, p.490 in Nagar & Geiger, 2007).*

Since the late 1980s, the practice of fieldwork has been very closely scrutinised. While issues of power, privilege, location and authorship pervade all research endeavours, the crisis of representation has been particularly paralyzing for those involved in fieldwork. Nagar and Geiger (2007) contend that western feminist social scientists, especially those focusing on third-world subjects have responded to the crisis either by abandoning the idea of engaging in fieldwork, or by engaging in a reflexive identification.

In this part of my process, I therefore examine the role of reflexivity as a methodological tool as it overlaps with debates and questions concerning representation and legitimisation in qualitative research. While all qualitative researchers, including those using critical, feminist, race-based, or poststructural theories, routinely use reflexivity, Pillow (2003) asserts that they use reflexivity without defining how they use it, as if a consensual understanding of it exists.

One of the most significant trends to surface from the use of reflexivity is the increased attention to researcher subjectivity in the research process. In other words, a focus on how does who I am, who I have been, who I think I am, and how I feel affect data collection and

analysis – that is, an acceptance and acknowledgement that how knowledge is acquired, organised and interpreted is appropriate to what the claims are. These reflections emerging from poststructural theory in particular, have generated further questions about a researcher's ability to represent and to know another – and inevitably questions the construction of our qualitative texts. Discussion of these issues is a given in qualitative research and researchers who engage in this enterprise cite a need to foreground the politics of representation by making visible, through reflexivity, how we do the work of representation (Lather, 1993; 1994).

However, not all scholars are charmed by the propagation of reflexivity. Daphne Patai (1994) for example, sees the proliferation of reflexivity at best as self-indulgent, narcissistic, and tiresome; and at worst, undermining the very conditions we wish to change. She launches a scathing attack on “people who stay up nights worrying about representation” (p.64) as privileged academics engaged in the erotics of their own language games (cited in Pillow, 2003). In the final analysis she argues that real problems still exist: “Babies still have to be cared for, shelter sought, meals still have to be prepared and eaten” (p.64). She boldly then questions the “one question that the new methodological self-absorption seems not to ask...Does all this self-reflexivity produce better research?”(p.69).

Pillow (2003) further contends that while she agrees with Patai that “we do not escape from the consequences of our positions by talking about them endlessly” (p.70), she does not believe that the solution is to stop talking about our positions. She therefore believes that we should explore *how* it is we go about talking about our positions. In other words, we should examine how we practice reflexivity, and how these practices influence, open up, or limit the possibilities for critical representations.

Going back to Pillow's (2003) argument that a consensual definition of reflexivity may not exist, the question for me remains how I would define reflexivity. I concur with Pillow's definition that she takes from Elizabeth Chiseri-Strater (1996). She makes a distinction between reflexivity and being reflective. “To be reflective does not demand an ‘other’, while to be reflexive demands both an ‘other’ and some self-conscious awareness of the process of self-scrutiny” (p.130).

However, in practicing reflexivity one has to be mindful of how we write our research subjects, issues or settings. The trend certainly has been to write them as familiar and as

knowable. In this way researchers utilise reflexivity in ways that are dependent on a modernist subject; one that is singular, knowable and static. However, coming from a poststructuralist angle locates the subject (and researcher) as multiple, unknowable, shifting and contradictory (Pillow, 2003).

How then, do I begin to write about who I am and what I think I know about myself and the participants in my study? In fact as I write up this section, I feel completely paralysed. The process of being reflexive cannot be boxed into one section of this dissertation. In fact, parts of who I am have been present even before the formalisation of this project and thus have been part of and shaped the project into what it is.

The need to know more, to understand what happened to me during my HELLP syndrome experience brought this project into being. As difficult as those experiences were, I always signal it as the turning point in my life. Having lost my beautiful daughter was unthinkable, unimaginable and I made an inner vow to make her short life and death count for something very meaningful in my life. Subsequent to my HELLP syndrome experience I experienced three first-trimester miscarriages. Thereafter, I had another pregnancy, but developed HELLP syndrome post-partum. My daughter was born at 35 weeks.

I think the sheer terror of my experiences to a large degree motivated me to want to write about my experiences. Somehow, I could never have imagined in my wildest dreams that things could go so horribly wrong within pregnancy. I think my view of pregnancy, albeit a very limited view, was that when one falls pregnant it always ends in a healthy baby being born. All my readings of popular magazines like *Living and Loving*, *Your Pregnancy* and *Your Baby* presented this idyllic view of pregnancy.

When I lost my daughter, I decided to write my story and have it published in one of the pregnancy magazines. Sadly, not one magazine at that time would publish my story. This motivated me even more to want to pursue the issue in a formal way. Having read similar stories on the internet also provided the impetus for me to pursue this avenue.

I think I was naive to believe that everyone who went through a similar experience wanted to talk about it, write about it or make sense of it. In my interviews with participants, I realised that some of them just wanted to forget about their experiences and move on with their lives. I realised that not all women have the need to make sense of such an experience. This was a huge eye-opener for me.

The women who were willing to talk were very hungry for information about HELLP syndrome. They were very interested in the factual information regarding the illness and wanted information about the prognosis for future pregnancies. Sharing the information I had read proved very helpful to them and they expressed the wish for more detailed information.

When setting out to conduct the study, I knew that I would not limit myself to a certain segment of the population only. My struggle, activist background and involvement in organisation taught and equipped me to deal with women across race and class spectrums. During my years of activism, I learnt that whatever barriers one encounters, one must find a way of overcoming them. Thus I intuitively knew that I would not allow anything to become an obstacle in my study. I was so thankful for having made this decision, especially when two of the participants expressed their gratitude to me for inviting them to be a part of the study.

As mentioned, a range of women participated in my study. In some cases our backgrounds were very different, but this did not appear to affect them or me in any way. The point of interest for these women was their experience of HELLP syndrome and they were extremely focused during the discussions. I listened to their stories and felt deeply honoured that they had agreed to share their stories with me. From my own process in therapy I had first-hand experience of how difficult it can be to translate feelings into words, particularly if those feelings are sad emotions. At times I did not have the words to explain what I felt.

At the time I conducted my interviews, I had been in long-term psychotherapy for many years. This I believe assisted me tremendously as I could be more present to my participants. I had my own space to talk about and process my own issues. For me, therapy was the greatest gift I could give to myself. In fact in a sense it gave me back to myself. However, it was a long and arduous journey, with many winding twists and turns. It took me three years before I could even contemplate dealing with such trauma and loss. The process was tough and I had to enter territories within myself that I had not even known existed.

However, the process assisted me in coming to terms with my previous loss and assisted me in my latter pregnancy with my daughter Bryn. This was an intensely anxiety-provoking pregnancy – literally a life and death struggle. I started leaking water at 13 weeks and was put on bed-rest from then until the end of the pregnancy. Therapy helped to keep me sane. When I terminated after a very lengthy period, my therapist said that what was important for

her during my pregnancy was to speak life into every situation, since everything prior to that pregnancy symbolised death for me.

As I write up this dissertation, I am in therapy again, and I find the space very containing for such a daunting task. I constantly reflect on this entire process and the meanings it brings to my life, and to those whose lives my work will touch. In some way, my desire is for my work to reflect the depths to which I had to go within myself in order to draw from and allow them to spill over into the writing of this study. Those depths reach back a long way and the journey there was neither linear nor coherent. Therefore, when listening to the participants in my study, I in no way expected their stories to be logical, coherent or singular. In fact I expected to encounter contradictions, confusion, questions and witness many emotions.

My study was set up to explore the emotional/psychological experiences of those who have had HELLP syndrome. Those questions were carefully phrased and attentively listened to. In a way, I also wanted to ‘check out’ whether participants’ experiences were similar or different to mine. I sensed this was the case for them as well, and they listened very intensely when I shared my experiences with them. So in some way we served as witnesses to each other’s experiences.

Where I differed from my participants was on the discussions of motherhood. All of them without exception had always wanted to be mothers. It was just a given. In my own therapeutic process, I discovered that on an unconscious level, I actually did not want to be ‘mother’. On later reflection, I realised that motherhood was not actually on my agenda; it certainly was not a priority. I almost became a mother by default. So, listening to women who ‘instinctively’ wanted to be mothers fascinated and enthralled me. In this regard I felt very different to most participants.

Being a woman in academia also positioned me as ‘other’ in some instances. While one participant was an academic and another was a clinical psychologist, in several other cases, women were unemployed and one woman had not completed high school. When asked how they felt about sharing with me, given our differences, they responded initially that they felt uncomfortable. But as the interviews progressed they felt more relaxed and comfortable, which led them to later comment that they soon forgot my academic background and in their words: “I find you very down-to-earth”. The camaraderie that developed was useful as this aided all participants in feeling more comfortable and hence they were able to delve deeper.

Two of the participants in the study were white. I knew one participant from a previous encounter, and this may have helped the conversation in some way. She also studied at the university where I taught, so we shared some common ground.

Writing from a poststructuralist framework, the workings of power must be acknowledged. In South Africa, race, class and gender have always served historically as lines along which divisions were entrenched. These differences may have created distance in some respects for the participants and they may not have felt comfortable verbalising their views. The language issue may also have been a problem especially for the African-language speaker and this could have represented my power as researcher in the interview context.

The discussions that emerged during this process were also largely a function of my presence as the researcher. One's own ideas always seep through interactions, whether consciously or unconsciously. Participants' own awareness of my positioning may also have elicited and shaped their response to me, as well as what they chose to share during the interview.

In the final analysis, I have to conclude that despite all the measures taken as a feminist researcher to level the playing fields they continue to remain very unequal. This awareness leaves me feeling somewhat uncomfortable. However, Pillow (2003) remarks that uncomfortable reflexivity then is “not about better methods, or about whether one can represent people better” (p.193), but as Visweswaran (1994) states, it is about “whether we can be better accountable to people's struggles for self-representation and self-determination including ourselves” (p.32). She further argues that this is no easy task and should not be positioned as such. “Qualitative research would be enhanced by more ‘messy’ examples, examples that may not always be successful, examples that do not seek a comfortable, transcendent end-point but leave us in the uncomfortable realities of doing engaged qualitative research” (p.193).

### **5.7. Ethical considerations**

Guidelines for ethical conduct emerged from medical and other types of intrusive research and resulted in considerations like informed consent, avoidance of harm, protection of privacy and confidentiality by Institutional Review Boards. However, different epistemological worldviews give rise to different ethical concerns. Logical positivist inquiry demands distance between the researcher and the researched but this may enhance ethical issues. In fact such ‘objectivity’ in itself can be conceived as an ethical issue because it could

lead to the objectification of others. In the same vein, one cannot assume that qualitative research leads to more ethically correct research, as a researcher may be more friendly and empathic, but chooses to remain uninvolved (Glesne, 2006). Ethical considerations in qualitative research therefore refer to an engagement with the nature of relationships with research participants.

For this study, the first level of ethical clearance was at an institutional level. The relevant institution requires all students' projects to be ethically cleared and therefore subjects all proposals to stringent ethical scrutiny. Secondly, my proposal had to serve at two tertiary hospitals ethics committees to gain access to potential participants. At this level it was made clear that I was to inform all participants should they decline to be part of my study, that their future treatment at the hospital would not be jeopardised in any way. This was therefore conveyed to all participants. A further concern raised was related to the issue of the sensitivity of the topic and how it would be dealt with. In this regard, I approached colleagues of mine who were registered psychologists, for assistance. This was agreed to and their telephone numbers were given to all participants.

Emotional work in qualitative research is a central issue and is dealt with in various ways. Not only are the emotions of the participants crucial, but so are the emotions of the researcher. Researchers deal with this issue in differing ways. For me to conduct this research ethically, meant having to process my own emotions which facilitated my understanding of the issues. I concur with Rothman (1982, p.5) who writes "I could not have understood it intellectually I don't think, if I had not experienced it emotionally". However, one must be mindful not to set up the idea that if researchers have not had an experience of an area they are researching, that their works are considered less in any way. I certainly think that my own experience assisted me in ensuring that I conduct my study in the most ethical way.

Issues of informed consent, confidentiality, privacy and anonymity are given within research, and yet does following protocol make one's study ethical? While as researchers we all inform our participants that no information or personal details will be disclosed, in some ways they are. However, what was important for me was assuring the participants that all ethical issues would be strictly adhered to and asking them to point out whether any detail they had provided could be incriminating. Thus the final say resided with them. I also asked them to grant written permission for their tapes to be transcribed by anyone other than me, and for permission for their information to be exposed to my supervisor and examiners. I also

informed them of the possibility that I would have a fellow doctoral colleague working with me, and I introduced her to them during the interviews. I felt it important that these issues be presented to them, so that they understood that their narratives would be analysed and made publically available in some format (for example in a published article), even while upholding their confidentiality and ensuring anonymity (See Appendix 111).

When making initial contact with them, I also presented an outline of the types of questions that I would be asking them. This provided them with an opportunity to think about things and decide whether in fact they wanted to get involved. However, I do acknowledge that I cannot safeguard them from anything, as one cannot guarantee what would emerge during the interview itself. At the start of the interview, I would mention these issues and once they consented, we engaged in the interview.

With regard to ownership and dissemination of the findings, all the participants felt that they wanted their stories to be told, to assist other women who go through similar experiences. Some of them noted that within disadvantaged communities, women had never heard of HELLP syndrome. They felt that more women needed to be informed about these issues.

One of the hallmarks of feminist research is to resist the potentially exploitative aspects of traditional research relationships by introducing the notion of collaboration (Chase, 1996). This translates into attempting to erase the distinction between the researcher and participants with a view to enabling all to share equally in authorship of the research project. However, no matter how hard we try to incorporate the participants' point of view the research analysis still predominantly reflects the researcher's interests and choices (Josselson, 1996). The basis of an ethical study therefore rests on the acknowledgement of interpretive authorship (Chase, 1996). As my study progressed, I became more aware of the difference between my own interests and those of the participants as they told their stories. My own interests in how hegemonic discourses and issues of power shaped the meaning-making process for women developed, yet they wanted their pain, suffering and lack of knowledge to be foregrounded in the study. In lieu of this disparity, it became critical to acknowledge the interpretive authority I had imposed on the analysis.

## **5.8. Conclusion**

In this chapter I outlined the methodology that guided this project. Broadly positioned in a feminist-poststructuralist framework, the procedures and methods used are informed by a

combination of phenomenological and discursive elements. Essentially complementing each other, these constitute a strategy to meet the objectives of my exploration of women's processes of meaning-making in relation to matrices of power and control when these women have had HELLP syndrome. I have also attempted to address how some of the methodological decisions taken have been influenced by both my ethical concerns and personal position in relation to this project. In the chapters that follow, I describe the analysis of how women experience and make sense of their HELLP syndrome experiences.



## CHAPTER 6: EMOTIONAL AND PSYCHOLOGICAL EXPERIENCES OF HELLP SYNDROME

As mentioned, the first aim of my study is to explore and understand the psychological and emotional experiences of women who have had HELLP syndrome. As outlined previously, and in keeping with the parameters of a material-discursive framework, this aim is addressed through a broadly phenomenological and discursive reading of their experiences. What is important to acknowledge at this point is that these experiences are not given foundational status as they will be explored and written up in a non-essentialised way.

When examining the way in which the participants constructed their experiences it is very challenging to distil these experiences in a way that extrapolates the core essence of the phenomenon, as is required by phenomenology. In phenomenology researchers seek for the essential, structure or essence of the experience and emphasise the intentionality of consciousness where these experiences contain both the external appearance and inward consciousness based on image, memory and meaning (Cresswell, 1998). If anything can be gleaned from the participants' conversations, it is the fact that their experiences were so diverse and varied. The way in which they constructed these experiences was determined by personal factors such as whether the pregnancy was planned or not, their partners' roles in their lives and relationships, their previous experiences of pregnancy and the general ideas they had about pregnancy and motherhood. The biomedical context in which they were treated was the other critical component and partly determined how they made sense of this experience in their lives. Corbett- Owen (2003) highlights the powerful role that the medical context played in shaping her participants' experience of loss, whether it was by suggestion or labelling, which not only affected how they felt about themselves, but influenced them insofar as the actions they undertook or failed to take. The other important aspect that became the focal point in the participants' discussions about their healthcare was the state-private divide and general dissatisfaction and resentment was expressed towards state medical care. As previously mentioned, healthcare in South Africa continues to be riddled with deep divisions based on economics, race and class dynamics.

In an attempt to provide an exhaustive description of the HELLP syndrome experience, it became evident that there were commonalities but also major differences in these experiences. One of the primary differences related to whether women had experienced miscarriages or stillbirths, or whether they had had live births. The other major difference

centred on whether they had been transferred to the Intensive Care Unit or not. It was these differences in the participants' experiences that became the structuring dynamic in articulating an exhaustive description of their emotional and psychological experiences. Below follows a description of their lived, subjective experiences which I have written in narrative form. Thereafter, I proceed with the analysis of the emotional, psychological and bodily aspects of this experience for the participants.

### **6.1. Descriptions and meanings made of the HELLP syndrome experience**

The onset of the experience was marked by deep intuitive feelings that something was wrong. These feelings were ignored, suppressed or discounted by either the participant herself, significant others or medical personnel. Some participants experience pain, while others did not. More generally it was expressed that pain seemed to serve as a messenger of sorts. The formal diagnosis of HELLP syndrome was met with complete surprise, shock and disbelief. This initial diagnosis catapulted medical staff into action and set off a whirlwind of events. At this stage most of the participants had either no knowledge or very limited knowledge of the disorder, and therefore did not fully understand the impact, consequences or seriousness of the illness. The rapid pace and the enormity of events culminated in some of the participants feeling completely unprepared for such an experience. Most of the participants had caesarean sections with the exception of two women who had normal births. The birthing decisions were made by gynaecologists and were based on the risk to both the mother and the baby.

#### **6.1.1. The Intensive Care Unit (ICU) experience**

The ICU signalled a very difficult time for women who had HELLP syndrome. It was a time where women stood on the threshold of life and death. Thoughts of dying and having near-death experiences were common. Three of the participants slipped into a coma and another reported slipping in and out of consciousness. One of the participants had to be flat-lined twice. One of the participants had acute respiratory disorder and had to be ventilated. The participants described this as a very lonely, confusing and bewildering time.

#### **6.1.2. Women who had live births**

Of the women who had live births, most of their babies were very premature and they had to be incubated. The neonatal intensive care unit (NICU) elicited many troubling experiences and emotions for these mothers. 'Traumatic' seemed the operative word in describing this drawn-out and tiring experience where time seemed to elongate to the point of feeling

'frozen'. The initial reactions of women when they were able to see their infants were shock and disappointment. Seeing their babies fighting for their lives rendered them completely defenceless and helpless. Deep feelings of fear were expressed as some of them did not believe their babies were going to survive this ordeal. Despite reassurances given by doctors about the incidence and prevalence of survival rates amongst premature babies, the mothers reported how hope faded. Seeing their tiny premature babies hooked to so many machines was disconcerting and made feeding difficult and complicated. State hospitals being short-staffed exacerbated the problems. Feelings of paranoia were prevalent for one participant at a state hospital where a baby had just been stolen. Having to leave their babies at hospital caused angst and resulted in many nights of worry and sleep deprivation. Participants who used public transport found the trekking to hospital each day exhausting.

### **6.1.3. Women who had miscarriages or stillbirths**

The loss of their babies was almost too much for mothers to contemplate while they were still trying to recover from their ordeal. Some of the participants felt stripped of life, cheated and robbed when they had to leave the hospital empty-handed. Leaving without the baby made these mothers feel that the process was incomplete. Thoughts of guilt, blame and the possibility of having being negligent were expressed. Some mothers expressed ambivalence around seeing the baby for fear of attaching and then having to let go. In instances where women were in general wards with other mothers who had live babies, there was a constant reminders of what they had lost. Profound sadness was felt and expressed at the loss of their babies. One of the participants verbalised her anger at God and questioned why this happened a second time.

In retrospect the participants felt that their bodies had betrayed and failed them. They described the entire experience as a whirlwind in which they had virtually no control, and many of them labelled the experience as difficult, painful and a disaster.

Consistent with the phenomenological method, this structural description will now be elaborated upon in an in-depth description of the fundamental structure. In this regard each of the constituent meaning clusters will be discussed and a variety of individual descriptions will be provided to illustrate the characteristics of the experiences as reflected by each specific meaning cluster. I have dissected the meaning clusters and grouped them into emotional aspects, psychological aspects, physical aspects and descriptions of the entire experience.

## 6.2. Emotional Aspects

The emotional aspects of this experience refer to the feelings expressed and experienced by the participants. The analysis revealed that a range of very intense emotions were experienced. However, the explanations for these emotions were deeply entrenched within discourses of womanhood, motherhood, biomedicine and patriarchy.

### 6.2.1. Intuitive sense that something was amiss

Northrup (1995, p56) defines intuition as the “direct perception of truth or fact *independent of any reasoning process*”. Some of the women interviewed expressed strong intuitive feelings about their condition despite (as we will see further on) having very little factual information about HELLP syndrome or its devastating consequences.

*I could tell immediately that something was much more serious.* (Maya).

*I knew something was wrong* (Soraya).

However, it seems that these feelings were not taken seriously by some medical personnel.

*I knew something was wrong. Deep down I knew something is not right. I just had a **bad uneasy feeling**. I told my husband something is not right– he must take me to hospital. At MOU they didn't take heed of me telling them my pressure's high. They also picked up protein in urine and they said it was fine. I felt I was not heard. It may not have saved the baby, but maybe I did not have to go through such an ordeal* (Kerishne).

Another participant spoke about how she reflected on this issue:

*In retrospect I should have trusted my gut. I should have trusted what my body was saying to me. In the face of medical science, in the face of this all-knowing doctor, who are you to question and not to trust their judgment? They are the experts on the body, but deep down I definitely had a sense you are not understanding me, you are not hearing what I am saying to you* (Micha).

The fact that the subjective feelings of women were ignored by medical personnel should not be met with surprise. The biomedical worldview of the body which is based on Cartesian dualism sees the mind as being superior to the body. Western medicine which is based on rationality, reason and logic, does not pride itself on paying too much attention to issues of emotions or feelings as these are seen as being associated with the body. Davis and Walker (2008) argue that the body that pervades midwifery and gynaecology is one constructed by

medicine and modernity. This body was completely disentangled from the mind and spirit and its various contexts so that it could be treated as a separate entity.

What Micha also seems to allude to is an almost handing-over of her body to medical expertise. Stainton et al., (1992) reports that this was a way in which women could regulate their anxieties by handing over their bodies or experiences to the external technological world as the source of meaning. As one of the participants in this study in Stainton's study articulated her feelings:

*You're the one taking the blood and doing the tests and running the scans and listening to my heart and putting me on oxygen. You tell me how I'm feeling 'cause I don't know.*

Northrup (1995) asserts that we have been taught that our disease-care system is designed to keep us in good health. We have been tutored to rely on doctors when we are worried about our bodies and our health. Moreover, we have been taught the 'myth of the medical gods' – that doctors know more than what we do about our bodies and that the expert holds the cure. It is not surprising therefore that women would argue as the participant in Stainton's study did: "You tell me how I'm feeling 'cause I don't know".

In a discussion of this nature, the quality of care in some of the state institutions in our country needs to be acknowledged. Some horrifying experiences were documented in local newspapers about how patients were treated in some of these facilities. One of the participants, Xoliswa, spoke about her first pregnancy and how she lost her baby at a local facility in a rural area.

*In a rural hospital with my second pregnancy, I was treated terribly. I was so ill with blood pressure and swelling. When I go to hospital I was two centimetres dilated and was sent home. There were no doctors on duty, only sisters. They took me for a scan and said the baby's heart is not beating. I called for help that evening and no-one came. So many babies died that night (Xoliswa).*

### **6.2.2. Feelings of loss of Control**

Feelings of not having control over their situations and circumstances were overwhelming for the participants and seemed to be a central to the way in which they experienced HELLP syndrome at all stages. These feelings of no control relate to three particular areas: they felt they had no control over what transpired inside their bodies; they felt a loss of control with

respect to their identity as a mother; and they expressed a lack of control regarding what transpired in the medical context itself.

Regarding the loss of control over bodily processes the following was expressed:

*I felt I had no control. My relationship to my body changed. I was disgusted at my body* (Maya).

*You have no control. You don't know what is going on inside your body, only if you do the blood pressure tests, then you will see – not that I could see* (Soraya).

Further, participants also reported feeling a loss of control with respect to their identity as a mother, who is constructed as the one who should be taking care of the child (in utero or after).

*Not in control. As a mother you want to feel in control* (Kayla).

*There was no control. So you feel helpless. You first think of your child. Mothers need to be made aware of what is happening to them. The more the mother is aware, the more she will try to prevent it* (Kerishne).

Finally, they felt they had no control over what took place in the medical context itself where their bodies, their pregnancies and their babies were under the control of medical expertise, distanced from normative relationships of care:

*I felt out of control. It was unpredictable and uncertain* (Evelina).

*It was an uncertain time. I did not know what to expect* (Jean).

*Birthing plans with your gynaecologist are normally about pain control and the type of delivery. They forget about complications. They need to talk about what would happen should there be a complication, should there be a stillbirth, should there be a death. How would you want us to deal with things, do we wait for you, do we incinerate, do you want a burial. It's about taking a bit of control back* (Miriam).

Having no control rendered the situation unpredictable and uncertain for some of the respondents. Kidner's (2000) study also locates the sense of no control within the self, the medical provider and at the experience itself. This sense of a lack of control was reported as

overwhelming and could relate to how the participants' normative expectations of these experiences were overturned and disrupted by what transpired during their pregnancies.

In addition, this sense of loss of control could also have been related to the rapid pace of events. When asked to summarise the entire experience in one word or a phrase, the participants described it as a whirlwind experience and as a disaster.

*The whole birthing experience happened so FAST(Soraya).*

*Things happened quickly.No time to processanything (Kayla).*

*All of a sudden I had a bloated feeling inside of me. Everything happened so fast.When I went to the MOU then you know it's just like my whole world it turned upside down (Samantha).*

*I could not make sense of anything.Everything was happening too fast (Micha).*

*They did more blood tests and said that the kidneys are getting worse and now my liver is affected. Organs deteriorated rapidly (Yvonne).*

From the time of diagnosis to the ultimate delivery, the pace of events was described as very turbulent.As indicated in the literature, once the diagnosis has been established, swift action has to be taken due to the rapid deterioration of the organs in the body.Sibai (1992) and others have documented that if termination of the pregnancy is not executed within 24 to 48 hours of the onset of the disorder, one faces the potential loss of both the mother and the baby.The consequences for the maternal – foetal dyad could thus be devastating and eventually fatal.These sentiments were also expressed in Kidner's study (2000).One of the mothers in this study said: "My experience with HELLP syndrome was incredibly whirlwind".

To understand these deep-seated feelings of not having control, it may be important to locate the possible source of this lack of control.Barbara Katz Rothman's (1994) discussion about the construction of motherhood serves as a useful premise.At this juncture her suggestions around ideologies shaping pregnancy and motherhood, particularly the ideology of technology,are useful.Medical models of childbirth are structured in an ideology of technology or as Davis-Floyd (2003) articulates it,in an ideology of technological progress.Chadwick (2006,p.219) similarly writes about an ideology of control and "the

power of what if..." demonstrating how women's 'choices' around childbirth are often made relative to an ideology of (technocratic) control. Northrup (1995) argues that our Western culture and its 'addictive' medical system promote the belief that technology and testing will save us, that it is possible to control and quantify every variable, and if we have more data from our studies, we will be well-placed to improve our health, cure diseases and live longer lives. So in a sense, the more normative experience of pregnancy and childbirth which is potentially fraught with feelings of loss of control and which is framed by a regulatory technological discourse which attempts to reassert control, is exacerbated.

The term 'ideology of control' taken from the work of Irene Diamond (1994) refers to the understanding that in modern Western society technology, science and rationality can control the uncontrollable impulses of nature, body and ultimately of life and death. Commensurate with Northrup's assertion, this blind faith in medical science and in obstetrics in particular, is that scientific, rational knowledge will result in 'truth', freedom from 'dis-ease', deformity and premature death (Northrup, 1995).

From a Foucauldian perspective the emergence of the life sciences (including medicine) ushers in a new form of power, namely 'biopower' meaning power over life (Braidotti, 1994). In this configuration, the body operates as the major location of biopower and is situated at the heart of the techniques of rational control. Thus in keeping with an 'ideology of control' is the motivation to control, manipulate and regulate the body to ensure disciplined citizens. Arney (1982) discusses a different type of obstetrical power which functions through monitoring and surveillance rather than by overt control and domination. Subjecting pregnant and birthing women to 'constant and total visibility' via the 'normalising gaze', the power of obstetric knowledge becomes widely dispersed and productive, working to produce pregnant and birthing subjects who themselves engage in 'technologies of normalisation'. Pregnant women therefore actively (re)produce themselves as ethical subjects through these technologies.

In her study of birthing women Chadwick (2006) talks about how pregnancy often challenges the standard relationship many women are invested in, of control over the body. Being a fully functional self in capitalist, technocratic and patriarchal societies, demands that people approximate the rational, autonomous, masculinist model of individuals who exercise agency and control and who experience themselves as having, possessing and controlling a body. The experience of pregnancy – which seems to uproot the

body and often expresses itself boldly in ways that cannot be easily rationalised or controlled – was amplified for the women who had an encounter with HELLP syndrome. As Maya says, she was disgusted at her body and her relationship to her body changed.

### **6.2.3. Feelings of Guilt and Negligence**

Most of the participants expressed the concern that they had been negligent and experienced severe guilt. These feelings of guilt were internalised and culminated in self-blame, which is discussed later in the chapter as a psychological component of this experience. The feelings of guilt expressed by one of the participants culminated in her questioning whether she may have been negligent in her assessment of her situation.

*I went through lots of guilt. Maybe I was negligent. (Miriam).*

For other participants, the feelings of guilt related to different aspects of their experience.

*I felt guilty about not seeking help (Maya).*

*I felt guilty about being so overweight my pregnancy (Kayla).*

*I felt guilty because I waited for so long (Evelina).*

As in Kidner's study (2000), guilt was expressed both in terms of the mother herself and the baby. Regarding themselves, some women felt that what happened was as consequence of what they had failed to do (Adolfson, Larson, Wijma & Berteru, 2004). The women in my study expressed concern that maybe they were overweight, maybe they should have sought help sooner or maybe they were just negligent. Adolfson *et al.*, (2004) suggests that for some women, miscarriage and pregnancy loss is constructed as a personal failure and an embarrassment. In addition, Long (2009) argued that because motherhood is constructed as a function rather than an experience, it is not surprising that the 'psy-disciplines' hold mothers responsible for producing and reproducing healthy offspring (Kruger, 2006). Thus when women fail to meet these expectations, feelings of failure and embarrassment ensue.

With regard to the baby, the guilt was especially evident with mothers who delivered prematurely.

*The first thing that I saw, when I saw my child laying under all that this pipes and drips and I mean and he was so small, and I just, I just broke down because I felt so guilty (Samantha).*

*You feel guilty when you are at home, then you rush right back to hospital (Kayla).*

*When I saw my baby for the first time it was so painful. I couldn't believe it was a baby because he was so small and I just lost hope. I was convinced he was too small to survive (he weighed 1.1 kilograms) (Xoliswa).*

These findings are consistent with those of Wereszczak et al., (1997) who examined how mothers of prematurely born children recalled their responses to their infants in the NICU. Three years after the birth of their infants, mothers still reported vivid memories of stress related to the appearance and behaviour of their infants, the pain and procedures as well as alterations in their role as parents. According to these mothers the size and appearance of the baby was particularly distressing. Even the mothers who received information prenatally found the small size of the baby and the amount of attached equipment to be shocking.

In a South African study conducted by Sanders (2006) on preeclamptic women, guilt also surfaced as a very prominent emotion. Some of the women felt guilty because they believed that they could have done something differently to ensure a positive outcome. In addition, these women also reported feeling guilty when they were repulsed by the sight of their tiny infants on delivery. Furthermore, the feelings of guilt were strongly related to the issue of blame.

On closer scrutiny it is apparent that issue of guilt is crucial. If women are left feeling such a strong sense of guilt, where does this guilt emanate from? Kruger (2006) argued that constructions about motherhood seem to emanate from ideas about nature, normality and morality, particularly religion. The pervasiveness of these beliefs powerfully influence the way women experience themselves and what is expected from them. Kruger (2006) further argues that disciplines like psychology as well as some feminist psychologies are responsible for the perpetuation of these mothering ideologies.

Kruger (2006) correctly points out that initially psychological research on mothering centred on children and their development. The women who did the mothering were completely erased from the equation. Psychological research on mothering therefore only focused on the instrumental value of mothering to society. This instrumentalist view also served as the premise for the ideology of intensive mothering (Hays, 1996) and the ideology of essential motherhood (DiQuinzio, 1999). Flowing from this, an ideal was created which prescribes that every woman in her nuclear family ought to be capable of giving all to her

child so that it will develop and be happy. Failing to live up to these constructed ideals leaves women feeling 'less than' and they continually question themselves regarding their mothering capacities and capabilities. Given these tacit directives, it is not surprising that guilt is experienced as a menace in women who miscarry or have medically complicated pregnancies.

#### **6.2.4. Deep seated feelings of fear were experienced**

The participants experienced deep feelings of fear associated with the intense obstetric emergency of HELLP syndrome. However, the fears experienced were for very diverse reasons.

*Fear with/without information. I was thinking when I come down to the nursery what if there is no more baby left?*(Soraya).

*There was a fear of death as I was not getting better* (Evelina).

*I developed a fear for seeing other pregnant women*(Evelina).

*I was very scared. I thought I was going to lose my baby and I thought I was going to die* (Jean).

*I did not think he [baby] was going to survive* (Yvonne and Xoliswa).

*I was so scared*(Micha).

*What scared me the most was when they told me about the liver failure* (Xoliswa).

*I was very scared because I had blood pressure problems again* (Xoliswa).

These intense fears experienced by the mothers centred on either losing their own lives or losing their babies. For Maya, Kerishne, Yvonne, Micha and Miriam, death was a reality and immanent. (As previously mentioned, Maya, Kerishne and Miriam slipped into comas and Kerishne had to be flat-lined twice). These sentiments were shared by women in Kidner's study (2000), in which she notes that fear was reported by every mother. One woman in this study also described a near-death experience (Kidner, 2000). Evelina's fears related to being fearful of pregnancy itself and seeing other pregnant women.

It is important to recognise that many women lost their lives during childbirth until the beginning of the twentieth century. Prior to this period, the mortality rate for women was

high (Polomeno, 1997). Northrup (1997) notes that as a society, (particularly Western society), we continue to treat normal birth with hysteria. As a gynaecologist in practice, she argues that the heightened anxiety about pregnancy and birth is partly the consequence of our collective unresolved birth trauma. Chadwick (2006, p 39) refers to this phenomenon as the 'shadow of death'. Nearly all of us, she believes, have unfinished business about our own births which we continue to project onto pregnant women. Therefore these fears of death intensify the hysteria we bring to childbirth as another aspect of our collective unconscious (Northrup, 1997). Based on her arguments it is therefore safe to conclude that fear is customary and even actively manufactured within the dominant frameworks of biomedical care in pregnancy and childbirth.

In medically complicated pregnancies, these fears seemed to be exacerbated as women reported actually having to face the loss of their own lives as well as that of their unborn offspring. Not only were fears expressed regarding their own situation, but they were also expressed at other women who were pregnant. It appears that all the fears carried by some of the participants were projected onto other pregnant women. She expressed during the interview the fear that the same thing which had happened to her, would happen to other women.

#### **6.2.5. Experiences of shock and disbelief**

Based on the participants' responses, it appears they were caught completely off-guard and were jolted by what was happening to them. One of the participants who is a doctor recounted how she went through her own files in hospital and felt as though she was reading someone else's story. This probably in some way speaks to the difficulty women have in the face of such extreme trauma, where the capacity to internalise what is happening is severely impeded and apparently not mediated by the care they receive.

*It was a huge shock to learn what I had (Soraya).*

*I did not want to believe anything until the end. It was difficult to accept that I had to give birth before the time (Kayla).*

*I never believed that things could go so wrong (Jean).*

*It felt like I was reading someone else's story. I did not realise that I had swollen to twice my size (Miriam).*

*In my mind I was still going to have this baby (Micha).*

*My initial reaction at the MOU was total disbelief at what was happening (Yvonne).*

The often vague nature of presenting complaints can make the diagnosis of HELLP syndrome frustrating to physicians (Kottarathil *et al.*, 2001; O'Hara, 1999). While some of the participants experienced discomfort, others reported experiencing no symptoms at all. However, when the diagnosis was made and confirmed, some of the women were shocked and experienced complete disbelief at what they were told. What I believe further compounds the issue for many women, is the absence of knowledge regarding the disorder. Pozzo, Brusati and Cetin (2010) contend that the transition from a non-threatening pregnancy to a threatening situation signals a critical moment for both pregnant women and medical personnel. At that particular moment, women tend to experience dread, astonishment and preoccupation.

Pregnancy and childbirth are presented in a very particular way in Western society.

*Pregnancy is something wonderful (Evelina).*

The received view of pregnancy is that when conception takes place the end result will be a healthy infant.

*Pregnancy has lost its innocence for me (Micha).*

This view was echoed in a study conducted by Cote-Arsenault & Morrison-Beedy (2001) in which some women regarded it as naive to expect a live baby as the ultimate gift of pregnancy, because of the losses they had experienced in their past pregnancies. To some extent the women's shock and disbelief could also be related to their understanding of the role of medicine during their pregnancy. Chadwick (2006) discusses the story line of birth's medicalisation as one of progress and salvation. The underlying assumption of this view is one of increasing safety and decreasing childbirth-related deaths. It is thus completely understandable that having to face such severe complications in pregnancy would be met with absolute surprise, disbelief and total shock.

#### **6.2.6. Feelings of vulnerability and dependency**

Being so ill resulted in most participants being bedridden and physically immobile. This immobility resulted in feelings of complete dependency and vulnerability. Stainton *et al.*,

(1992) suggest that the roles of others are intensified and extended in medically complicated pregnancies. The usually supportive relationships of the husband, parents and in-laws are stretched and often involve more physical care as well as child care and household management. The woman's dependency on others is also increased as multiple professional caregivers of various specialities may get involved. (Stainton, et al., 1992).

*I was dependent on people around me. Dependency made me **vulnerable** (Kayla).*

*I could not move around (Maya).*

The women clearly found it challenging to be bedridden. In studies conducted by Gupton et al., (1997); Maloni and Kutil, (2000) and White and Ritchie, (1984) women reported that being bedridden and immobile left them feeling confined. In addition they reported that they felt left out of events and activities.

Miriam's comatose state and having to be ventilated in the process exacerbated her vulnerability as she was unable to communicate verbally.

*I had lots of questions, but because of the ventilator, many questions remained unanswered. The only way I could communicate was by writing down on paper. That was mentally and physically tiring. I broke down three days later. I was medicated, given some antidepressants. I then rejected it. I rather wanted to talk about it, even if I had to write (Miriam).*

Physical immobility was painful enough; being verbally impeded appeared much more challenging. The image that emerges is one of being trapped inside a body that is racked with pain and disease.

*It was avoided for a while, until I was taken off the ventilator into the general ward. That was three weeks later (Miriam).*

In this case the dependency was accentuated as she was dependent on the doctors and her family members to reconstruct the event for her.

*She says my questions were answered slowly. Because I am enlightened about medical conditions, I sat down with my folder and I came to realise what had happened (Miriam).*

*When your hands are tied, you are at the mercy of others. Being vulnerable is not a very pleasant experience. I was totally dependent on help, did not want to upset anybody. The nursing staff made me feel so small. They made me feel like nothing. The nursing staff were very unhelpful. They passed ugly remarks. The nurses spoke to patients as they would to children (Evelina).*

In Evelina's case being dependent upon and being patronised by nursing staff rendered her completely vulnerable. As mentioned, South Africa's healthcare system leaves much to be desired. A study conducted by Jewkes (1998) on the quality of care in family planning clinics in the Eastern Cape in South Africa, found that staff were equipped with sound clinical knowledge of procedures and processes but that negative attitudes prevented them from delivering a good service. Findings from this study cite that women-users of health services repeatedly reported poor health-worker attitudes as their primary difficulty.

#### **6.2.7. Feeling that the process was disrupted/interrupted**

Because all of the women, apart from Jeanas a first-time mother, had other children, they understood the gestational process which dictates that women are pregnant for approximately nine months. Having to deliver prematurely left them feeling that the process was disrupted. There also seemed an inherent understanding that pregnancy lasts for nine months as this time is needed for the foetus to grow and develop.

*There is a reason why one is pregnant for 9 months (Kayla).*

In a study conducted by Black *et al.*, (2008) similar findings were reported. Women experienced the end of their medically complicated pregnancies as sudden and unexpected, catching them off-guard completely.

*Throughout the day the doctor came to check if I was dilating, but my body was not ready to give birth. It was a very abrupt ending (Micha).*

Black *et al.*'s study (2009) also demonstrates the link between the disruption of high-risk pregnancy ending prematurely and the ensuing adult developmental challenges for mothers. Their study reveals distinct developmental differences between first-time younger mothers and more experienced mothers. Younger mothers in their study explained how unencumbered socialising was replaced with the responsibilities of motherhood. For these first-time mothers, these experiences culminated in fast-tracked maturation, leaving them

out of sync developmentally with their childless contemporaries and those with normal pregnancies. In my study Jean who was 19 years old at the time, expressed similar sentiments.

*I regret young motherhood sometimes. It means loss of my freedom. My child always comes first. I can't always look back. I have to look into the future (Jean).*

As in Black's study, Jean's situation is constructed as a turning point for her and forced her into adulthood prematurely. Black and her colleagues (2009) also note in their study that adolescents and young adults inhabit an ambiguous developmental space; they are adolescents by age but are shouldered with responsibilities commonly reserved for older persons. Older mothers in her study described this situation in relation to their previous experiences. These mothers felt competent, even when this was their first pre-term infant, and made the needs of their children at home a priority – a finding not supported in my own study. Some of the mothers in my study reported the opposite to this, stating that their children at home were neglected because of the worry and fear attached to the survival of their infants.

*My focus wasn't on him [son] anymore it was now on this child [premature baby](Samantha.)*

*My son was also looking forward to having the baby. He was with me all the time. I had to pull myself right, otherwise my son would have been a lost case. For my son to continue with his life I had to put this behind me (Kerishne).*

The process also seemed incomplete for those women who lost their babies, again pointing to the received view of pregnancy which announces that after being pregnant for nine months, the end result is a healthy infant.

*Going home without the baby didn't feel right. It felt incomplete going through the whole process and then the loss and then the closure (Miriam).*

*Just a week or two before that I actually went for a check-up and everything was fine, even though my BP was a bit up. After a repeat my reading was normal and the nurse said everything's fine. I did not always understand what the nurses were telling me. I did not understand that I am losing my baby, and that they are telling me to terminate my baby (Yvonne).*

In an interesting study examining sacred maternities and post-biomedical bodies, Pamela Klassen (2001) engages in the problematising of both constraints and possibilities of birthing bodies through an ethnographic analysis of North American home-birthing women's narratives. Two of the women she interviewed were veterinarians and they described their decisions to homebirth based on their views of the significance of procreation for a woman's life on philosophy that is a melding of God's will with evolutionary imperatives. One of the participants says: "It's the cycle of life that's meant to be, and it's completed in birth ... This is what God meant; this is one of our intended focuses on this earth" (p.9).

Viewing what women in my study were talking about in some ways implicitly refers to this cycle of life as something that is God-given and natural. Having this process disrupted or interrupted culminated in participants feeling robbed and cheated which emerged as a further strong theme in framing emotional responses.

#### **6.2.8. Feeling cheated**

Powerful feelings of being fleeced emerged during the interviews. Participants explained how they felt robbed and cheated for different reasons through this process. For some, feeling this way stemmed from the premature ending of the pregnancy, while for others it related to the loss of their babies.

*I still wanted my big tummy. I felt robbed. I was disappointed. There is a reason why one is pregnant for nine months (Kayla).*

*I wanted to be pregnant for nine months. I felt robbed (Jean).*

In Kidner's study (2000) six of the nine women who participated shared feelings of loss and grief regarding the HELLP syndrome delivery which was different from the expected pregnancy outcome. One of the women in this study recalled: "I just cried, I just thought: this isn't the way pregnancy is supposed to be. I mean you have visions of natural childbirth and your husband there and so exciting" (p71). Another participant in Kidner's study also expressed how she felt robbed of the experience of having the child as normally as can be, which one deems normal.

*I felt cheated because I was not given enough detail. When I left the hospital I felt empty and cheated. Going home without the baby didn't feel right. It felt incomplete. (Miriam).*

*I remember walking out of hospital feeling... I can't even describe how I felt. I can't ever recall feeling so devastated (Micha).*

Micha also lost her daughter and she described the emptiness leaving the hospital without her baby in her arms. A study by Adolfsen et al., (2004) reveals how women spoke about the loss of their pregnancies and children. One of the participants in this study talks about the "feeling of utter emptiness that occurs after the little living creature that was there no longer exists" (p.551). The women who experienced miscarriages spoke about how they felt deprived of something after their operations. The authors of the study concluded that the miscarriage seems to be experienced as a loss that can be a feeling of loss or something physical such as losing a body part. In my study however, the miscarriages occurred at least after 20 weeks gestation and in the case of Miriam it was the death of a full-term baby.

#### **6.2.9. Feelings of confusion and bewilderment**

Confusion and bewilderment were expressed during different stages of the process. For Yvonne the confusion surfaced at the beginning when she went into hospital.

*How could the nurse tell my husband I am ill. What is wrong? (Yvonne).*

For Micha when the diagnosis was made, everything seemed confusing.

*When the gynae came I heard the sister saying HELLP, but I had never heard that term in my life. I was bewildered, confused. I did not know what was happening to me. (Micha).*

The other participants expressed their confusion in the following ways:

*I don't know what I felt at the time (Soraya).*

*I'm like all confused (Samantha).*

*I was confused, did not know what was going on around me (Jean).*

*In ICU I was stressed, lonely and confused (Xoliswa).*

In Kidner's study (2000) bewilderment was expressed in relation to women's symptoms being misdiagnosed and the diagnosis of HELLP syndrome being delayed. Confusion arose from the symptoms of the mothers remaining unchanged. On one day she would be told everything is fine; the next day she is informed that she could lose her life. Kidner's study

also revealed attempts by doctors to normalise symptoms that women were experiencing. Doctors attending to the women in her study sent women home and told them to “take it easy” or go on bedrest or to follow a low-fat diet.

#### **6.2.10.      **Profound Sadness****

Profound sadness seemed to underpin the entire experience for women. Many of the participants spoke about how they wept during their experiences. Some cried when they saw their premature babies, while others cried at being treated so disrespectfully by nurses at a local state hospital. In Jean’s case, the circumstances of the pregnancy were just too painful for her. She cried when the father of her baby would not acknowledge her pregnancy.

*I just cried. I cried for months. I cried when I saw all the pipes and machines and goedetjies. I wasn’t scared because I didn’t know what was happening, but I cried (Soraya).*

*For six months after my pregnancy I would sit in my bed and just CRY (Kerishne).*

*I did not have any privacy. There were lots of tears. I did not have any privacy. The nursing staff were very unhelpful. They passed ugly remarks. The nurses spoke to patients as they would to children (Evelina).*

*I cried because of the rejection. I felt sore because father would not acknowledge the child (Jean).*

*I broke down three days later. I was medicated, given some antidepressants. I then rejected it (Miriam).*

*Sometimes I just want to be alone and cry (Xoliswa).*

*I cried because in state hospitals there is not only people who lost their babies, but you hear babies crying around you and that finished me (Yvonne).*

The experience for women seemed filled with deep psychic and emotional pain. The crying and tears may have been an intense expression of the deep sadness and loss they experienced.

### 6.2.11. Feelings of anger

Feeling angry was expressed unashamedly by some of the participants. What becomes evident is that the participants were angry for different reasons. On one hand, anger was expressed at the loss of the baby; on the other hand, it was expressed at nursing staff and medical care.

*I was very angry at my loss (I screamed at someone). I was also angry at perceived blocking of information. I wrote them a stinking letter. Got no feedback. Two/three times I walked out of the hospital. The medical side of our government is pathetic (Kerishne).*

*The nursing staff made me feel so small. They [staff] made me feel like nothing. I felt angry and rebellious at times. (Evelina)*

Feelings of anger were also expressed by the women in Kidner's (2000) study. Their anger was directed at their own bodies and at the medical provider. In my study, women also expressed feeling betrayed by their bodies (this is discussed as a separate meaning unit).

The anger expressed by my participants was palpable. Kerishne exploded and said she felt paranoid when no-one was sharing information with her. She also lodges strong criticism towards the government and state care. The word 'pathetic' is used by her to describe state care. Her feelings are understandable given that when she initially went for help, she felt that she was not heard. When transferred to a state facility she slipped into a coma and had to be flat-lined twice. She lost her baby and almost lost her own life. The plea for help is clearly seen in her words:

*It was more stressful, knowing I was not getting any answers. It's like try to help me heal. It will help me understand what I went through (Kerishne).*

In Evelina's case she talks about how small or inferior the nursing staff made her feel.

*I wanted to be a good patient. If you ask others [nursing staff] it is a problem (Evelina).*

She clearly positions herself as a patient and says she wanted to be a good or compliant patient. However, in the face of the attitudes of medical personnel this became challenging and caused feelings of anger and resentment. A key thread thus emerging from the excerpts is that whatever the challenging experiences were for participants, they were exacerbated rather than mediated by the responses of medical staff and the 'caring' professions. In

addition, in cases of extreme trauma, dealing with one's own pain and discomfort is already challenging and therefore disrespectful attitudes from nurses compound the problem.

One of the participants (a teenage mother) explained her anger towards the father of the child and *how* she resorted to self- mutilation.

*I would walk against the sharp objects, or against the furniture to hurt myself. There are marks on my stomach. It was painful. I felt sore because the father would not acknowledge the child. I was very frustrated. I was angry with the father and therefore wanted to hurt myself physically. Everytime I heard a story I got angry. I turned my anger inward. I discovered I was pregnant at 16 weeks. I felt something was not right. I was angry when I ended up not being healthy (Jean).*

Her case was ironic in that she was angry at the father's failure to acknowledge his child and in a way wanted to end the pregnancy; yet at the end when the baby was fully developed and she was ill, she was angry at the fact that she was not healthy.

Yvonne's anger was directed at God as is evident in her story.

*When I was grieving I was sad, I was confused, I was angry. God why, why, why? I was angry at God. Why are you taking away this second baby? (Yvonne).*

She talks about how she and her husband and men of God came to pray for her and for her baby. When her pregnancy ended and she lost her baby, she felt her prayers were not answered and she was angry.

#### **6.2.12. Feelings of helplessness and powerlessness**

Feelings of helplessness and powerlessness seemed to pervade this experience for all the women. However, some of the participants were explicit about these feelings in the face of the medical establishment.

*In the face of medical science, in the face of this all-knowing doctor, who are you to question and not to trust their judgement (Micha).*

*I felt powerless and helpless. I felt **powerless** in the face of the establishment (Evelina).*

*I felt helpless; I felt I couldn't do anything. I just have to hear what the doctors and sisters have to say, and just take their word for it (Soraya).*

*There was **no control**. So you feel helpless. You first think of your child (Kerishne).*

*I felt helpless. Not in control (Kayla).*

*I felt helpless and powerless (Yvonne).*

Commensurate with Kidner's findings the women in my study also felt that decisions about the types of interventions (medications, delivery and so on) were often made without *explanations* or input from the family.

*I questioned the doctors about the tablets that they prescribed that was supposed to help (Yvonne).*

Writing from her experience as a gynaecologist, Christiane Northrup, says that as a doctor she was trained to be "paternalistic, the all-knowing outside expert" (1995, p9). Furthermore the public are conditioned to believe that medical personnel are the paragons for healthy behaviour. Yet, she quotes reports from the University of California where 50% of doctors themselves do not have a personal physician – something they advocate for their patients. She therefore points out the contradictions in that people regularly hand over control of their own health to less than perfect models of unhealthy living.

Many feminist theorists have argued how the medicalisation of pregnancy in general alienates women from their own experiences and how it marginalises women's lived experiences with pregnancy, resulting in women's perspectives rarely being told, heard or given any authority (see for example Davis-Floyd, Oakley, 1984; 1992; Young, 2005). Feelings of powerless and helplessness are the consequences of medicalisation in general. In cases where pregnancies are complicated, women are much more reliant on these reproductive technologies and medical knowledge. Most of the decisions made in the case of HELLP syndrome are left to the attending professionals. Due to the insidiousness and the rapid deterioration of the disorder, decisions have to be made instantaneously and women have very little say in decision-making. The combination of these factors I believe renders women completely helpless and powerless. In the HELLP syndrome experience doctors literally take over as both the mother and baby's life are endangered.

Based on the results, it is evident that HELLP syndrome is an emotionally charged and taxing experience. While participants had deep intuitive feelings, these feelings were often minimised or discounted by both the participants themselves and healthcare

providers. Intense feelings of being out of control, guilt and negligence, fear, shock, disbelief and vulnerability earmarked the experience. In addition, participants were left feeling confused, sad, angry, helpless and powerless. The obligatory termination of their pregnancies, irrespective of gestational age, culminated in the often abrupt disruption of their process.

On closer inspection it appears that these feelings are deeply entrenched and stem from major systems and beliefs that are rampant in society. Ideologies of control seem to set women up in perpetuating notions that medicine and science have 'the body' under control. Yet when faced with HELLP syndrome participants reported feeling extremely out of control which in turn renders these very recipients of such beliefs vulnerable and completely powerless.

A Foucauldian understanding of power further advances this notion of control since the body is seen as the primary site of biopower and is located at the centre of the techniques of rational control. In obstetrics, power functions through monitoring and surveillance, subjecting pregnant and birthing women to 'constant and total visibility' via the 'normalising gaze'. The concept of rational control is thrown into question through pregnancy and this notion is totally obliterated in a high-risk situation where participants felt completely out of control and were unable to exercise any control or had minimal control over their situations. Coupled with these emotional aspects were the more psychological components which also left participants reeling.

### **6.3. Psychological/Cognitive Responses**

Some of the participants' psychological/cognitive responses to their experiences emerged and are reflected in the themes below. These responses included thoughts of dying which were based on their near-death experiences as well as the fear of death which permeated this experience for most of the participants. For those participants who had near-death experiences, there was also the sense of vacillating between different levels of consciousness. While some were physically comatose, they described experiences and mental images they saw. In addition, the participants expressed how they lacked knowledge of HELLP syndrome resulting in not understanding what was happening to them.

### 6.3.1. Thoughts of dying and near-death experiences

Thoughts of dying were uppermost in the participants' minds as many of them faced death. Kidner (2000) reported that the maternal experience of HELLP syndrome was saturated with a fear of death and remained a powerful influential factor in the decision to avoid future pregnancies. Below follows extracts from some of the participants in my study:

*Thought I was going to die. I thought I had checked off the planet. It had been so hectic (Maya).*

*He stood by me and was holding my hand and thought I was dying (Micha).*

*I don't know, if I don't make it like now like speaking in such a negative way (Samantha).*

*I had a near-death experience (Evelina).*

Kidner's study (2000) confirms what women described in my study. Some of the women reported that the near-death experiences they had constituted the worst part of the experience for them. One of the participants in Kidner's study remarked: "I just had all kinds of things running through my mind and thinking I can't die, I have a child to raise, this is the child we have been waiting for, it would be unfair if I die. God can't let me die" (p.65). While thoughts of dying were very prominent for some of the participants, others faced death and vividly recalled these near-death experiences.

Those participants who had near-death experiences vividly described how they slipped in and out of consciousness. While they were in a physical coma they described the mental images they saw. Maya described this comatose state in very cognitive terms.

*Coming out of anaesthetic, something is happening in my head (hypnogogic, something happening in my head). It's like a dream. I am playing the piano. Grandmother who had died was there, playing a piece of Chopin (Maya).*

*Then I was slipping in and out of consciousness (Kerishne).*

*After that, it was a haze. I was in a coma (Miriam).*

*I was drifting in and out of consciousness (Micha).*

In Kidner's study (2000) one participant reported: "I can remember, well honestly, like I remember looking for the light and it terrified me that I wasn't seeing it, because I thought I was going to alternative places, but now I realise it was because I wasn't dead".

### **6.3.2. Lack of knowledge and understanding**

The lack of knowledge and understanding was significant for the participants and was linked to the emotional experiences of fear, guilt, shock and disbelief. Besides the fact that most women stated that it was the first time they had ever heard the medical term 'HELLP'syndrome', they could not fully understand the impact, consequences or seriousness of the disorder.

*I wasn't scared, because at the time I was in danger, I didn't know. I had no information. Nobody told me what I had, or what the diagnosis was. I had no idea how serious it was (Soraya).*

*I did not understand the impact of the illness (Evelina).*

*There was lots of ignorance. I was scared. I did not understand (Jean).*

At the stage of recruiting participants for this study I spoke to the head of high-risk obstetrics at the local state hospital. He explained the challenges involved in relaying such difficult information to those patients who had HELLP syndrome. What compounded the issue, he said, was the language barrier, particularly in a county like South Africa with 11 official languages and English not always being the mother tongue. Having to relay difficult information in an unfamiliar language to the patient presents a significant challenge for doctors in South Africa.

According to Kidner (2000) the women in her study reported that the state of not knowing was pronounced when very little information was shared with them by the healthcare team about the diagnosis, pathophysiology, prognosis and treatment.

*It was more stressful, knowing I was not getting any answers. The answers I received were very vague (Kerishne).*

*As I was lying there, I felt clueless (Micha).*

*I was thinking, how could the nurse tell my husband I am sick and this is very serious? What is wrong with me? I did not always understand what the nurses were telling me. I*

*did not understand that I am losing my baby, and that they are telling me to terminate my baby” (Yvonne).*

Presenting knowledge and taking knowledge in are two different things. In some instances it appears that women were presented with minimal information regarding the illness as in Soraya’s case, when she explained that nobody told her what she had. However, taking in information when everything is in such turmoil, obviously seemed very challenging, to say the least. What participants may be alluding to in some instances is that they could not absorb this information, nor could they understand the impact or deleterious effects of this disorder. In a study conducted by McCain and Deatruck (1994) examining the experience of high-risk pregnancy, women and their partners stated they felt the doctors had overloaded their minds the night he was discussing the issue with them. Clauson (1996) in her study explores uncertainty and stress in women hospitalised with a high-risk pregnancy. She asserts that higher uncertainty scores for some women may have been related to altered cognitive capacity or the ability to process information due to internal stimuli such as pain, discomfort, danger or any physiological dysfunction potent enough to distract resources of attention. The women in her study admitted with premature labour, bleeding, premature rupture of membranes, or hypertension were dealing with physiological events that may have impaired more accurate appraisal of their situation (Clauson, 1996). Similarly, I suspect that in the case of some of the participants in my study, the situation was simply too overwhelming and when information was presented, they could not fully relate to it.

The role of information sharing is noticeably deemed important by one of the participants. Kerishne spoke about information as an appeal for help in her healing process.

*It’s like try to help me heal. It will help me understand what I went through (Kerishne).*

The role of knowledge that is regarded as fundamental to these women cannot exclude a closer examination of knowledge and power. Foucault describes the link between knowledge and power, suggesting that they operate in a mutually generative fashion, working to strengthen each other. One of the first issues a pregnant woman is confronted with in hospital is the utilisation of scientific medical jargon. It is one of the many strands in an overall web of power through which medical staff are able to maintain superiority over their patients, using the power of medical discourse over everyday common language. This use of coded language functions to exclude the patient from medical discourse, a language heavily

laden with knowledge. A woman during pregnancy and childbirth, unable to decipher this code is denied the opportunity to fully participate in decision-making. Even though she may have an astute understanding of the situation from her own perspective, the authoritative knowledge of medicine is valorised over a woman's embodied knowledge of herself.

Knowledge in the case of Kerishnewas a call for help with her healing process. She iterated that having an understanding of what happened would help her heal. Her story also expresses the need to know, since she said she was more stressed by not knowing what was happening and why it happened. She also mentioned that when she did receive answers they were vague. Thus it appears that having knowledge and understanding served a more important purpose, namely, that of healing. Northrup (1995) draws a distinction between healing and curing. Medical science trains doctors to cure through external treatment, medication and surgery and treats the symptoms and not the root cause. This external treatment does not necessarily address the factors that contributed to the symptoms in the first place. Healing goes deeper than curing and must come from within. However, while healing and curing are different, curing and the restoration of physical function may accompany healing.

In the final analysis participants expressed their lack of knowledge of the disorder itself. This lack of understanding of the impact, consequences and seriousness of the disorder worked for some of the participants, but was deemed inappropriate by others. In the South African context, however, the provision and relaying of such critical information is even more difficult due to language barriers. Besides the external barriers to communication, a number of internal factors such as pain, discomfort and danger also presented their own set of problems and arguably played a role in the way the participants received and made sense of this information. Furthermore, knowledge provision was seen as important in their healing process.

What also underscores this process and cannot be ignored is the role of knowledge in the medical context itself. In this regard the link between knowledge and power needs to be acknowledged, as well as the way in which knowledge has been used in medicine to set up privileged positions on one hand while maintaining exclusionary practices on the other.

### **6.3.3. Feeling unprepared for such an experience**

The shock, disbelief and being caught by surprise culminated in some of the participants thinking that they were completely unprepared for the experience they endured. This experience is well articulated by the question posed for some of the participants:

*Is it possible that things can go so wrong in a pregnancy? (Micha).*

While Yvonne said she remembered that she had read an article in a local magazine on HELLP syndrome, she spoke about how at the time she paid scant attention to the information. However, when she was faced with HELLP syndrome, she requested that her husband bring that very article to her in hospital to read.

*When I was in hospital, and they said I have HS I asked my husband to bring back that magazine (Yvonne).*

*I was mentally unprepared for this (Kayla).*

*I was so not prepared for this (Yvonne).*

Kidner (2000) reports that a whirlwind of activity is sparked once HELLP syndrome is recognised and formally diagnosed as attempts are made to save the mother or baby or both. This whirlwind of activity coupled with a lack of knowledge surrounding the disorder resulted in the participants feeling completely unprepared for the magnitude of such an experience. Decisions had to be made swiftly and there was very little time to think. The participants were therefore left feeling unprepared and this in turn resulted in the women blaming themselves for many things.

### **6.3.4. Locating blame**

The participants in my study seemed to have entered into an intensely introspective and contemplative period following their HELLP syndrome experiences. This involved questioning themselves and their actions, and critically reflected on their own abilities to mother successfully. According to Gardner's 1994 analysis of historical documents, pregnancy is a fairly recent topic for public discourse. Gardner quotes Evans (1875) who asserts that children are made by their parents, not sent, with all their imperfections on their head, from heaven. Primary to this radical shift in thinking of pregnancy and birthing is the emergence of the tenet that reproductive processes are the responsibility of individual agents, who are competent in making major decisions that influence both the well-being of

the foetus and the mother-to-be. The availability of this discourse therefore opened up spaces for women whose pregnancies had not concluded with 'successful' births, or had otherwise been inconsistent with the normative claims of motherhood to ask questions like 'Why did this happen? What did I do wrong? Who is to blame?' The issue of blame in the HELLP syndrome experience was portrayed as a huge one. Blame seemed to manifest on two levels, namely, internally and externally. On an internal level, blame was expressed subtly in the following ways:

*Is it possible that things can go so wrong in a pregnancy? Maybe I had too much GAVISCON? Mentally, emotionally, I think Gaviscon left a bad effect on me (Kerishne).*

*If I could do it differently, it could have been through being more relaxed and taking more time out. Maybe I should have had my children at a younger age (Miriam).*

*I did wonder if there was something that I could have done differently (Yvonne).*

*A part of me feels I must have done something wrong. The hardest part was trying to think what you did and didn't do (Kerishne).*

*I took my health for granted, abusing my health (Kayla).*

Jackson and Mannix (2004) contend that mother-blaming is a pervasive and serious problem and it has been established that the professional literature has strong and entrenched mother-blaming messages. Once again the discipline of psychology rears its head in this regard. Theories such as the attachment theory of Bowlby purport that mothers are primarily responsible for any and all problems that emerge with their children. Other psychological theories that place the mother at the centre include cognitive-developmental theory, learning theory and Freudian theory. From a feminist perspective there is general consensus that these notions are burdensome to women and do not place equal responsibility on male shoulders.

Jackson and Mannix (2004) argued that the concept of blame and liability directed at mothers ensues from the moment of conception, and continues throughout the pregnancy and child's subsequent life. In their article, Jackson and Manning quote Burrows who argues in a legal case that it is easier to blame individual parturient women for 'inflicting harm' to

their unborn children than to contemplate the role played by societies and governments for policies that are not supportive to women, particularly to mothers.

In their study on mother-blaming, the authors confirmed that blame placed on women by others was experienced as burdensome. Occasionally they reported it was something with which they burdened themselves (Jackson & Mannix, 2004). Commensurate with what the participants in my study felt, it seems evident that these women internalised the mother-blaming attitudes of the messages and people around them and hence blamed themselves for things that were often beyond their control and that could not be linked to actions or omissions on their part (Jackson & Manning, 2004). In addition these authors cite a study conducted by Schroeder (1996) where women with high-risk pregnancies experienced guilt and self-blame if they were unable to adhere to strict bed-rest, even when they were required to attend medical treatment.

Jackson and Manning (2004) further assert that mother-blaming discourses are deeply misogynistic. They contend that the biomedical discourses from which mother-blaming tendencies emanate are deeply-rooted male dominated discourses. These authors therefore demonstrate how this burden of blame takes its toll on women and how it may also be experienced as guilt, feelings of inadequacy, anger and self-blame.

Furthermore, one of the participants blamed her mother for her genetic make-up.

*I blamed my mommy, for like giving me this like the doctor explained to me that hypertension is something that you inherit. Afterwards I felt a bit guilty because she wasn't there to defend herself. (Samantha)*

On an external level, some of the participants blamed the quality of medical care. Miriam who is a doctor tried to rationalise and says she could understand why her gynaecologist could not detect earlier on that there were complications, as she alludes:

*Maybe if you are a super specialist in the field you know they would have picked it up. My brother and sister (who were medical doctors) literally had a fight with her (gynaecologist) because of her negligence (Miriam).*

In her talk she acknowledges that being a specialist (gynaecologist/obstetrician) was not sufficient; one would have to be a super specialist to have picked up her condition. This speaks once again to the difficulty in diagnosing this illness, as up to 80% of all cases are

misdiagnosed, which then has serious repercussions for the maternal-foetal dyad (Kidner, 2000).

The quality of medical care also surfaced in relation to state versus private care.

*I am not knocking (state) medical care, but a mother's touch is different to medical care. The care at the state hospital was non-existent. You had to ask for pain relief medication. I took out my own drip (Kayla).*

While this participant was under the supervision of a gynaecologist in private practice, she was transferred to a state hospital on diagnosis.

*At MOU they didn't take heed of me telling them my pressure's high. I felt I was noheard. It may not have saved the baby, but maybe I did not have to go through such an ordeal (Kerishne).*

These participants were all at a local state hospital. As previously mentioned, any exploration concerning pregnancy and childbirth in South Africa, must be cognisant of the racialised, cultural and class-based divisions that mould, constrain and produce women's extremely unequal maternity experiences in this country (Chadwick, 2008). The differences between the private and public health sectors in South Africa are so huge that any form of pain relief is rarely offered in state care (Jewkes & Mvo, 1997; Abrahams & Jewkes, 1998). This was clearly articulated by Kayla. In addition, studies conducted by these authors demonstrated the demeaning and derogatory ways in which participants were spoken to and treated.

More generally, Yvonne who was also at a state institution questioned the effectiveness of medical intervention itself and seemed extremely disillusioned.

*Despite all medical intervention, I felt weak when things did not work out. I felt useless. I felt all this for nothing (Yvonne).*

The disappointment in medical intervention is evident and once again may signal the deeply ingrained belief of medical science as progress and saviour (Chadwick, 2007). Underlying this cultural script is the notion that for childbirth to be safe it has to take place in a hospital setup with medical backup. Hence Yvonne's expression may be testament to this very storyline which has become so deeply ingrained in the psyches of many women.

Yvonne also questioned God.

*God why, why, why? God is the one who gives life and takes life away (Yvonne).*

### **6.3.5. Use of defence mechanisms**

Defence mechanisms were utilised in order to cope with the severity of their situations. Imes, Clance, Gailis and Atkeson (2002) assert that it is important to be mindful of the ways in which people block or cloud awareness through the use of defences. Denial of the severity of the syndrome itself was reported by some of the participants.

*I was in absolute denial. I did not want to believe there was anything wrong with me. I am going to prove you wrong. Well it proved me wrong hey? I blocked things out (Kayla).*

*I tried to understand what had happened to me. I called a colleague at a research institution and tried to understand what had happened to me from an intellectual point of view (Micha).*

*With my second pregnancy I was happy, but there was also fear. I kept blocking it out saying that it was going to be fine (Yvonne).*

Maya who is clinically trained in psychology spoke about the defence mechanisms her husband utilised to cope with his own emotional state at the time. She reported how she felt he projected all his safety issues onto the safety of their son. At that stage Maya was transferred to a state hospital as she had developed an embolism. Just before her arrival, a baby had been stolen from that institution, hence her husband's fears. Her understanding of the situation, however, was that his fears for her safety were being projected onto their son.

*Difficult experience [tired sigh]. Baby had been stolen sometime before this event. All my husband's anxieties about me were projected onto the safety of our baby (Maya).*

The psychological aspects of the HELLP syndrome experience encompassed thoughts of dying, drifting in and out of consciousness, feeling unprepared and feeling a lack of the necessary knowledge to assist in understanding the disorder and to aid in the healing process. Self-blame seemed to be the issue that underpinned the experience for the participants. Since mother-blame is so pervasive and mothers are generally held liable from the moment of conception, it is not surprising that the participants tried to locate the blame

for what happened both within themselves and at external sources. Furthermore, to cope with a dizzying array of psychological and emotional issues, the mothers in my study also commonly employed defence mechanisms in an attempt to deal with the gravity of their situations. Besides the psychological issues there were the bodily aspects to deal with.

## **6.4. Bodily Aspects**

### **6.4.1. Intensive care unit experience**

Five of the participants ended up in the intensive care unit. This experience was described as stressful, difficult and lonely.

*When I woke up I was in ICU with pipes and everything in me. I bled internally. Doctors told me they may have to remove my womb. I was flat-lined twice (Kerishne).*

*When I was in ICU, I was so lonely, I stressed, and I was so confused. I know when someone is in ICU, their life is in danger (Xoliswa).*

*I was allowed two visitors at a time. I was not aware of what was happening around me (Micha).*

*The second day I was struggling more and more with breathing. I was given oxygen. I was then taken to ICU and by the third day was ventilated because I was blowing up and struggling profusely to breathe. After that it was a haze. I was in a coma (Miriam).*

Based on the transcripts of the interviews, the ICU experience was very challenging for the participants and represented a time of confusion and disorientation.

### **6.4.2. Experience and the meaning of pain**

Some participants reported that they experienced no pain, while others experienced it at different stages of the pregnancy. More generally the women felt that pain seemed to serve as a messenger of sorts. For those who experienced no pain, it was believed that had there been pain it would have served as a warning that something was amiss.

*If there was some physical pain, it would have been easier. If there was pain, I would have paid more attention (Kayla).*

*I had no stabbing pain, but I had a pressure problem. I was flat-lined twice (Kerishne).*

*The worst thing is I didn't feel anything. There was no warning. The body does not warn you (Evelina).*

The participants who experienced pain experienced it either quite early on in the pregnancy or post-partum.

*The pain stuck around. Went on for about a week. I also had intense post-partum pain (Maya).*

*I had bloatedness/pressure on my torso. This feeling made me nauseous. I took all kinds of meds, but it did not help (Samantha).*

*I had epi-gastric pains post-partum (Jean).*

*I had a sore tummy and could not breathe (Xoliswa).*

*I was ill from the beginning. I had discomfort and epi-gastric pains (Micha).*

*I had a funny feeling in my body/headaches and was very swollen (Yvonne).*

According to Leder (1984/85) pain always involves an emergence of meaning. "It is never given as bare, un-interpreted sense-datum to a detached observer" (p.259). Though this may be so of all precepts, pain is the one which most clearly comes conveying its own interpretation; namely that it hurts. The sufferer need not decide on the matter. Pain is the very embodied experience of the unhappy, the bad, the wrong, as immediately felt rather than deduced or induced. Leder (1984/85) further asserts that pain points toward injury, disease, the internal failure or external invasion of our being. Given these notions, it is completely understandable that some of the participants felt that there were no warning signs of what was to come. It almost appears as if not having any pain provided a false sense of security to these participants.

Leder (1984/85) continues his argument noting that even Descartes acknowledged that pain validates one's identity with one's own body in a radical, inescapable way. Simultaneously it does so in a way that we confront the body as other which is what happened in the case of Maya: 'Body becomes an OTHER'. In our normal day-to-day functioning we are unwaveringly our body, but suddenly pain renders the body disharmonious with the self.

Leder continues his thesis by contending that the pain which separates mind from body can separate and alienate self from its world. This he argues often encompasses a dialectic of unity and contradiction. Pain defies any fantasies of pure transcendence, of a self – detached from social and material bases. Pain grounds us, brings us back to our situations, our dependencies. However, this reality to which pain returns us is never completely home to us.

The perspectival nature of embodied experience is exposed not as the source of autonomy, but of loneliness. Pain thus forces us outside the ‘natural’, perceptual and social world we have taken for granted. The isolated subject is left a proto-solipsist. While pain is not metaphysically private, it brings with it destitution. In the final analysis it launches an experience of primordial aloneness, of the distance separating self from the world (Leder, 1984/85).

#### **6.4.3. Body betrayal and failure**

This was one of the few instances where the mother’s body emerged in the interview and thus demonstrates the ways in which dominant discourses of maternity and motherhood patrol the boundaries of subjectivity. More than just foregrounding dominant discourses, the maternal body also challenges them. In the case of some of the participants the mother’s body is most visible because of its failure to function in a less than optimal way so that a healthy baby could be birthed.

Participants expressed strong sentiments regarding their bodies during this time. Some of the women felt that their bodies had failed and betrayed them.

*My body failed me* (Yvonne, Micha).

*My body betrayed me* (Evelina and Micha).

These feelings of body betrayal and failure led Micha to conclude that:

*Pregnancy has lost its innocence for me. I am not naive anymore, thinking that if I start off pregnant, I will have a baby* (Micha).

Rich (1976, p 40) writes “The body has been made so problematic for women that it has often seemed easier to shrug it off and travel as a disembodied spirit”. Bordo (1989) concludes that representations of the body in Western culture conceptualise it “as something

apart from the true self and as undermining the best efforts of that self” (p5). The underlying idea is that the truly liberated and disciplined self is able to foster rational thought, which is the instrument of the self, purely on the basis of its freedom from the impulses of the body. This mind-body dualism clearly surfaces with some of the women in my study. As articulated by Yvonne, Micha, Evelina and Maya, their bodies were split off from their true selves and seemed to undermine these efforts, which in this case was giving birth to healthy babies.

Emily Martin (1992) writes that feminist poststructuralism indicates that both past and contemporary biomedical discourses subscribe to the image of the body as a prototype of industrial society or a machine. The menstrual cycle for example is described as a “mechanised system each month... the hypothalamus acts as an elegant interpreter of the body’s rhythms, transmitting messages to... set the menstrual cycle in motion” (p.40). Utilising the Marxist concept of alienation, she depicts childbirth as a form of alienated labour in which the birthing body is likened to a machine and childbirth is thought of as a form of factory production. Her analysis of obstetric texts highlights how the labour of the birthing body is reduced to the mechanical activity of a uterus machine. In such a conceptualisation of childbirth, the subjectivity of the woman is completely effaced and the woman is reduced to being a passive host for the contracting uterus (Martin, 1987, p61).

The fact that women felt that their bodies had failed them seems to mirror this sense of alienation and fragmentation constructed in medical discourse. In these instances it is pertinent that women seemed unable to resist the underlying assumptions that self and body are separate (p89). This certainly seems to demonstrate that women themselves have internalised medical notions of female bodies and reproductive processes.

Another of the participants relayed absolute disgust at her body and recounted how her relationship to her body changed.

*My relationship to my body changed. I was disgusted at my body. Body becomes an OTHER. Body changed.(Maya).*

Bartky (1989) contends that a variety of cultural discourses have espoused that women inhabit an ‘inferiorised body’ (p. 20). It is not surprising therefore that women experience their bodies as the enemy. “I am defective not just for others, but for myself: I inhabit this body, yet I live at a distance from it as its judge, its monitor, its commandment”(p.21).

Bartky (1989) furthers her argument and asserts that this blaming of the body may surface to function as a way to exonerate women from judgments that attack their sense of self, as their 'transgressions' are split off and projected onto a pathological condition, over which they have no control. Since the focus of this projection is the reproductive body that is inherently positioned as disordered, unruly and deviant, the result of this self-policing is the direct assault on the women's corporeality (Ussher, 1997).

On a more subjective level Leder (1984/85) contends that "surfacing as thematic object, moreover, as recalcitrant to the personal will, the body seems something other than, and opposed to the I" (p262). We observe the painful body as though from a distance, prod it, point at it, take it to the doctor for examination. The alienation and objectification accomplished in the medical encounter merely extends a phenomenological shift already started by the illness. The painful body thus emerges as a thing or as a threat, prison or locus of suspicion. It has betrayed us, or we have betrayed it. We therefore believe that we are bound together as unenthusiastic partners, and after serious pain we may fail to regain our former trust (Leder, 1984/85).

Based on the interviews, the physical aspects of the illness presented its own challenges. For those participants who ended up in ICU, it was a distressing and difficult period. The body emerged quite visibly through bouts of pain and in the participants' words, through its 'betrayal and failure'. Pain seemed to serve as an important conveyor that something was wrong.

Strong expressions relating to their bodily functions were articulated. Due to this perceived betrayal, participants felt that their bodies sabotaged the project of the self, which in this case was to birth healthy babies. In addition, this failure of their bodies to reproduce in a 'healthy and normal' way seemed to mimic a sense of alienation and fragmentation that Emily Martin alluded to in describing the image of the body as functioning as an industrial machine.

The intensity of these feelings resulted in total disgust for one of the participants, which could be argued corresponds to the notion that women's bodies are inferior. Bartky (1989) argues that once again the blaming of the body may operate in a way to vindicate women from appraisals that turn on their sense of self.

## 6.5. Conclusion

In this chapter I have tried to highlight the intensely traumatic subjective lived experiences of women who have had HELLP syndrome. The experience itself was described in varied ways by the participants themselves.

*It was a disaster. Everything not going according to plan (Maya)*

*I was touched by it. It was a tough time (Kayla).*

*My experience was very different to the typical experience (Miriam).*

*It was that struggle between life and death. It was a very lonely experience (Micha).*

*It was painful experience for both parties (Yvonne).*

*The whole experience was terrible (Evelina).*

Naming and labelling the experience seemed important for all participants. The commonality that underpins this experience was its catastrophic nature and how this event translates into how painful, terrible, lonely and difficult the entire experience was.

Based on what was elicited in the interviews it is evident that such a traumatic event has had some profound effects on these women. What is clear from their discussions is the confusing and troubling aftermath of this experience for the participants. Another striking feature of this experience is how it complicates and compounds various issues for women, particularly with regard to how pregnancy is subsequently constructed and how this translates into their interpretation of seeing other pregnant women. Pregnancy for some is constructed around deep fears and insecurities (understandably so).

Having been exposed to a high-risk pregnancy also throws into question many aspects that would otherwise be taken as givens, for example, one's body. Only once their bodies 'malfunctioned' (Martin, 1992) did women seriously contemplate the role of their bodies in general, and in reproduction in particular. In extreme cases (Maya) the body became the source of absolute abjection.

A further poignant point to introduce is how this entire experience foregrounds the issues around the baby and completely effaces the experience of the mother herself. This became

particularly evident when I examined the medical context (covered in the following chapter) in which this entire experience took place.



## **CHAPTER 7: FRAMEWORKS OF MEDICAL INTERVENTION AND BIOMEDICAL DISCOURSES**

The second aim of my study is to analyse the framework of medical intervention and biomedical discourses and the role they play in women's understandings of their experiences of HELLP syndrome. According to Willard (2005), biomedical discourse is defined as the rhetoric used in traditional Western medicine. Sara Hayden (2001) describes how this rhetoric functions as a discourse of power, normalising and disciplining the body, particularly the female body. Looking at the definition of biomedicine itself Willard draws on a definition proposed by Eskinazi (1998) who defined biomedicine as medical practice that focuses on the "molecular, physiological and pathological mechanisms believed to form the basis of biological processes" (p.1622). Biomedicine therefore emphasises interventions which treat biological pathologies rather than preventing disease or creating the conditions of health.

In this chapter I will therefore be providing an analysis of the discourses which women drew on to explain and make sense of their HELLP syndrome experience. It becomes apparent that their talk and stories are embedded in ideological frames such as technocratic medicine, patriarchy and contemporary challenges of the South African healthcare system. Northrup (1995) writes that for the last five thousand years, Western civilisation has been based on the mythology of patriarchy: the authority of men and fathers. She asserts that if all our beliefs and activities emanate from an underlying mythology, then it is perfectly logical to conclude that because our culture is "ruled by the father", then our view of our female bodies and our medical system will also adhere to male-oriented rules (p.5).

The analysis in this chapter focuses on maternal healthcare in South Africa and incorporates issues such as nursing versus medical care, and how intervention for HELLP syndrome is steeped in a culture of technology. This chapter then presents an analysis of the discourses and metaphors the participants utilised in order to make sense of their experiences.

### **7.1. Private versus Public Healthcare**

Women's talk about their encounters with the medical context was located within, and shaped by, the structure of healthcare in our country. In discussing what transpired during their time in hospital, it became evident that a number of binaries were erected such as private versus public healthcare, women versus men and nursing versus medicine. However, women always commenced their stories by identifying where they went to when they started experiencing problems. Inevitably this always culminated in a discussion concerning

healthcare in our South Africa. The public versus private divide always seemed to occupy centre stage in their talk. Maya describes it in this way:

*Like at VP [private institution]) everything is and I mean this concretely and uninformed and emotionally, everything is padded over. Everything is wallpapered and polished and covered. And everything is neat and nice and clean and everyone smiles and helps you. You know it was all like um cha cha cha smiley market happy clients. I thought whereas at GS [state hospital] it was like stripped everything off. There is no pussy-footing around anything. People are dying. The floor is dirty. You've got a problem, somebody else is dying next door so you wait your turn (Maya).*

Any investigation of reproduction and childbirth in South Africa must be cognisant of the racial, cultural and class divisions that produce women's extremely unequal experiences of maternity in this country. This was very evident in the way the participants related their stories. This division was referred to all the time, since all but two of the participants (Micha and Miriam), experienced care at both types of institutions either because of lack of equipment or lack of expertise in private care. Sadly, after more than a decade of democracy, South African society remains steeped in inequalities that can be witnessed in the very disproportionate ways in which women of different races and classes experience maternity. Miriam who is an orthodontist remarks:

*I was thankful I was in a private facility. Had I been in a public facility the scenario would have been completely different (Miriam).*

The public hospitals were portrayed as:

*grim and unpleasant. At GS it was like stripped, everything off. There is no pussy-footing around anything. People are dying. The floor is dirty. You've got a problem somebody else is dying next door so you wait your turn (Maya).*

Kayla who is an ex-nursing sister said that care was non-existent. Plagued by political and economic constraints, many of these institutions are short-staffed which inevitably affects the quality of care.

*To be quite honest I discharged myself (um) I nursed a couple of years ago. The NICU where babies were was brilliant, I cannot fault it whatsoever; it was superb, top of the*

*class but the maternity ward section, it wasn't, it wasn't comfortable that's a disgrace. The toilet facilities and especially the hygiene in the maternity, you know you'd expect that section to be clean and the women that go, shame the people from the townships and that, they're coming to give birth and it's only a few days rest I suppose in their whole lives that they can have a clean bed to lie on. Um nothing like that, you don't want to take a shower there. I didn't do that, I'm not racist, I'm not full of nonsense, but I'm not going to, I won't even bath my dog there. You know they looked on you once and [pause] I'm not going to judge or anything (Kayla).*

What is interesting to note is that both of the participants who reflected on the physical surroundings were white middle-class women. Examining the above excerpt it becomes apparent that some women positioned themselves not only in private versus public healthcare systems, but also in terms of 'white' versus 'black' (racialised) binaries. While these notions were echoed infrequently in Chadwick's study (2006), they were far more prominent in mine. Women in Chadwick's study spoke about how the possibility of being compelled to give birth in a state facility haunted them. In my study this was not merely a fantasy or some distant dread – it was the reality for most of the participants. All of the participants in my study except for Micha and Miriam, ended up in state hospitals. Even though Maya was at a private hospital, she was re-admitted to a state hospital when she developed anaemia for which she needed radiation treatment. The differences noted by participants did not only relate to structural disparities in care but also pertained to the differences in how they were cared for.

### **7.1.2. Disparities in care: Nursing versus Medical Care**

What emerged from the interviews were the tremendous disparities in care. The way in which women were cared for and treated, particularly in certain state hospitals surfaced continually as an issue during the interviews, with some of the participants vehemently protesting about their treatment. Kerishne complained of the 'no care attitude' of staff who constantly told her she had nothing to worry about.

*I don't wish it on my worst enemy to go through this (Kerishne).*

*The nursing staff made me feel so small. They made me feel like nothing. They were unhelpful, passed ugly remarks and spoke to patients as they would to children (Evelina).*

Jewkes *et al.*, (1998) reported on the poor treatment women received from healthcare workers with their attitudes being cited as the primary cause for concern. Jewkes asserts that while nursing discourse usually mandates ‘caring’, nursing practice in South Africa is more often than not characterised by humiliation of patients and includes physical abuse. What this study demonstrates is that patients making use of sections of Cape Town’s obstetric service experience verbal abuse which manifested as scolding, being shouted at and general rudeness; nurses failed to respect patients in general and their autonomy in particular; and that many experienced random acts of unkindness, physical violence or neglect. Although this study was conducted in the Cape Town region, Jewkes *et al.*, (1998) contend that these findings were similar to studies conducted in other provinces in the country (for example see Mathai, 1997; Wood *et al.*, 1997).

Another article titled *South Africa’s Failing Maternity Care, a Human Rights document*, (08/08/2011) also speaks about a lack of oversight and accountability for recurrent problems in the health system. This Human Rights Watch document comments on how abuses committed by health personnel contribute to South Africa’s substandard maternity care and in the process undermines one of its top priorities, namely to reduce its high maternal death rate. This report also documents maternity care failures which include abuse of maternity patients in the Eastern Cape, subjecting women and their newborns to great risk of death or injury.

However, some of the other participants who attended a different state hospital sang their praises.

*This state hospital is the best. I just believe in them. They are supportive and nice to you, like they know you personally. They will always encourage you (Samantha).*

*The nurses at the day hospital were very nice. I only saw nurses. They would scold you if you did not do what you were told (Jean).*

*The nurses cared a good deal for me. They were there (Yvonne).*

*The doctors and staff were very nice and were very supportive (Xoliswa).*

The use of the word ‘nice’ to describe some nurses at state institutions was also encountered in Jewkes *et al.*’s (1998) study. For some of the patients, narratives of abuse or neglect concluded with being rescued by a ‘nice’ midwife who, for example, cleaned the floor or

lifted the woman onto the bed. 'Nice' sisters were reported to explain or show women things; be caring towards the mother and baby; praise the women for delivering well; and did not shout or speak rudely to them.

Miriam who was at a private facility commented on the good nursing support she experienced:

*I had good nursing support. I got extra special care and that is part of the reason I pulled through (Miriam).*

Not only did these disparities relate to state/private care, but they also related to gender. Based on the participants' talk, it seemed as if they were disgruntled by nurses who were predominantly women. Miriam whose gynaecologist was a woman also expressed strong feelings about the nature of her care.

*I feel she failed. Scans should have been done earlier on. The 22-week scan was not done. I was told that she broke down, she could not cope with the situation. She was not sharp enough to pick things up earlier (Miriam).*

The doctors who attended to the participants were predominantly males. Except for Kerishne who slammed what the doctors had told her, none of the other women spoke negatively of them.

*I thought the doctors were talking the biggest load of rubbish, when they told me my life is in danger (Kerishne).*

In fact when the participants referred to doctors in their talk it was always in the context of information giving and sharing. Rarely were doctors' attitudes spoken about. For example Xoliswa when talking about her doctor, said:

*I was taken to hospital and the doctor induce me. He gave me tablets to let the baby come out. This did not work and the doctor said my son and I we in danger (Xoliswa)*

Micha provided a lengthy explanation of her doctor's involvement in her experience.

*My BP was quite high, and the attending sister thought it was because of my anxiety. When the gynae came I heard the sister saying HELLP, but I had never heard*

*that term in my life. The doctor came and took my hand and I thought OH God I am dying (Micha).*

Yvonne always referred to doctors as 'they'.

*They kept on telling me to be calm, be calm, be calm. You are fine. Now all of a sudden they were telling me that the pregnancy is making you sick. They told me the kidneys were affected and then afterwards the liver and then the platelets (Yvonne).*

Referring to 'they' could be related to what happens at tertiary hospitals where students are taught. Many residents and students consult with patients in addition to the doctor. Maya in her interview alludes to this by proclaiming:

*I was surrounded by medical students. The ward round was **unbelievable** (Maya).*

The silence surrounding the 'caring' aspect of medicine was noticeable. It certainly appears that dualisms like women/men, caring/curing and nursing/medicine were erected with the power being invested in the latter category. Traynor (1996) comments on the well-known argument that nursing embraced the male-constructed values of (medico) scientific knowledge as its model for knowledge development in order to gain autonomy and social status. In this way he argues that in the arena of knowledge, women have been colonised by men. He further contends that caring is both the primary activity and key value for nurses and this caring orientation is constructed as diametrically opposed to scientific knowledge and values which are the central tenets of medicine. These dualisms became quite evident in how women spoke about the way in which they interacted with both doctors and nurses. It was expected of nurses who are predominantly women to be responsible for the caring aspect while doctors were expected to operate in a more objective, curative kind of way.

In an interesting study, Cassell (2004), explains both the emotional and professional divisions she witnessed in her study. She identified a culturally female-identified expressive role that nurses (both male and female) had to perform. Nurses, it was written, were more interested in patients' stories and the personal aspects of their lives. Doctors, on the other hand, assumed a culturally masculine instrumental role. Cassell (2004) observed that doctors (both male and female) focus on disease, dysfunction and cure, whereas nurses seemed more involved in care. She further asserts that doctors concentrate more on the disordered

body, while nurses are involved with the sick person. Hence it is evident that these dualisms are constructed and operate in very tangible ways in medical contexts.

### **7.1.3. Context: A culture of technology**

During their hospital stay, mothers' narratives reflected two discrete technological cultures: her own pregnancy in which technology was focused on her body (ICU); and the baby (NICU), in which technology centred on the infant. The ICU experience was spoken about more in personal, experiential terms than in terms of the role that health personnel played. The participants spoke about what was done *to them* and virtually nothing was said regarding their interactions.

*I was alone in ICU. The phone rang a lot. It was my dad who was still in Johannesburg. The BP machine wakes you up (Maya).*

*When I woke up I was in ICU with pipes and everything in me. I can't remember, but the staff told me they brought the baby to me to say goodbye (Kerishne).*

*I was then taken to the ICU and by the third day was ventilated.. after that I was in a coma. Three days later I was told the baby had died. I woke up with a ventilator so I knew there was some seriousness in my situation. I had lots of questions, but because of the ventilator, many questions remained unanswered. I broke down three days later. I was given anti-depressants. I then rejected it. I rather wanted to talk about it, even if I had to write it down (Miriam).*

#### **7.1.3.1 The ICU: A highly monitored environment**

The ICU experience seems to symbolise the space where medical staff takes total control. Wohlreich (1986) argues that those medical personnel who choose to work in obstetrics often are attracted to that field as a 'happy' speciality (p61). These staff may feel particularly distraught about the unpredictable result and complex emotional reactions in high-risk patients. Intervention in this case may be targeted on either the foetus or the mother, as the presence of two patients simultaneously is the unique characteristic in obstetric care. In medically complicated pregnancies treatment of disease in the mother often poses risks to the foetus, whereas treatment aimed at foetal preservation may be uncomfortable or stressful for the mother. This can be a challenging dilemma for the physician who must weigh risks and benefits of any treatment for both patients (Wohlreich, 1986).

At one level, Wohlreich (1986) offers quite an intra-psycho explanation for physicians' interactions with their patients. She contends that the way in which physicians may react to patients is contingent on the physician's personality structure. If the doctor sees herself/himself as the protector of the foetus, she/he may minimise or feel irritated by the mother's difficulties in adjusting to treatment demands. On the other hand, a physician over-identifying with the mother may experience heightened distress or guilt about subjecting her to discomfort to save the pregnancy. Thus the degree of fit between expectations and needs in the doctor-patient relationship will define the level of comfort each experiences in their interactions. In the final analysis, the doctor's response to his/her own feelings and to the patient's emotional needs can heighten or mitigate the strains that each of them faces in perinatal management (Wohlreich, 1986).

The NICU experience, irrespective of whether it was state or private healthcare seemed to herald extensive involvement from healthcare personnel. Soraya recounts:

*Baby was in NICU because her lungs were not fully developed. The sister at the hospital said we must take it one day at a time. The doctors talk to you about the baby's progress. I trusted what the doctors said. The NICU was brilliant (Soraya).*

Samantha reported:

*Being a new mother, all I wanted was to take my child home, yet the doctors told me that my child has to stay in hospital for three months (Samantha).*

Wereszczak *et al.*, (1997) report that the NICU environment is a very technical and highly monitored environment. Lupton and Fenwick (2001) describe neonatal nurseries as being far from tranquil, with nurses bustling and talking, bright lights, medical staff coming and going, and parents visiting their infants. Mothers in the Wereszczak *et al.*, (1997) study recalled the noise level as the most stressful aspect of this environment. They recalled the monitor alarms as noxious and these often prevented their babies from falling asleep. One mother thought that the NICU environment "would kill my baby with all the noise, confusion and traffic" (p36). In addition to the noise, mothers most often remembered all the ill and dying infants and the stress associated with so much sadness in these wards. Seeing the baby for the first time also created discomfort for the mothers in my study.

*I didn't want to touch IT for two days.I cried every time I walked into the NICU (Kayla).*

*I felt helpless.Children in the nursery diedit was very scary. It could have been my child (Samantha).*

*I was disappointed in having such a small baby (Evelina).*

*The baby was so small he had to be kept in the incubator for two days.When I saw my baby for the first time it was so painful.I couldn't believe it was a baby because it was so small and I just lost hope(Xoliswa).*

*The hardest thing that haunted me was am I going to see my child?*

These findings are consistent with findings from a study conducted by Padden and Glenn (1997).Most women in this study had been surprised and shocked by the preterm birth, but most recounted feeling relieved when they saw their infants.Many in this study also reported feeling distressed at the appearance of the infant.The mothers in my study, as in Padden and Glen's study, reported stress at seeing their babies in these highly technological environments where they were hooked to so many machines.

*My baby was hooked to lots of machines.He weighed just over a kilo.It was apraying time for me. Pray today and see tomorrow (Soraya).*

*I can't believe he had all those needles stuck in him(Samantha).*

Monitoring of the baby in the NICU is a key aspect as it is indicates progress or the lack thereof.While some of the participants found witnessing all the technological equipment difficult, they knew this technology was designed to assist their infants to develop and grow.

*I didn't enjoy that at all especially with the tubes feeding her and the drips areuncomfortable you know, you just want to pull that thing out heybut then againevery, when they weigh them in the morning, you know you literally standing thereholding your breath.Please let her pick up weight thank God she swallowed the whole syringe (Kayla).*

However, mothers usually had to rely on medical personnel to interpret monitoring and life support machinery. Despite these interpretations some of the participants experienced tension between they what the doctors were telling them about their babies and what they saw.

*I couldn't believe it was a baby because it was so small and I just lost hope. I did not think he was going to survive. The doctor said no, miracles do happen at this hospital. They showed me pictures of newborns to show me they are big and alive (Xoliswa).*

Personal monitoring of their baby's progress was made through the machines being switched off, as Soraya remarked:

*I could monitor the progress of my baby through the machines being switched off (Soraya).*

Mothers also monitored the growth of their babies through the shifts that were made in the hospital. Once the baby gains sufficient weight it is moved from one section to another. These signs were definitely viewed in a positive light and were seen as progress.

Coupled with monitoring is the growth of a premature infant.

*You have to have a lot of patience with the baby, you know the growth, everything grows very slowly (Soraya).*

*My baby weighed 1.8 kilograms. I did the kangaroo thing the growth of the baby is a huge thing. I felt helpless, not in control. Any grain or millimetre of growth is important. The hardest part is the weight gain (Kayla).*

*The weight is monitored every day. Whenever my child if my child picked up weight and its 5 grams or 2 grams he picked up, then my doctor told me, Mrs A you must see that as an achievement you know, because they are so tiny and it's like but, but some of their willpower is strong because he was a fighter, he, it's like he never gave up (Samantha).*

From the interviews it was evident that this aspect of the mothers' experiences was very challenging and difficult to contend with. Therefore communication with medical personnel was central to their meaning-making process at that time.

Interaction and communication with medical personnel surfaced as important issues in the NICU context. Padden and Glen (1997) found that overall, communication with both doctors and nurses was highly regarded by mothers in the NICU. The mothers in my study spoke about their interactions in quite a positive way.

*The doctors talk to you about the baby's progress. I just trusted what the doctor said to me.* (Soraya).

Kayla described what had happened to her:

*it was everytime I walked into intensive care I just burst out crying. I couldn't, I didn't change her nappy (um) she was just too small, looked like a little pigeon. So this one sister she must have seen something that [pause] she literally took put me in a chair, she said you sit here now and she disconnected or took my child out of the thing and she put her on my chest. And that's the best thing she could have done.* (Kayla).

Xoliswa recounted her experience:

*They were so nice, all the staff there. Every day I went there they were so nice they were so supportive. All the time they would just told us, no this baby is going to be fine. Sometimes if I didn't go maybe on Sundays, they just phone me to tell me the milk is finished.* (Xoliswa).

Similar to Padden and Glenn's study (1997) it appears that the mothers felt they could talk to the staff and they were sensitive to their needs. It also seems as if the nursing staff was the primary source of information and support for families, and parents appreciated this aspect of care.

Based on the information women in my study provided, it becomes apparent that nursing staff more than doctors are constantly present in the nurseries, particularly in the NICU. Lupton and Fenwick (2001) maintain that nurses act as gatekeepers mediating the relationship between parents and their infants. Issues surrounding the care of the infant therefore have to be negotiated with these nurses throughout the hospitalisation period. Mothers are thus compelled to engage in a dynamic in which nurses hold the power by virtue of familiarity with the setting, its routines, technologies and specialised vernacular, which often leaves mothers feeling alienated and afraid.

The narratives of mothers also began to reveal that power relations are dynamic, produced and reproduced through the everyday activities and social encounters in the hospital. The material conditions of these contexts (ICU and NICU) play an important role in reproducing and structuring these activities and encounters. In addition, the words (spoken and unspoken) shape and give meaning to these experiences. In this instance discourses of technology become important and have shaped women's experiences of their stay in hospital in fundamental ways. Samantha highlights this point in her interview:

*But em, you know, unforeseen circumstance and we never know what is going to happen next so, that is just how I remember that. And sometimes when I look at the photos of my son and I and I look at him now then, it's like I can't believe that he is that small little thing with all the needles sticking through him and, and he's now so big and I mean he's not a sick child, luckily nothing is wrong with him and then that was the hardest part of spending, I mean after the birth, you could see your child, and I and that was the thing that was like haunting me. I want to see my child, and I can't see my child 'cause I'm also in bed and sick with this drip hanging all over me, and eventually when I do see my child it's almost like a big disappointment (Samantha).*

In addition to the frameworks of intervention and a culture of technology which shaped the experiences of these mothers, other biomedical discourses could be traced in the women's dialogues as elaborated below.

## **7.2. Biomedical Discourses**

In this section I focus on the intersection between biomedical discourses drawn upon and the women's accounts of their experiences when they were hospitalised for HELLP syndrome. When reading the texts of the participants, what seeped through was the metaphorical language used to describe their interactions. The metaphors utilised were: medicine as science, body as machine, doctor as God, and the foetus as super subject. Risk discourses were also drawn upon to explain and understand part of their experience.

### **7.2.1 Medicine as indisputable scientific truth**

The discourse of medicine as science filtered through some of the participants' talk. While it was not directly alluded to, it certainly came across as an unspoken assumption that medicine is a science or an 'expert practice' based on science. This became particularly

evident when participants questioned why they were not receiving any definitive answers to their queries. This is what some of them had to say:

*Then you feel grateful, so if (um) science or the medical or these studies that you guys are doing can help then gosh I would hate to lose a child after so many months. I mean that would be traumatic hey? (Kayla).*

*I felt can't this people tell me what all this is about because this is GS (state hospital) this is a professor here why can't he give me answers, I wasn't satisfied at all (Yvonne).*

*and it's not just one doctor, they like a group, they will examine your child thoroughly and you know they will, always tell you like this is what is happening with your child, and this what they going to do now and he was actually on a (em) I think steroid study. He was on a steroid study (Samantha).*

While this metaphor seems fairly innocent at face value, it masks a number of unassailable assumptions. Firstly, the medical establishment is one of the institutional fruits of a capitalist system, and thus its guiding principles are economically determined. Hospitals, medical insurances, pharmaceutical companies and cost-watchdog businesses are major industries whose interests revolve around their own profits (Petersen & Benishek, 2001). The medicine is science metaphor thus hides the fact that medicine is business. Petersen and Benishek (2001) further argue that this metaphor also operates to uphold exclusionary practices, retain a power-elite and control resources, in a capitalist society. High infant mortality rates, the absence of cures for leading diseases, failing to decrease the spread of infectious diseases such as HIV/AIDS and practically ignoring ailments afflicting minorities are examples of this. This very point was actually made by Kerishne:

*I think to myself, how, if this is the attitude medically in that profession, what about those people who cannot afford it? I mean my nanny she suffers from blood pressure and I make sure I take her, her tablet. I phone my sister who's a pharmacist I say look here, she's got blood pressure problems but the government hospital is giving her that, that and that. She says you know take that thing and just flush it because she has to take ten of those tablets to come up to one normal tablet. So basically buy her other tablets because I cannot trust them.*

*One of the sisters at the hospital, the matron actually, the one in charge of the ward I was, she told me that. It's like, I mean you always hear that these hospitals play Russian roulette, who we going to save, who we going to do something about? It's like I always thought it was a big joke, but they did that with me?* (Kerishne).

The medicine as science metaphor also culminated in the split between mind and body and the growth of allopathic medicine. The significance of this split also resides in its gendered nature (Petersen & Benishek, 2001). As males presided over the science of healing the body, a single monolithic system was established that prohibited by law all other modalities of healing and subjected women to working in submissive, conforming roles vis-à-vis the male dominated profession. Medicine as science is reductionist in nature and it promotes another trope for treating the body, namely, 'body as machine.'

### **7.2.2. Mechanistic model of the body**

Implicit in the metaphor of medicine as science is the assumption that the body can be separated into its component parts and that doing so will permit the broken parts to be fixed. Based on Cartesian dualism medical practitioners viewed the body in a very mechanistic way and disconnected the body from the mind (Willard, 2005). As a result of this, the body came to be construed of as a machine that could be manipulated and fixed. Sarah Nettleton (1995) in her analysis of biomedicine states that in this worldview medicine embraces a mechanical metaphor presuming that doctors act like engineers to repair that which malfunctions. Other critics like Lupton (1994); Farquhar (1996) and Martin (1987) assert that the pervasiveness of the machine metaphor has resulted in an overdependence on technology to treat isolated parts of the body instead of examining the whole person. Emily Martin's (1987) famous description portrays this sentiment: "This machine metaphor depicts a body of the machine age engaged in orderly assembly-line production on a rigid time schedule, divided into parts, each with a separate function" (p99).

Martin (1987) argues that the conceptualisation of reproduction as a form of production is very prevalent in the dominant medical/health discourse. In this storyline the woman is the labourer, the body the machine, the baby the product and the doctor or medical staff the supervisors or foremen of the labour process. According to these accounts, the body does not belong to the woman giving birth, it functions almost independently of her will or desires, and the uterus is presented as an involuntary muscle that automatically performs the task.

This discourse was quite evident in the women's talk when they were being treated in hospital. Kerishne related her experiences:

*Ja, ja multiple organ failure. Like I said my kidneys and lungs collapsed. I had internal bleeding when they did like a C-section and the one (Kerishne).*

During the course of her interview Kerishne continuously made reference to her blood pressure which had sky rocketed and this culminated in serious problems for her. She also breaks her body up into these component parts to try to analyse and understand what had happened to her:

*As far as [pause, sigh] my kidney failure and everything that went wrong. I mean medically I must thank God that I'm alive because I flat-lined twice in the operating theatre and I had a blood transfusion (Kerishne).*

Xoliswa also describes the way in which doctors explained what had happened to her:

*They told me about the liver failure. So I was just scared about maybe the liver can stop working. Ja, they just gave me tablets and I was feel better but not better (Xoliswa).*

Yvonne commented:

*They told me the kidneys were affected and then afterwards the liver and then the platelets yes the platelet count (Yvonne).*

What the women were saying is very typical of how doctors treat illness and how they explain disorders. They are medically trained to concentrate on their disordered bodies (Cassell, 2004). Doctors listen for symptoms – medical evidence of what the patient could be suffering from or markers of progress of an already diagnosed disorder (Lorber, 1997). Bhattacharya, (n/d) asserts that biomedicine is predominantly concerned with the objectified bodies of patients rather than the embodied patient as an experiencing person, as is evident in the fragmentation of the person into speciality-specific parts, for example, psychiatry and gynaecology, and the clinical focus on seeking the biological causes of disease. The split that has occurred between 'embodied' subjecthood of the person and the 'objectified' body of biomedicine has culminated in a struggle between 'material' and 'non-material' components of the body. These days we call this inhumanity 'clinical detachment' or something similar which sounds less emotive and more scientific. However, this

mechanistic view of the body no longer suffices as both patients and physicians have begun to recognise the value of elements such as faith, hope and compassion in the healing process (Bhattacharya,n/d).

### 7.2.3. Medical doctors as gods

The idolisation of the doctor as a god with infinite wisdom and final authority is a common metaphor used in biomedical discourse and more importantly shapes medical practice (Northrup, 1997; Willard, 2005).The ensuing sections will therefore be devoted to this discourse utilised in women’s talk.Many of the participants expressed complete faith in their doctors and questioned them when things went wrong.

*I always used to tell them doctors, but I’m on these tablets, but now why is this happening to me?What was the point they said well we don’t have an explanation for you.I was like why you said this will help so now why?(Yvonne).*

*I should have trusted what my body was saying to me, but in the face of medical science, in the face of this all-knowing gynaecologist, who are you to question their judgment? (Micha).*

*so I just trusted what the doctor, they say we must take the baby out, its going to be fine, it’s going to be fine (Soraya).*

Willard (2005) reminds us that because of the shift that healthcare made into the public sphere and its concomitant take over by a male establishment that the image of healthcare was transformed into a highly complex scientific enterprise requiring expert intervention.Patients were taught to implicitly trust the doctor as he/she served as the best source of knowledge about their body and as the person most capable of translating relevant scientific research published in medical journals. Northrup (1997, p.9 ) further argues that “in medicine you are trained to be the higher power of your patient”.Reasoning from her own experience rather than scientific observation, she finds that the doctor as god metaphor reflects the highly patriarchal and hierarchical medical model.She asserts that it is ‘natural’ for the medical establishment to base its philosophies on a patriarchal model since it is the defining organisational paradigm for the majority of our institutions.She thus contends that this masculinist approach to medical care is detrimental to women in that they become extremely passive in the context of a paternalistic relationship with a doctor.The authors of *Our Bodies, Ourselves* contend that the hierarchical nature of the doctor-patient relationship

is perhaps one of the major means through which medicine has achieved its social control over women's lives (BWHBC,1998).

#### **7.2.4. Infantilisation of the patient**

The medical encounter is one arena where the dominant ideologies of society are promulgated and where individuals' compliance is sought. The subtle force of this phenomenon derives from the presumed objectivity and helpfulness that the symbolism of scientific medicine conveys (Waitzkin, 1983, p.181 in Lorber, 1997). Northrup (1997) asserts that as a doctor she was trained to be paternalistic. Lorber (1997) argues that doctors' power and authority in the medical encounter stem from their gatekeeping position in the social structure of Western medicine.

Western medicine positions the person suffering from a particular ailment as the patient and in this way regulates the patient's subjectivity. The regulatory power of the medical establishment therefore seems to hinge on its ability to inscribe the patient as a generalised subject who exists primarily as a passive site for the operation of rationalist procedures (McKenzie & Carey, 2000). This sentiment was expressed clearly by Maya:

*and um and also to get the ward round experience is just unbelievable. You know you sort of sleeping and suddenly you wake up and you are surrounded by nine medical students and the doctor, and you are some interesting case, you know the subject to being, the subject was unpleasant (Maya).*

In this instance Maya's use of the word 'unbelievable' describes her experience of being scrutinised and examined in this tertiary setting by medical students and the doctor. Very little consideration is accorded to the woman herself as she is placed at the centre of medical scrutiny.

*I was totally dependent on help I didn't want to upset anybody. I put my own needs on hold. I wanted to be a good patient. If you ask others then it's a problem (Evelina).*

Speaking about being a patient in this regard meant accepting the role unquestioningly, but it also alludes to the issue of compliance. Evelina alludes to the fact that she wanted to be compliant and do as she was told when she was in hospital. McGrath (1998) contends that in the hospital context, the patient is completely stripped of her/his identity because of being subjugated by institutionalised medical power and hence all behaviour and access to

others is directed by the demands of medical treatment. Drawing on the work of Goffman (1968), McGrath (1998) writes that hospitals represent spaces where the patient is disrobed of social identity, and re-inscribed (through acts such as the public provision of private information on hospital admission charts, dressing in hospital attire, removal of personal possessions and the imposition of hospital rules and rituals) with the passive task of being just a body ready for bio-medical processing. Through these rules and regulations, hospitals command a passivity and submissiveness of patients. Coupled with this is the loss of control, agency and autonomy which Evelina expressed in her interview. McGrath (1998) furthers her argument by stating that the idea that these expectations of institutional control and patient passivity have become so routine and a part of hospital life that this dynamic is rarely questioned.

Taussig (1980) cited in McGrath (1998) depicted the ill person as a “dependent and anxious person malleable in the hands of the doctor and the health system, views this routine acceptance of control as a reification of the actual process of manipulation concealed by the aura of benevolence” (1980, p4). Such a dynamic can also be understood through discourses that naturalise phenomena. In other words, such an acquiescence of control could be understood as the power of medical discourse that completely dominates the hospital organisation to such an extent that it is construed as natural and legitimate: simply *the* way of structuring the healing experience. Such a discourse naturalises the process of power inequalities and abuses and is therefore no longer seen as one of several ways of doing things, but is simply embraced as common sense (McGrath, 1998).

The patient-doctor/nursing relationship by its very nature is asymmetrical and often sets the patient up as a child. Rudolfsdottir (2000) in her study found that pregnant women are infantilised through the way in which they are addressed and positioned in relation to the experts. In her study she focused on booklets and hand-outs that were distributed to pregnant women. While the booklets were designed to assist pregnant women and the new mother, she describes how patronising the tone of the articles is. These same sentiments were expressed by some of the participants especially in relation to how the women in my study were treated by the nursing staff. Evelina reported how patronising the nursing staff was:

*The nursing staff were very unhelpful. They passed ugly remarks. The nurses spoke to patients as if they were children (Evelina).*

Jean reported:

*I felt the nursing staff was helpful, but they scolded you if you don't do as you were told*  
(Jean).

The fact that patients were scolded and positioned as children indicates behaviours that nursing staff believed were acceptable ways of relating to both adults and children thus naturalising adult-child power relations.

In short, medicine's understanding of healing devalues the privileged relation the woman has to her pregnant body and the foetus. Moreover, in contemporary society where obstetricians are still primarily male it often reduces the likelihood of bodily empathy between physician and mother. In a context of authority and dependence that defines the doctor-patient relationship the pregnant and birthing mother more often than not relinquishes her power and therefore lacks autonomy in these experiences (Young, 1990).

#### **7.2.5. The foetus as 'super subject'**

Sonography through its ability to present visual images of the foetus inadvertently positions the foetus as 'super subject'. Barad (1998) in Keane (2009) reports however that the experience produced when the ultrasound transducer interacts with the pregnant woman's body is understood to be the material reality of the foetus. This kind of techno-realism, where a very specialised technological display is taken as the material truth of the human body and its condition is emblematic of contemporary biomedicine. In discussing the construction of foetal personhood Lehner (2003, p.547) in Keane (2009) states that "the redundant logic of techno-science is revealed in its conflation of representation and the real truth is presented by technology, and yet it is invisible without that exact technology".

Rodolfsdottir (2000) contends that often the literature on pregnancy and childbirth positions the foetus as supersubject, and consequently transforms the body of the pregnant woman into a mere vessel or incubator. In one booklet which she examined, the illustration completely erased the mother-to-be and the image consisted only of the contours of her body enclosed around a foetus with adult features enhancing his/her status as a subject. Kaplan (1992; 1994) adds that constructing the foetus as sacred serves to reinforce the child as the subject of motherhood.

Maya in her interview alludes to this sentiment of being an incubator for the developing foetus. She recounts:

*and so I read that article in the New Yorker about sort of preeclampsia thing. I thought yes that's actually maybe the way it feels for me. It doesn't feel like this you know, all of this archetypal loving mother producing. I don't feel hostility. I just feel it's hard work. It feels like hard work and that my body is not a good incubator you know and it was also sort of it the thing that you've built something up and then it's suddenly gone. Even if you didn't want it to begin with and it just, you know, it really evoked in me a lot of stuff around um and I think this fits in with HELLP syndrome about the imperfect host. Um there's nothing I'm not a good breeder you know. Darwinianly I should be zoned out of bearing children, it's because I'm not good at it. I'm not the fittest. I'm not a good host for having babies. I'd never be chosen as a surrogate because it just doesn't go smoothly (Maya).*

Based on what was expressed it is evident that Maya sees her role as being that of a host or incubator to the foetus and because two of her pregnancies went wrong (one first-trimester miscarriage and the other HELLP syndrome) she feels she is an imperfect host. Furthermore Maya relates this to Darwin's theory of survival of the fittest and in this sense feels she should be zoned out of bearing children.

Bordo (1993, p72; 77) asserts that in medical and 'foetal rights' discourses, a pregnant woman can no longer think of her own body as her home, instead she is reduced to a "mere life-support system for the foetus". In a study conducted by Schiend and Lupton (2000) one of the participants who had an unplanned pregnancy voiced that she was merely a vessel for her baby to enter into the world. This participant conveyed that she felt rather disconnected from the baby stating that:

*in a sense there's something using you as a host, but it's not that sort of clinical (or) as horrible. I don't mean that, I just felt a real loss of identity and autonomy (p.37).*

Rudolfsdottir (2000) discusses how material on pregnancy promotes the notion that mothers-to-be should engage in activities that make the womb a more hospitable environment for the foetus. Literature on pregnancy often discusses various dangers to the foetus but fails to acknowledge the dangers to the mother herself. In the case of HELLP syndrome the placenta is compromised due to a lack of blood flow. Intra-uterine growth

retardation occurs because of this and hence foetal growth is often compromised. Curtin and Weinstein (1999) discussed the consequences of HELLP syndrome for infants and found these babies were subject to more severe intra-uterine growth retardation, have abnormal blood smears similar to the mothers and they were lower in birth weight than their premature counterparts (Joern et al., 1999). Furthermore Portis *et al.*, (1997) quotes perinatal mortality as high as 367 per 1000 live births. As mentioned, when their babies were born very prematurely and were very tiny, mothers in my study cried and expressed severe guilt at “having done this to their baby” (Samantha).

According to this super status to the foetus has also given rise to many discourses of risk. MacKinnon and McIntyre (2006) contend that when medical personnel examine pregnant women they are commonly looking for risk factors or risks that have been earmarked as significant through medical science. Risk discourses have therefore become endemic in both medical science and society at large. Some of these risk discourses therefore inevitably filtered through during the interviews as HELLP syndrome is considered a high-risk condition of pregnancy.

#### **7.2.6. Risk Discourse**

Traces of risk discourses were apparent in some of the participants’ talk about their experience. For Micha the first encounter with risk was when her gynaecologist recommended that she do the alpha-foetal-protein test to evaluate whether there was any significant risk for Down’s syndrome. She recounted her experience:

*My gynaecologist said let’s do the screening for Down’s syndrome I remember the day I was at work he called me and said to me your triple test has come up high risk and the risk is so high for you. It’s a 1 in 20 chance of having a Down syndrome baby. I was very upset about it, I ran out here and I went to stand in front and I cried. Then he scheduled an appointment with Dr L who specialises in amniocentesis and went to to her and she did the major scan first and at that point I was about 18 weeks pregnant and she said there was too little amniotic fluid in the amniotic sac. The anxiety, I kept thinking is my baby going to be okay. After the amnio you are supposed to be off your feet for 24 hours, you can’t get up because of the threat of miscarriage as well. After three weeks I called the receptionist to find out my test results as she said oh by the way your test results came back and they normal just like that that was the worse three weeks*

*of my life not knowing if my baby was going to be normal and if not normal what was I going to do (Micha).*

Gross (2010) asserts that the socio-cultural scheme of risk-medicine has major ramifications in the area of prenatal care and hence women's childbearing experience. In a position to provide the technology to manage and control the pregnant body, medical science may engage in more intensive management to ensure the health of the growing child and potential future citizen. Ideas of risk, danger and illness are often projected onto the pregnant body by different social groupings, and maternal responsibility is thus defined as a preparedness to accept definitions of 'high-risk' pregnancy and to shoulder increased biomedical surveillance.

The resultant aftermath of risk-medicine is that pregnancy may become a time of trials and challenges, of uncertainty and anxiety. Gross (2010) cites research that has been conducted to demonstrate how the practice of new genetic screening tests is often unsettling and anxiety-provoking for women belonging to the risk groups. This angst was certainly expressed by Micha when she spoke about the screening tests she had to go through and how she felt when the test resulted in high-risk for Down's syndrome. She described how she could not contain her emotions and fled in the face of the news being relayed to her by her gynaecologist. As Micha was clearly not prepared for such news, these tests definitely increased her anxiety. Gross (2010) contends that this is particularly significant when the tests conducted are not diagnostic but statistical which means they are based on probabilities. Rather than resolving uncertainty, screening highlights uncertainty, causing it to play a more central role in a woman's experience of pregnancy.

In Maya's case the following unfolded:

*I drove to Dr L and I got there and then I walked in and said I'm sorry but I haven't thought this through and I don't want an amnio. And she was not impressed with me. I said I'm sorry I know it's a waste of time but I just booked it without thinking it through and I don't want it. She wrote this note back to my doctor about my being ambivalent and and I said I don't care.*

*my gynae does her little scan but I just, kind of feel um, it sort of ja um how to explain, I think I have some anxiety about it but I, I'm ready for it. Like whatever happens, happens. There's a sense of inevitability that hasn't been there with either of the other*

*pregnancies It's just my gynae summed it up. Statistics don't mean anything to the ordinary person. And there I was googling when I got back from LM because she was so horrible to me. She practically makes you sign these are your risks of having chromosomal abnormalities so then I came home and googled everything that could possibly go wrong. And um, statistics mean nothing. That 30 percent recurrence thing it doesn't mean anything. It doesn't reassure me (Maya).*

Yvonne describes the risk associated with HELLP syndrome in this particular way:

*How do I prevent it from happening again 'cause they can't tell me you might be lucky this time. You might have your child or you might not. It's like a gamble. (Yvonne).*

What does that gamble mean for you? (Interviewer).

*Well, I'll take the chance because I really want to be a mother. I really want a child. (Yvonne).*

From the excerpts it is evident that some of the participants in my study were confronted with discourses of risk (Maya and Micha) as well as the issue of risk as it pertains to HELLP syndrome itself. According to MacKinnon and McIntyre (2006) the classification of risk factors provides a space for medical personnel to give medical advice to pregnant women. Maya points out how she decided to go for an amniocentesis during her pregnancy but decided not to go through with the procedure as she felt she had not given it adequate thought. She recounts how she felt chastised by the attending gynaecologist when she refused to have the procedure done. MacKinnon and her colleague (2006) observed how women in their study were reprimanded when their behaviours did not mirror the nurses' understandings of pregnancy risks and they relayed how nurses were actively engaged in teaching women to be vigilant with self-surveillance.

What is also noticeable in Maya's extract is the meaning associated with statistics. She expresses how statistics don't mean anything to the layperson and how it appears to be a medical construction relevant only to medical personnel. This sentiment seems in line with what both Zinn (2006) and Carolan (2008) allude to. Both authors point out the tendency in risk research to differentiate between objective statistical/technical risks as 'real' risks and social or subjective risks as biased perceptions of objective risks. Carolan (2008) in her article states that statistics are most commonly used by medical personnel, while a more

subjectivist/social approach considers risk as a social category. In this case risk is considered in an individual way and is influenced by the social, cultural and political milieu in which the person finds her/himself. Maya explains how she went through each possibility and had to make decisions based on what she believed. She says:

*I thought okay, if my child has Down syndrome, I'll cope, it could be worse. If my child has Turgen Hungen or whatever the other thing it will die by the time it's two and I'll survive. You know, I actually, I just thought, I went through each case scenario and I thought I'm going to be okay. I don't need to panic (Maya).*

The risks with regard to HELLP syndrome were expressed in different ways by Maya and Yvonne. Maya asserted that the 30% chance of the syndrome recurring meant nothing to her as it did not reassure her. Yvonne spoke about risk and equated it with taking a chance as the outcome could not be determined beforehand. Gross (2010) argues that risk analysis is based on the premise that future events can be predicted with more or less accuracy based on present knowledge. She uses the example of proteins found in a woman's blood and argues that one should be able to predict the outcome of the pregnancy based on that information. However, the prediction of the recurrence of HELLP syndrome becomes particularly problematic as the predicted outcome is not definitive. Rather, it is based on probability. Yvonne's doctors clearly pointed this out and explained that one cannot predict with absolute certainty, which led her to conclude that it is a gamble: "You may have a child or you may not".

In the final analysis, in the HELLP syndrome experience of women, discourses of risk present two groups of scenarios: one related to prenatal screening and the other related to the possibility of future recurrence of the disorder. In both instances it appears as if the issue of risk held very individualised meanings for some of the women in my study. Rather than alleviate anxiety, the issue of risk seemed to create more angst amongst participants. Risk-medicine therefore has powerful implications for child-bearing women. Gross (2010) calls for a more sustained examination of what seems the most particular, and probably the most peculiar epistemological basis of risk-medicine, namely its quest for knowledge of the indeterminate and its pursuit for power and control over the unpredictable.

As a result of having discussed and outlined the biomedical context of HELLP syndrome and having examined how these contexts shaped women's experiences, it has become

apparent how these shaped the passage of the participants into motherhood. White *et al.*, (2008) acknowledges that there are positive outcomes associated with prenatal screening and argues that advances in these techniques have greatly improved the potential for healthy birth outcomes for women with medically complicated pregnancies. However, women with complicated pregnancies experience numerous stressors and this according to Stainton *et al.*, (1992) definitely impacts on how such a woman progresses into motherhood. It is the issue of motherhood and how it is constructed and experienced by these women that the following section addresses.



## CHAPTER 8: ANALYSIS OF MOTHERHOOD

The third aim of my study is geared towards understanding the role discourses of motherhood played in relation to how women who have had HELLP syndrome experienced their passage into motherhood and their meaning-making process in this regard. As previously mentioned motherhood spans both personal and political dimensions. On a more personal level motherhood constitutes a component of identity but is also expressed as a particular relationship that is lived in the context of a family and community. At a broader societal level motherhood as an institution is 'pregnant' with cultural and political meanings (Arendall, 2000; Rich, 1976). Therefore as Foster (2005) argues when women's pregnancies are at risk, as in the case of HELLP syndrome, their desire to have a child as well as their responses to risk must be understood within the cultural and relational contexts in which this desire is birthed. This section of my thesis attempts to understand the experiences of women who have lost their infants, as well as those whose infants are hospitalised immediately due to their premature births. This part of the analysis then examines how women practise and experience motherhood in a context in which there are significant constraints surrounding how they may interact with their newborns. Lupton and Fenwick (2001) assert that the baby's hospitalisation has major ramifications regarding how women see themselves as mothers, and how they construct and relate to notions of the 'good mother'.

While the discussions with participants were very open and unfolded in particular ways, in a sense I tried to order the analysis by imposing achronological ordering of their passage into motherhood. Thus the analysis begins with a discussion of their motivations for choosing or not consciously choosing motherhood. Thereafter the discussion proceeds with an examination of the threat to motherhood that is so endemic to high-risk pregnancies. Once those threats are surpassed the passage into motherhood is explored for those mothers who had live babies. For those mothers who lost their babies to HELLP syndrome, an attempt is made to unravel what 'lost motherhood' means. The analysis continues with a more general examination of the discourses of motherhood that the participants drew on to explain and make sense of their experience. In the meaning-making process participants also drew on discourses of religion, spirituality and existentialism. This section of the analysis concludes by scrutinising what the entire experience meant for these women.

### **8.1. To be or not to be a mother?**

As previously mentioned, the decision to become or not to become a mother has a most profound effect on a woman's life. Sevon (2004) asserts that the choice to become a mother is a multi-layered process that is not entirely conscious, clear-cut or rational. Meyers (2001) contends that decisions about motherhood and child-rearing are not as autonomous as they could be. She further asserts that in the discourse of reproductive freedom and choice there seems to be a fair amount of controversy among feminist scholars regarding the degree of women's autonomy with respect to motherhood decisions. She acknowledges that this disagreement is understandable, for such autonomy may be difficult to trace. Many factors including personal, social and culturally transmitted mythologies influence these choices. The interviews clearly suggest this, as some of the participants stated that they had not consciously planned having children (Maya and Micha), while Yvonne had a very clear trajectory for her life. However, Maya sums this sentiment up succinctly by stating: "I never decided not to have children." Therefore by acknowledging that while motherhood may not have been chosen consciously, the possibility exists that it was always lurking unconsciously.

*Um, I suppose my first pregnancy was let's say, yah, it was unplanned. I hadn't ever thought that I wouldn't have children... but we'd only been married for about a year and I thought, we both thought, that we'd wait. We wanted to have five years of child-free marriage to travel and stuff. So it was a surprise to me(Maya).*

*Pregnancy to me was a beautiful thing because I wanted to have a family...because I love children I tell myself one day when I get married I want two or three kids...that is a beautiful thing when a woman falls pregnant and a baby growing inside of you (Yvonne).*

Meyers (2001) in her paper draws attention to patterns in women's conversations about motherhood decisions. and comments that their testimony clusters around two poles, namely casualness and adamance, both of which are represented in Maya and Yvonne's talks. Two studies which Meyers draws on, describe how women did not give the matter much thought. Having a child was considered automatic in quite a nonchalant way (Ireland, 1993 and Lang, 1991 cited in Meyers, 2001). In addition she writes that culturally transmitted traditions of joyful motherhood sponsor this casual refusal to reflect. The flip side of automatic childbearing is fashioned by obsession, anxiety and despair. Meyers (2001) thus believes that

the blithe assumption that one will become a mother may mask a desire that has the unyielding, obstinate character of compulsion.

### **8.1.1. Being a mother is primary**

Another reason for the participants wanting to become mothers seemed to be related to the dominant discourse on the primacy of being a mother for feminine identity. Yvonne speaks about motherhood as something that is absolutely essential to all women and references biblical texts in this regard. In the context of her high-risk situation, she speaks about the willingness to take the risk, even though it may be detrimental to her health, because she wants to fulfil this imperative of being a mother.

*Motherhood is something that all women must go through... for me you know in the Bible it says you must be fruitful and multiply but I mean there is a lot of women out there that always says I don't want to have children (Yvonne).*

*How do I prevent it [losing the baby] from happening again 'cause they can't tell me you might be lucky this time. You might have your child or you might not. It's like a gamble. (Yvonne).*

What does that gamble mean for you? (Interviewer).

*Well I'll take the chance because I really want to be a mother. I really want a child. Yah being a mother is very important to me. It is primary to me (Yvonne).*

*...I felt like I have to be a mother. I have to have children I have to see to the family and I just felt like too much is expected of me. Not particularly related to you know the family itself the one to bear the children and being the one to mother the children, but on top of that, em that I have the responsibility of looking after not only my immediate family but also like my mom and this brother that's the medical doctor (Miriam).*

Adrienne Rich (1976) asserts that ideologies of reproduction define 'woman' in terms of 'mother' in ways which regulate the lives of all women: those who are mothers as well as those who are not. Motherhood is constructed as obligatory, normal and natural for women, for their adult identities and personal development (Woollet & Boyle, 2000). The salience of this discourse across multiple contexts is borne out by contemporary empirical research. For example in a study examining discourses of motherhood among Thai women in Northern Thailand researchers found that most of the participants felt happy in producing a

child because they were able to fulfil the role of womanhood as it is expected in the Thai cultural context (Liamputtong *et.al.*, 2004).

### **8.1.2. Correcting one's own experiences**

When speaking about their motivations for becoming mothers, participants rationalised their desires as in some way related to an opportunity to correct their own experiences of childhood. While Maya verbalised this directly, Yvonne spoke about it much more indirectly. What is noteworthy is Maya's assertion that the choice for correcting one's experience is often done quite unconsciously.

Was becoming a mother always a part of your plan? (Interviewer)

*I think probably sort of unconsciously. Ja, I'd never I'd never had a strong feeling to be a parent um suppose it's more motivated by my um know correcting, correcting one's own experience. You know, when I thought about becoming a mother like I'm not going to be like my mother. I'm going to do it this way. (Maya).*

*... to see that little child and I'm her mother knowing that child came out of me, nurturing that baby, I want to care for that child, I want to give him or her everything that I didn't have. I want to give everything to my child, everything of the best (Yvonne).*

When you say everything you didn't have, what does that mean? (Interviewer)

*I mean in a sense of when I grew up everything wasn't there for me as, as my father would say okay my child...em like when I grew up we struggled because my father wasn't always there in the sense of nice time and you know go to your friends and drink, and my mother and to struggle alone (Yvonne).*

In her interview Yvonne explained what being a child meant for her. She explained how her father was not around and drank excessively and this left her mother virtually as a single parent. Yvonne wanting to become a mother was in a sense to give to her children what she believed she failed to receive as a child. Moor and Silvern (2006) speak about parental empathy which is a necessary element of adequate parenting. Parental failure of empathy therefore speaks to deficiencies in the capacity for empathic attunement and responsiveness, mirroring and personal validation of the child. This lack of parental empathy for her which normally is so subtle and often goes unnoticed may be the very reason Yvonne now

believes and feels the compulsion to have a child to correct her own experience through having her own children.

The motivations for having children elucidate the importance attached to having children and raise how a high-risk pregnancy could jeopardise what some of the participants may have wanted to accomplish, albeit on a deeply unconscious level. For some of the participants this resulted in a thwarting of these 'goals'.

## 8.2. Motherhood thwarted

For those participants whose desire to have a child was very strong, the loss of their babies meant that the possibility of becoming a mother was thwarted. This idea of motherhood thwarted was also linked to the idea that not having one's own biological child would mean that one is not a 'real' mother.

*I didn't feel good because I wanted this baby. How can he [the doctor] tell me that the baby inside you is making you sick? It's either you or the baby or both of you.* (Yvonne).

And that night between when they told you that there are problems and the next day, what happened to you that night when you were lying there? (Interviewer)

*I was scared. I didn't even want to sleep. I was crying and they tried to calm me down but I was literally shivering. I could not stop, I could not stop. I was very, very scared cause I really loved this baby because I was very, very, we were both very excited to have this baby.* (Yvonne).

*...I want a child so badly, I don't want to adopt. I don't want to do all these other things. I want to fall pregnant naturally but also scared that I might go through this thing again.* (Yvonne)

In this extract Yvonne seems to invoke the unthinkable. 'How can this baby growing inside of me cause me to be ill? In addition, how can something I want so badly make me so ill and in a sense prevent me from achieving the desires of my heart – to be a mother?' The paradox and contradiction are arguably impossible to comprehend.

Long's (2009) study discusses the possibility of the mother's body being an infecting body and how the women in her study expressed anxieties about the possibilities of their babies

being infected with HIV. In this sense it was the imaginings of the mother's body infecting the innocence of the baby that caused the horror for the mother as she had to contemplate that she had done this to her baby. Long contends that the horror of the mother's body recedes in comparison to the dread of the infection of innocence. In Yvonne's case the story is completely reversed because the doctor is telling her that her baby is making her ill. Therefore in Yvonne's case she has to contemplate innocence or the baby's body being the infecting body.

Yvonne's response also highlights the uncertainty and unpredictability she felt when being told that she has to terminate her pregnancy. Stainton *et. al.*, (1992) acknowledges that there is always a measure of unpredictability in every pregnancy, but asserts that this exists as background to the 'normal' progress of the infant's prenatal and postnatal development and maternal adjustment. However, in their study of high-risk pregnancy, uncertainty occupied centre stage throughout the high-risk perinatal situation. Their findings revealed that uncertainty in becoming a mother to this infant preoccupied the participants' talk (Stainton *et. al.*, 1992). Stainton and her colleagues argue that for these women, the meaning implicit in the high-risk maternal identity is that the possibility of attaining the expected and hoped for maternal role is thwarted by the high level of uncertainty in the situation. Thus the trajectory of the maternal experience is altered from what is culturally expected to one in which the unknown dominates, culminating in feelings of lack of control, non-involvement and dependence on others as has been evident in my study. For a woman with a high-risk pregnancy, the passageway into motherhood is saturated with unknowns and the notion of becoming a mother itself is thwarted.

### **8.3. Passage into Motherhood**

Giving birth with HELLP syndrome clearly is an extremely stressful and anxiety-provoking experience. Not only did the participants have to contend with their own health, but they also had to contend with the health of their premature infants. Thus the passage to motherhood was characterised by enormous challenges often resulting in feelings of alienation, despair and grief. This pathway to motherhood contained a myriad of negotiations with themselves, families and medical personnel. At face value what was disclosed often appeared neutral, however closer scrutiny of these talks reveals how various discourses utilised by women served to maintain existing power relations. The ensuing sections examine what this pathway entailed for those women who had live babies.

### 8.3.1. After the ICU experience : The practice of motherhood delayed

*I think with so much drugs it's quite hard. I can't remember much in ICU. I remember being, I remember just having this little baby put on my chest for the first time and sort of mmm..You know sort of feeling when, when you not quite there. And sort of looking and, and um but there's so much pain that you kind of you not, it's all a bit surreal. So I think the first time I really kind of got into the experience was probably a day and a half later. Coming back down to the maternity ward, and I think the difficulty there I felt was um, was just being able to do stuff. And er, you know baby would always have to be brought to you (Maya).*

Maya was also in the intensive care unit similar to some of the participants in Kidner's study (2003). These new mothers stated that they could not completely share the initial bliss of parenthood because they were just too ill. In this study many of the new mothers described their post-birth experience as 'horrid' (p.49). One of the participants in Kidner's study recounts: "I was a new mother and was so sick and I couldn't enjoy going to visit my daughter in the nursery" (p.49). Maya in her interview talks about how hard it was to function given the medication she was on, and the pain she had to endure. This led to her feeling 'not quite there'. In other words, she describes herself as being unable to be fully present both physically and emotionally. She continues by asserting that she believed attachment to her child was definitely delayed as a result of her condition. Being 'so out of the loop', she acknowledges that everything else became secondary with survival becoming the pinnacle of her experience.

*I was just so out of the loop in the beginning um. I mean I don't think there were any attachment problems I think I was, I didn't feel there were any attachment problems I think I was, I didn't feel there wasn't I didn't feel like I don't want to attach to this child or anything like that but it did take longer. Because I was just trying to live, trying to get over these huge obstacles of health. And I didn't feel guilty then. That was just ... survival(Maya).*

Furthermore, she alludes to the possibility of her attachment to her son being delayed. What is interesting in this case is that the participant is a clinical psychologist and definitely reflects some of the psychological discourse around attachment in her talk. Marshall (1991) alerts us to the way in which these knowledge(s) are constructed and highlights the methodological problems inherent in these studies on mother bonding. However she

maintains that this type of research is used to maintain certain hospital practices while simultaneously serving the ideological function of positioning women as the primary caretakers in the home, and thereby justifying the existing patriarchal social order.

Frizelle and Hayes (1999) argue that often when women discuss their own experiences of mothering, the discussions are based on and regulated within the parameters of psychological and medical thinking, thereby perpetuating particular notions of motherhood. In this instance the work of theoreticians such as John Bowlby and Donald Winnicott are seminal as it provided the platform for the emergence of a powerful ideology of motherhood (Kruger, 2006). Bowlby proposed that the fundamentals for mental health are set in motion right at the outset of a child's life. The tacit assumption is therefore that the mother becomes the primary figure who is capable of providing the necessary backdrop for healthy child development to ensue and for this reason she is singled out as the person primarily responsible for her offspring. This work, among others, has been instrumental in catapulting the widely accepted belief that mothers need to be fully and constantly available to their young children.

It has often been acknowledged that this idealised version of motherhood sets up and constrains women in various ways. Nicolson (1986) for example, continually propagated the idea that postnatal depression is directly linked to the disjuncture between women's expectations of motherhood versus their actual experience of motherhood. Often women are tempered into feeling guilty when they are unable to live up to these idealised expectations. Maya however, expressed that she was simply too ill to do anything except concentrate on improving her health. Hence she did not feel guilty at that point. Having voiced the opinion that the practice of motherhood was delayed, some participants explained how this impacted on the process of making sense of becoming a mother.

### **8.3.2. Motherhood sidelined**

Kidner (2003) in her study contends that the overriding theme of the maternal experience for the participants was loss. One of these experiences related to the loss of the initial joys of motherhood. One of the participants in Kidner's study felt that what had happened to her was not the way it was supposed to be. The participant describes the visions of natural childbirth she had with her husband fully present and participating in the birth process. Another participant expresses how ill she was and therefore was unable to experience what she termed 'the joy of giving birth'.

In my study Maya reported:

*I think it was quite a difficult thing to juggle because I sort of was dealing with my own survival. And that really was the primary thing you know like being ill, getting better, going back to hospital, getting better. That the whole...even just trying to make sense of becoming a mother was sidelined (Maya).*

Maya talks about how being so ill made it very difficult for her to make sense of her experience on one hand, and on the other, how it relegated the process of making sense of becoming a mother to the margins. In this regard it appears as if all bodily processes took over completely and the work of becoming a mother had to be put on the back burner. For women who have had HELLP syndrome, becoming a mother occurred in a biomedical context and seemed to constrain women in various ways.

### **8.3.3. Being a new mother in hospital**

*I mean after the birth, you could see your child, and I can't see my child 'cause I'm also in bed sick with this drip hanging all over me, and em, and eventually when I do see my child then it's almost like a big disappointment. And I mean being a new mother, it's like you just want to take your child home and I asked them how long is my child still going to be in hospital, so em the doctor said em just seeing he is so premature he will have to stay for another three months and that alone was very traumatic for me. I mean to leave your child in hospital alone, not knowing what is going on (Samantha).*

Samantha appears to have a very definite idea about what mothering entails when one's child is born and this is because she has another son. Her ideas have been shaped by her previous experience. She strongly expressed the desire to take her child home but because of his prematurity, was unable to do so.

Black *et al.*, (2009) noted that a turning point for mothers in their study was taking the infant home for the first time. Home seemed to represent becoming the mother of this particular infant. For these mothers, being able to take the infant home reduced the liminal quality of early mothering. In other words these mothers felt they could exercise more control over their infants' care, and had more time and a place to get to know their infants intimately. Going home thus meant being able to establish bonds between the mother, the

infant, and their extended social world. In the final analysis mothers could forge deeper relational bonds with their infants in the absence of hospital routines.

What Samantha's discussion evokes once again is the disruption to what she and many other mothers perceive to be the 'normal' and 'natural' process of the commencement of motherhood. Miller (2007) in her study found that women unashamedly expressed how their birth experiences defied the 'superiority of nature' and their faith in it; and this inadvertently set the stage for the uncertain and confusing period of new mothering to come. The high-risk situation that my participants found themselves in seems to highlight this aspect and points out how extreme these challenges become. Samantha explains how a basic need like seeing her newborn could not be fulfilled because she had a drip "hanging all over her". Thus the start of motherhood is complicated by the mother's and infant's illness.

#### **8.3.4. Motherhood and the NICU**

For mothers who have interrupted pregnancies and resultant premature births, the passage into motherhood is shaped by the NICU experience. Lupton and Fenwick (2001) describe the experience of giving birth to a premature or medically ill child as one that created feelings of alienation, despair and grief for the women in their study. Furthermore, women reported that motherhood arrived too soon and they were ill-prepared for this experience. Similarly, the women in my study expressed the difficulties they encountered when their babies were born prematurely. Kayla says:

*The most difficult part was the two months that my child had to stay in hospital because every night I use to cry myself to sleep...then the night took so long, like an eternity for one day to pass. You feel removed from the baby. And I can't hold her and it took me two days I think before I could hold her. Em. Everytime. What I did do though was I expressed milk. Yah they fed her. And it's like two or three mills at a time. Tiny.*  
(Kayla).

Kayla in her interview articulates the difficulty she faced when she was unable to hold her baby immediately following the birth. The distress she experienced was palpable in her talk and points to the prime need that some mothers have to hold their newborn infants. However in her case, 'holding' referred not only to the act of bonding, but to being able to

establish for herself whether her baby was alive or not. Thus holding in the case of prematurity refers to a much more primal need, namely to establish life or death.

*For the first two days I couldn't bear it. I was, H my husband was involved, I walked to the incubator and I picked her up and I walked. That's what bad for me. I'm crying there by the incubator. I get so worked up you know. But until one afternoon this nursing sister she literally disconnected Rebecca and she put her on my chest and then it was okay. Then I could feel you know. And okay she is breathing. She's not dying she's alright (Kayla).*

Based on what some of the participants said, it is evident that the first few days of motherhood was experienced as extremely traumatic and distressing, which as Lupton and Fenwick (2001) correctly contend, is very different to the glowing images of blissful early motherhood that pervade popular discourse.

*...I then, I think for me the worst experience wasn't the HELLP it was having a premature baby in the intensive care, with this little indented chest and tubes stuck to her.(Kayla).*

The notion of 'being a mother' seemed difficult to achieve during these early days. The women constantly referred to feeling 'removed' from their baby and not being 'prepared' for motherhood.

*I worried a lot when my baby was taken to be put in the incubator. When the doctor arrived I asked him where my child was and if my child is okay. He then explained to me my baby is too small. He weighed 1.7 kilograms. They then fetched me to go and see him in the incubator. When I was okay they wanted me to go home and leave my baby there. I said no I am not going to leave. I am going to stay in hospital with him. As he grew they would bring him to me to wash and I could hold him. (Jean)*

Being a mother with a premature baby also meant that the usual duties of managing a household and being there for other children, was expected to continue

*I thought I just said to myself I'll take everyday as it comes, you know. And I neglected my eldest child...em and he was almost becoming estranged from me and em, I spoke to, to this woman from my mother-in-law's church and she said I must realise I got two children and the my other son needs me just as much as my baby needs me(Samantha).*

In a study conducted by MacKinnon (2006), women reported how difficult it was to manage the usual household chores while being on bedrest to prevent premature labour. In my study Samantha highlights the conflict she experiences with trying to be there for her premature baby as well as her older son. While late modernity has ushered in many changes for women, society still holds women responsible for care work in the family (DeVault, 1991). The work of caring full-time for a premature baby as well as caring for the rest of the family has the potential to cause significant hardships for some women.

Another aspect of motherhood and the NICU related to control. Lupton and Fenwick (2001) relay how women spoke about being allowed or not being allowed to handle their own infants in particular ways. The comments of the nursing staff made mothers acutely aware of the rules and regulations with which they had to comply. This in some way culminated in mothers feeling that they had very little control over their interactions with their infants. However, with time, these feelings began to recede and a strong urge to reclaim the role of mother took its place. Kayla alludes to the lack of control she felt (which I believe was partly self-imposed), as she expresses how difficult it was to touch the child in the beginning, but also due to the interactions in the NICU itself. She says:

*..and then I started to become in control again because I'm changing her nappy now; the thing came out of her mouth and she could suck on a bottle again (Kayla).*

Thus it appears with picking her infant up and holding her, a confidence developed so that eventually she could change her baby's diapers. The action she was able to take heralded significant strides in reclaiming control and perhaps taking authority.

*We will take turns with the kangaroo care, and that is actually what I think helped and so I'll put him whole day there here in my bra, he was so small he could fit into my bra... the hardest part when you go to hospital everyday and your child has picked up like a five grams or something you think, versus when is this child going to pick up a whole kilo?(Samantha).*

For participants in my study the NICU experience ushered in many conflicts and challenges. Because of the immediate termination of the pregnancy which was sudden and unexpected, mothers were ill-prepared for motherhood. With their babies being incubated, the participants often felt removed from their infants. This sense of removal left them with feelings of not being in control which in some instances seemed self-imposed, while

simultaneously being caused by interactions with the NICU personnel. When they eventually were able to get close to their babies, the holding seemed to satisfy a very primal need which related to establishing whether their infants were dead or alive. In addition to all the above-mentioned challenges, mothers also felt the strain of being responsible for siblings at home. These pressures marked the commencement of motherhood and signalled a very difficult time for most of the participants.

#### **8.4. First months of motherhood**

Maya graphically describes the first few months of motherhood and how difficult it was for her. She does however acknowledge that she thinks the process is similar for those mothers who had ‘normal babies’, probably referring to those who had full-term babies and were not faced with medical complications.

*...I was sitting and then you'd feed and then and then I think it's the same even if you have a normal baby, those first shell-shocked months where you think there's no vacation from this. It's relentless. So that became and that soaked up all of my energy. Feeding, winding, sleeping, waiting (Maya).*

These sentiments are very common and have been expressed by women in various studies (Lupton, 2000; Miller, 2007). Deborah Lupton (2000) in her longitudinal study interviewed mothers and fathers from just before the birth of their babies, up to 16 to 18 months after the birth. What was evident from the data was that ideas about the ‘good mother’ have not changed substantially since the 1970s. Lupton argues that that features of contemporary motherhood continue to be shaped by dominant discourses of the ‘good mother’ as well as through the embodied relationship that women have with their infants. The mothers in Lupton’s study reported that they had far more physical and emotional contact with their infants than their partners, because they saw themselves as the primary caregivers. Having to care for and constantly think about their children’s needs and desires inevitably resulted in a juggling of their own needs with those of their children. Lupton (2000) therefore argues that, similar to pregnancy where subjectivity may be described as ‘split subjectivity’,... a body subjectivity that is decentred, myself in the mode of not being myself (Young, 1990, p.162), other embodied experiences may be related to childbirth and caring for infants, such as breastfeeding, serve to fragment subjectivity and embodiment. This relentlessness of having to care for the baby led to feelings of the body becoming an ‘other’ which is discussed further

on. While the first few months were described as being difficult and fraught with challenges, some of the participants went back to work and described work as being salvation for them.

#### **8.4.1. Early days of motherhood: Work as salvation**

Maya in her account tries to explain what those early days of motherhood meant for her. She feels that she was mildly depressed and that going back to work early was her salvation.

*I took him and then he was in with me at work, every day and well everyone looked after him you know...everyone knew him all around the offices because the messenger would take him all around with her in a little pouch. That was really important to me. I sort of came back to work early...um because I was struggling, I think I was depressed, mildly depressed, not enough to seek help but, but I would sit at home and I would sort of I couldn't I couldn't think about it, I wasn't processing anything. And going back to work was salvation for me. I sort of felt less lonely, I felt um the community of women at my work were very supportive and they'd tell me stuff and I could ask them. I knew nobody with children (Maya).*

Teresa Arendall (1999) in her decade review of motherhood, speaks about maternal employment. She argues on the basis of having reviewed the literature in this area, that employment benefits women because there are generally higher levels of well-being and lower levels of depression and anxiety. In reviewing studies by Hughes and Galinsky (1994), Mirowsky and Ross (1997) and Roxburgh (1997), she asserts that employed mothers who were in a position to afford high-quality child care, who were supported by partners and who could avail themselves of flexible workplace options experienced the least distress as working seemed to provide them with a sense of control over their lives. Other studies revealed that having supportive colleagues and a supportive workplace culture seemed to result in lower levels of work and family conflict. In her conversation Maya explains how her supportive work environment and colleagues assisted her during a challenging time and perhaps served as the impetus for preventing full-blown depression.

Evident in the participants' talk was an element of reflection on where they were 'at', with reference being made to their own mothers. In Maya's case she explains that the model of child-rearing she had was based on that of her mother. For Maya therefore, having a child represented the end of a woman's life. She relates how enlightening it was for her to realise that she could work and still be a mom.

*And I think for me, because my mother stopped working as soon as my brother was born, that was my model. That you have a life and then it ends and then you become a mother. And that actually you can do both. It was sort of an epiphany for me. And then I thought I and then ja, I thought okay this baby can fit into my life and I was excited and everyone was excited and none of my friends had babies. I mean I was (29) but sort of slow breeders, my friends (Maya).*

Work seemed to be an important mediator of stress for her, and also represented a space where motherhood and work could possibly co-exist.

### **8.5. Body of (m)other**

*...and then added to that was this ongoing feeding and the baby so all over you that you just, your body becomes an 'other'. It's not yours any longer you know and sometimes sort of it comes back a little bit. But then I think, then again you go through another pregnancy then your body changes and everything drops and droops and flabs and changes (Maya).*

Long (2009) in her book *Contradicting Maternity* which documents the narratives of mothers living with HIV/AIDS, begs the question, "Where is the mother's body?" (p.146). Maya was the only participant who mentioned her body in relation to motherhood. Therefore in my study the mother's body remained fairly absent in women's talk of motherhood. In her study Long (2009) recounts the instances when bodies were referenced. They were done so in relation to either the baby's body or to the woman's body as an HIV-positive person. This marginalisation of the mother's body facilitates an understanding of the power and pervasiveness of dominant discourses about motherhood that privilege the baby and relegate the mother to the periphery. I agree with Long (2009) in that examination of the instances where the mothers' body comes to the fore, not only highlights dominant discourses, but also challenges them. She further asserts that the mother's body cannot be rendered completely docile, and thus it infiltrates and pressurises (at the boundaries of subjectivity) the hegemonic discourses that declare that the mother's body and her identity are intrinsically of less value than that of the baby.

In her excerpt, Maya alludes to the experience of her body as 'taken over' by the baby and expresses how at some points it "feels as if it sort of comes back a little bit". Raphael-Leff (1993) writes about the way in which pregnancy reconfigures the body and therefore it is not

uncommon for women to experience pregnancy as an invasion of their bodies. Parker (1995) argues that this can be very difficult for women to acknowledge, let alone accept in the face of powerful idealisations of motherhood. This situation becomes more complex when pregnancies are at risk, as the participants expressed their gratitude for not only surviving this ordeal, but that their infants also survived. Given these experiences it may not be surprising that the participants in my study would not mention such issues for fear of being perceived as ungrateful.

In short, the passage into motherhood for women with high-risk pregnancies, is fraught with challenges and contradictions. Their experiences of having premature babies set the scene for how motherhood was to be expressed and experienced. Fortunately from this cohort of mothers, all babies survived and at the time of the interview were doing well. However, not all of the participants in my study had live babies. Five of the participants lost their babies during their HELLP syndrome experience. The ensuing sections focus on their losses and what this meant to them.

#### **8.6. Motherhood lost?**

All of the participants who lost their babies, experienced the loss between 24 and 26 weeks into their pregnancies, with the exception of Miriam who delivered a full-term baby who died a few days after her birth. The cause of her death remains unknown; doctors suspected it was pneumonia. Of the four participants who lost their babies, three of them had other children. Yvonne was the only participant who did not have any children. Therefore the loss for her seemed far more pronounced and profound as it represented not only the loss of her babies, but also the loss of motherhood itself.

Stillbirth or perinatal loss confronts women on many different levels. For example, it may challenge women's image and preparation for motherhood, but it may also challenge them on a social or cultural level. On a more personal level it is argued that because the mother believes she can no longer project the role of protector, this results in intense guilt and creates conflict between perceptions of herself and her body (Hsu, *et al.*, 2004). On a social level individual interpretations of loss need to be understood in the socio-cultural context in which they occur. Scheper-Hughes (1985) contends that cultural meanings shape how maternal sentiments are expressed as well as the cultural meanings of mother love and child death, and therefore influence the experiences of attachment, separation and loss (cited in Hsu *et al.*, 2004).

While pregnancy loss is quite a common occurrence, discussion of its importance and the resultant suffering of women has been relatively absent from medical discourse and public culture (Keane, 2009). Representing an uncommon juxtaposition of death, childhood, sexuality, female embodiment and reproductive failure, miscarriages and stillbirths continue to be experienced as shameful and isolating events. Layne (2003) states that feminists have “abandoned their sisters in need” and inadvertently (I suppose) contributed to their pain by “retaining a studied silence” on pregnancy loss (2003, p239). Below follows a discussion of how the participants in my study experienced the loss and the meaning-making process for them.

### **8.6.1 Broken dreams**

Hsu et al., (2004) in their study reported how their participants developed future plans with their babies at the centre of these plans. From Yvonne’s interview it is evident that she continually holds these images of her babies and constantly reminisces about what could have been. She also has very vivid images of what she would have been doing had her babies survived.

*I’ve dreamt about it but not always no, not really if I see children running around or even on TV commercials with babies, I feel like having my own child...like that’s how the first one could have been three years old now and the second one would have been two years. (Yvonne).*

So what would you be doing as a mother?(Interviewer).

*Loving my children, giving them the best, not spoiling them as in making them brats but giving them the best ... em... to nurture them teach them the right way, respect and all things(Yvonne).*

For some of the participants the loss of their babies signified broken dreams. In Yvonne’s case it was not merely the loss of her physical child, but also the loss of being a mother.

### **8.6.2. Severed connections**

Stillbirth or intra-uterine death is extremely difficult to deal with. Cacciatore (2009) asserts that the emotional effects of giving birth and death simultaneously are often misunderstood and she claims are very rarely examined beyond the superficial rhetoric of perinatal death.

She continues by stating that women who give birth to a dead baby may feel disenfranchised from social groups in which babies and children are deemed important. One aspect of giving birth to their dead babies or having had babies who died shortly after their birth, left the participants in my study feeling that their babies were invalidated.

*The hasty burial or incineration of the foetus invalidates the baby itself and your connection...I consider myself very fortunate because I had that contact. It was the first birth where I actually had immediate contact with the child after the delivery. Um I don't feel it's fair. I don't think it's fair. I think you know it's bad enough going through the process and then the loss and then no closure. I don't think that's acceptable(Miriam).*

The common thread that seemed to weave this part of their experience together was the fact that after their babies were born, either incineration took place or their babies were buried hastily. This seemed to result in their feeling that the connections they had with their infants were severed rather abruptly

*...I remembered the room was dark, lights were dim and everything around me felt like death, there was no other way to describe it. I was lying there and they came back to me and said there is no foetal heartbeat anymore. The afternoon she was still alive because I saw her on the scan, she was moving and she was still alive(Micha).*

*After ICU, when I woke up then I was told he didn't make it. I got upset and they, I believe they brought him to me to say goodbye. I can't remember but seeing the photos that's how I know they did bring him to me to say goodbye. And that's when my husband had the funeral (Kerishne).*

Layne (1997) in her article and subsequent book (2003) discusses how the silence surrounding pregnancy loss can and should be challenged, particularly by feminists. Although she discusses her own experiences with multiple miscarriages, this knowledge certainly is relevant in my study. As Miriam alluded to the way in which the hasty burial led to feeling that the baby itself was not validated, Layne tries to unpack the reasons for this. She argues that pregnancy loss is subjected to what Foucault called the “triple edict Puritanism – taboo, nonexistence and silence” Foucault also asserts that there are many silences, not just one and they play a pivotal role in strategies that underpin and permeate discourses.

Layne (1997) argues that at the level of popular culture one of the most significant indicators of the socially sanctioned nonexistence of these events is the fact that there are no appropriate greeting cards for such events. Extending her argument, she contends that there is a general lack of accepted cultural scripts for how to behave in such circumstances. This cultural denial of pregnancy loss impacts enormously on women, their families, friends, and more.

Another area where pregnancy loss is paid scant attention is in many lay educational materials available on pregnancy and childbirth. Layne (2003) writes that popular books and magazines on pregnancy often take women through a step-by-step process, but fail to make explicit that the pregnancy may end at any point during the gestation.

In the final analysis, these silences surrounding pregnancy loss leave women feeling that something in the process is amiss. Due to the discomfort that all parties feel, there are often attempts by those close to the mother, to get everything finished as soon as possible. Hospitals have their protocols about burial or incineration, but these procedures seem to negate what women truly need. Having to bury or discard the bodies of their infants left women questioning and feeling that the life they were carrying was not validated. In addition, due to the nature of HELLP syndrome, termination of pregnancies occurred rapidly thus adding to feelings of being disconcerted and connections being almost brutally severed. Losing their babies was extremely difficult for the participants and seemed incomprehensible. Miriam kept on saying: "It's just not fair." The death of an infant invokes very powerful feelings which inevitably result in certain taboos in society.

### **8.6.3. Powerful taboo – infant mortality and maternal death**

Layne (1997) correctly asserts that death and near-death always raise tricky issues of meaning. However, to determine the meaning of the death of someone who never lived outside the uterus is particularly problematic. Maya speaks about it in this way:

*You know it's just, for me is that I mean it sounds a bit of um I don't know what the word is but sort of trite but it is, is essentially trite this sort of tension between life and death but the whole experience of having a baby is new life and eggs and storks you know, sort of the arrival of the new life but if you were at the same time coming to terms with death, or near-death, such it is just too much, it's a very different thing you know. I think it's infant mortality you know, small infants and maternal death it's a*

*very powerful taboo...because it challenges something very [ativistic] and ancient inside of us. (Maya)*

Maya therefore juxtaposes life and death and explains how difficult it is to come to terms with almost having lost her own life and immediately being confronted with a new life. In her understanding, this is too much – almost unthinkable. She also alludes to the idea that she believes that small infants and mothers dying is a very powerful taboo that challenges something very primal inside all of us.

Given these taboos, it makes sense that there are powerful silences surrounding pregnancy loss. In some ways society has not developed a discourse to talk about infant death or maternal mortality. Thus while these taboos persist and silences continue, the women who had HELLP syndrome and lost their babies, struggled to cope as they spoke about all the reminders they were left with.

#### **8.6.4. Many reminders**

In the minds of close relatives and family members of the participants, the miscarriage was over, the babies had died and now life had to move on. For the participants however, this did not reflect their emotional response. Although they described their HELLP syndrome experience as a whirlwind experience, they noted that there were too many reminders and this made it difficult to forget and move on.

*The body, well there are lots of reminders. You know sometimes people forget that I was pregnant. Like you know I obviously gained weight. The tummy's there. Um and because they don't see physical things people forget that I was recently pregnant. I was. I just had a baby. People expect you to move on immediately. I found that my immediate family too and you know, so you had the loss we will sympathise with you at the time everybody moves on with their lives and so I'm expected to move on too. Being on maternity leave was a constant reminder(Miriam).*

From the excerpt one can see how corporeal being pregnant is. Miriam is reminded by her body all the time that she was indeed pregnant. Thus while there is no baby as tangible evidence of her pregnancy, she talks about her stomach that was still enlarged.

For the mothers who delivered in state hospitals being placed in general wards where other mothers were with their live babies seemed insensitive and inappropriate. Being placed in general wards served as constant reminders to mothers who had lost their babies.

*...because this is a state hospital it's not like in this ward there is only people who lost babies. You hear babies crying all around you and that also finished me, hearing babies crying. I was... God can't they just put me in my own room because I can't handle that (Yvonne).*

*From ICU I recovered nicely and they sent me down to the general ward. General ward was a bit hard. I think that's when reality hit me. Because I was with quite a few women in that room there was two that were waiting for their delivery..." (Kerishne)*

From these excerpts it is clear that women found that being placed with mothers who had live babies served as constant reminders of the losses they had experienced.

Other reminders the participants spoke about were photographs that had been taken of their babies. While a photograph provided women with something tangible, it also served as a stark reminder of what they had lost.

*I still have photos of my, the one I lost. I look at it quite often and ... [participant breaks down]. He was going to be everything for us.... (Kerishne).*

*The fear of getting too close and then having to let go, I think that was what was scary, but now I'm very glad. I still have a photo of her because I have something tangible. She did exist, she was a fully formed baby and now I suppose I can let go (Micha).*

It appears that the reminders women were confronted with ranged from very bodily, corporeal processes after their pregnancies to their physical locations in hospital to the photographs that they were left with as evidence of the existence of their pregnancies and babies.

In the final analysis what does lost motherhood mean to these participants? In order to understand what it means to not become a mother, it is important to examine what it means to become a mother. Barbara Katz Rothman in her article *Recreating Motherhood* (1993) writes about the contradictions of the world we live in: the world in which she studies motherhood, mothers her children and lives her life. Rothman observes that in

Western capitalist, technological and patriarchal societies the relationship between women and their children is not based on the duration of the pregnancy, nor on the intimate connections with the infant as it develops or moves inside her body, nor as it comes out of her body and then suckles her breasts. Rather, women are thought to be related to their children in the same way men are, through their 'seed'. According to this model, what is considered to be the most significant are the ingredients, and she argues that in this regard men and women are deemed equal. Rothman believes that the entire process of gestation is completely devalued. The patriarchal model according to Rothman (1993) is 'seed in baby out' (p.124). Therefore when the desired result is not achieved (that is, a live baby to bring home), the entire process of pregnancy according to Rothman (1993) is judged to be worthless, or not worthy to be acknowledged.

Based on the interviews in my study, this is exactly what participants were alluding to. They felt that their losses and their babies were not validated or acknowledged sufficiently by close family members, loved ones or medical personnel. Layne argues that this inability to acknowledge these losses also stems from a more general silence in society and is subjected to Foucault's "triple edict of Puritanism – taboo, nonexistence and silence". The powerful taboos surrounding infant mortality and maternal deaths compound the issue and leave women who have lost their babies completely outside the discourses of childbirth and motherhood. Maya alluded to this impossible situation of having to deal with new life while concurrently having to face her own near-death experience.

The stark reminders that women were left with were extremely challenging and difficult to deal with. Unfortunately, the limited understanding of those closest to them made it even more difficult to process their loss. The absence of appropriate discourses in these situations left women feeling alienated and lonely in their grieving process.

*... my children hadn't seen me for the entire month...and for me being on maternity leave that was the time for them. So in a sense I was pleased. Lonely when they were at school and obviously going back to my experience and then ... without them...*  
(Miriam).

However to contemplate the possibility of never having a biological child of her own was simply not possible for Yvonne, nor was she willing even hypothetically to consider this. For her, being a mother was primary and natural and therefore no other possibility existed.

Thus while she grieved and mourned the loss of her babies, she was not willing to mourn the possibility of never being a mother. Entrenched discourses of motherhood formed the basis of her talk all the time. This bears testimony to the pervasiveness of these hegemonic discourses and the profound impact they have on the individual lives of women. Various cultures also have very particular ideas and understandings of miscarriage and loss. In South African society, various African cultures construe loss in a very suspicious way.

### **8.6.5 Loss and culture**

Xoliswa was the only black, African-language speaker in my study so she spoke about the dowry system and how this impacted on her relationship with her partner during her first pregnancy.

*In 2003, it was family problems happening. Because in our culture you know if you are pregnant by somebody by a man it must he must have to pay your parents the money, for example R2000 or R1500 for the damage he has done. So I wasn't married yet. So my husband (boyfriend then) wasn't working. Em, we were staying in East London together and then we went home. Then I told my parents that I was pregnant. Then they ask if the, if my boyfriend is going to pay the money. Then I said I don't know but I think his mother is going to because she's helping with the sister's child too you know. But things didn't happen, didn't go like that. When I was six or seven months pregnant I got maternity leave and went home. And at seven months things got so, it wasn't nice at home. We had quarrel everyday because he just ask me when is this boyfriend of yours going to pay the money(Xoliswa).*

How does your culture see it when women lose their children? (Interviewer)

*They just, they don't understand why they don't understand maybe God doing that. They always place themselves, they always place themselves in, maybe the child is a witch or something like that. Like if you lost your child I would say that one knows about that and this one knows about your loss of the baby you know(Xoliswa).*

South African society, like many other societies, views motherhood as an important symbol. Lewis (1999) comments that the title of 'mother' in South African society, is a vital indicator of a woman's strength and social standing. She argues however that the title embodies the essence of women's social standing and therefore has very little to do with individual women's experiences. Harnett, Khan, Shivambo and Mnisi (1996) report on how

childbearing is celebrated as a symbol of achievement and success. In their study in a rural north-eastern part of South Africa, Bushbuckridge, a mother is spoken to with respect and she acquires the status of an adult thereby bidding her virginal status farewell (“vuntombi”), which is characterised by subordination and uncertainty.

In her interview Xoliswa states that in her culture the child that is being lost is seen as a witch. Historically women who did not conform were seen as witches. Giddens (1989) wrote about how classic fairy tales entrenched the idea that women who did not become wives or mothers were depicted either as witches or as fairy godmothers. Ritchken (1989) in Watson (2006) argues that it is generally accepted in anthropological literature that a witch is a traitor, illustrative of all that is anti-social and unnatural to a particular society. Hence to be labelled a ‘witch’ is to be positioned in an antagonistic relationship to the rest of society. In Xoliswa’s case, labelling the child as the witch could in some way be construed as the miscarriage in itself being viewed as completely unnatural and something that is not supposed to occur. Thus one could argue that in African cultures, having had a miscarriage, positions women as anti-social or as deviant. These subject positions leave women feeling powerless as these dominant discourses (which the next section examines) continue to prevail, sometimes unchallenged, in society.

### **8.7. Discourses of motherhood**

This section of the analysis examines the dominant discourses of motherhood that the participants drew on during their interviews. These discourses served to further exacerbate the challenges the participants experienced in becoming mothers. In contemplating what had happened during their pregnancies, they reflected on what mothers do or are supposed to do. Ideologies of intensive mothering, namely the pressure on mothers to be the primary caretakers for their children (Hays, 1996), and ideas of ‘mother-blame’ filtered through the participants’ conversations. The ideology of intensive mothering sets motherhood up as the ‘ultimate fulfilment’ (Marshall, 1991). The ideal or ‘good’ mother is personified as all giving, self-sacrificing and ever-bountiful (Bassin, Honey & Kaplan, 1994, p2.). Intensive mothering practices thus position the mother as the primary caregiver. Within such a framework the mother is supposed to devote all her time, energy and material resources to her child(ren), prioritising her child(ren)’s needs above her own. Hays (1996) argues that the child is considered priceless and hence no sacrifice is too great. Intensive mothering

therefore embraces child-rearing practices that are child-centred, expert-driven, emotionally absorbing, labour-intensive and very costly (Youngleson, 2006).

The second ideology that wove its way through the interviews was what feminist scholars have labelled as 'mother-blame'. This term speaks to mothers being held accountable for the actions, behaviours, health and well-being of their children, even when they are adults (Jackson & Manning, 2004; Rich, 1976). This concept also includes situations where women are blamed for being abandoned or poor. These ideological strands permeated the conversations of the participants as can be seen below.

In this part of the analysis I draw on the work of Michel Foucault (1975). Power is central in his analysis and he argues that it is anonymous but omnipresent. In other words, power cannot actually be located; it is everywhere and therefore exists inside us as well.

#### **8.7.1. Your child(ren) always come(s) first**

Maya and Miriam both spoke about the central role they play in their children's lives.

*I felt, the first thing I felt was wow you know I am so fortunate to have survived it. My focus has always been around my, my children. They very little, they not demanding, but they very close to me. And er, if they were to choose anybody in the world it would be, they would choose me (Miriam).*

Maya alludes to a very over-protective stance where she took a chance with her HELLP syndrome pregnancy by delaying her visit to her gynaecologist to check herself out. Subsequent to her experience with HELLP syndrome she said: "I always err on the side of caution". She explains how she tried to be 'macho' about things in the beginning, but that it got her into serious trouble and she almost lost her life. In retrospect she now believes that you do not expose your children to the same risks you would expose yourself to.

*You don't take chances with children that you take with yourself (Maya).*

In this case I believe her angst is justified, particularly when one has gone through the ordeal she has. However what is striking is the fact that she still feels that she would take risks with herself, but not with her child. This does leave me with a sense of the child enjoying supremacy while the mother is silenced into conforming and believing that the child's health takes precedence over her own. Woollett and Phoenix (1991) contend that motherhood has been professionalised in the way that medicalisation has infiltrated the

subjectivity of mothers in particular and the broader social sphere in general. Medicalisation upholds broader discourses which pertain to the secondary nature of the mother's identity as in positioning the foetus as the 'super subject' (Rudolfsdottir, 2000). Medical expertise therefore constructs maternal health as important insofar as it supports the health of the baby. This view seems to have been internalised and embraced by many mothers, especially when confronted by medical complications. When complications do arise, the first source of blame for mothers is themselves.

### **8.7.2. Mothers are responsible for life and death**

The concept of blame and liability directed at mothers commences from conception and continues throughout pregnancy and during the child's life. Jackson and Manning (2004) assert that we reside in an ever-increasing litigious society which pressurises women even more. In their paper Jackson and Manning draw on the work of Burrows who explores the legal and ethical issues of women's responsibilities to a foetus during pregnancy. Burrows asserts that it is easier to blame individual parturient women for 'causing' harm to their unborn infants than to consider the role played by societies and governments for developing policies that are not considerate or supportive to women, particularly women as mothers.

The issue of mother-blame often results in feelings of guilt. Maya in her interview speaks about the guilt she felt when she was telling her son the story of his birth.

*...when I feel that guilt now and it's interesting like you know we'd tell the kids stories like about the day they were born. So I sometimes feel guilty when I tell A... I think part of it is motivated by guilt. I sort of feel like I almost checked out and then what would have happened? And then I saw that film with Richard E Grant, it was six months after A was born. It's a nice film about, Richard E Grant plays this character and his wife dies in childbirth and he's left. And I remember watching this film and just becoming uncontrollably upset out of the blue. And I just wept and wept and wept because I suddenly thought I could and my godmother who was watching with me said 'oh this is so like you, this could have happened to J [husband] you know.... And you know when you've been a mother for six months you think no one else would be able to love your child as you do and so aw and what would have happened?(Maya).*

Jackson and Manning (2004) reported similar findings in their study. They found that women blamed themselves and on occasion were blamed by others for things that were

outside their control. What was evident in their study was how the women themselves internalised the blame. The internalisation of this type of blame can be explained in Foucaultian terms where we no longer require external mechanisms to control us. We become our own watchdogs.

Foucault speaks about a 'carceral continuum' whereby surveillance can be centralised or decentralised. Henderson, Harman and Houser (2010) argue that as a society and particularly mothers, have simply internalised many messages to the extent that they have become normative.

Lupton (2000) in her study of first-time mothers uses quite a psychodynamic orientation and draws on the work of Nancy Chodorow to explain the idea that mothers should feel a diffuse responsibility in relation to others, particularly their children, even for things that are completely out of their control. She found that women's responses did tend to subscribe to the belief that mothers should feel responsible for their children in ways not expected of fathers. Thus the mothers in her study were willing to take this responsibility, seeing it as an inevitable component of being a 'good mother'.

### **8.7.3. Motherhood: The natural thing**

Becoming and being a mother was considered the 'natural' and 'normal' thing for all mothers. Kayla alludes to the fact that having a child is not something that one thinks about; rather it is something so natural that the principle of having the child does not require any thinking through.

*Sometimes because when I deal with people, because I'm in the jewellery industry people get engaged, get married. Or first they study, get engaged, they do things in the right social order that society expects. And then when they come for their anniversary I ask them when are you having a kid? And they got all this planning. No we not ready there, we not. And I'm like, I don't express my views, but I'm amazed that people think about having a child. Okay, I know that sounds irresponsible but... obviously you must think of finances, but with H and myself we in those days we were poor. We got married with brass bands but we love each other. And when I fell pregnant the first thing was not to abort it. This was our kid, and we didn't just have sex and that's it. It's life that's growing (Kayla).*

*So I think when you finally get married you will have kids...the natural thing, and after marriage – babies (Yvonne).*

*I always wanted a baby. It is anyone's path. Anyone longs to have a baby. The older you become the more you long to have a child (Jean).*

From these excerpts it is clear that the participants regarded having a child as natural and a normal part of life. Kruger (2006) asserts that ideologies constructing motherhood have served to scaffold the meaning-making process, fostering desires and expectations, influencing subjective experiences and contributing to identity formation. She further argues that the mothering role more than any other role in society has been “invested with ideological meaning and cultural significance” (p.2).

Foucault asserts that we are all enlisted into subjugating ourselves through self-evaluative processes and being judged in relation to societal norms: the normalising gaze (Burr, 1995). Being a participant in the social milieu in which one is positioned culminates in the internalisation of dominant discourses as normative standards. These normative standards operate to produce conformity which in turn annihilates autonomy, restricting the individual to the possibilities of alternative subject positions, further subjugating them to normative standards (Ulrich & Weatherall, 2000). The subject positions we ascribe to therefore set the parameters for negotiating our lives and form the foundation for defining the self. Motherhood is such a subject position and it is extremely challenging for a woman to avoid taking on the image of the maternal when it is constituted so powerfully and benevolently as part of a woman's identity, giving her status in the family and community, and valorised as woman's most important female role (Ireland, 1993). This is evident in the participants' talk where for Kayla and Jean it is such a 'natural' thing to become a mother. What is there to think about or contemplate? It is 'anyone's path'.

For Yvonne, coupled with motherhood being so deeply entrenched, was the absolute impossibility of contemplating not becoming a mother. This is how she expressed this sentiment:

And if you don't ...if not or let's not say if you don't, hypothetically if you would not become a mother, what would that do to you? (Interviewer)

*I don't even want to think about it. I can't answer you on that.(Yvonne).*

Would it mean failure? Would it mean... (Interviewer)

*I can't answer you on that because that is not even on my mind.*(Yvonne).

Because of this naturalised, essentialised discourse, motherhood is constructed as inherently located in a woman's nature. Motherhood is therefore constructed as instinctive with all women having the capability to nurture instinctively. These constructions were evident in the participants' narratives as can be seen below.

#### **8.7.4. Maternal Instinct**

Motherhood is constructed as intrinsically embedded in a woman's nature. In other words, most people including women themselves believe that all mothers are able to deal with things competently, easily and naturally or instinctively. Welldon in Frizelle (1999) argues that the majority of women know very little about babies but they often expect that a "maternal instinct will come to the fore and will perform miracles" (p.18). Maya's account certainly challenges these conceptions as she talks about days after the birth of her son when she was re-admitted to a state hospital and her son was taken from her that she panicked and felt this maternal instinct come to the fore. In her case, she refers to a protective part of herself that seemed to emerge. She also says that it was the first time that she felt this sense.

*It was when I was in GS [Grootte Schuur] and I woke up and the and he wasn't there. And that was the first moment I thought I-I-I had that surge of you know maternal instinct, to try and who's taken my baby and where is he? ...And that was after being at GS for a day and a half and that was the week after he was born, you know* (Maya).

What Maya seems to suggest is that this 'maternal instinct' which is supposed to be present from birth, actually is not, and it certainly is not innate but is something that develops over time. In addition while she uses the term quite broadly, she does not define it for herself, which could also be indicative of the discourses available to us. The experiences of participants who had HELLP syndrome challenge the dominant discourses of motherhood being natural and the maternal instinct therefore being instinctive.

The section above attempted to highlight how the ideologies of intensive mothering and mother-blame came through the discourses so prominently in the participants' talk of motherhood. The analysis demonstrates how deeply entrenched these notions and beliefs

are. From the moment of conception women are held liable and accountable for all aspects of the child's life and well-being. Foucault's analysis of the 'carceral continuum' makes visible the function of power and demonstrates how we are recruited into subjugating ourselves through self-evaluation and being judged in relation to societal norms. This normalising gaze sets women up and positions them in defined ways. Having outlined the discourses that women drew on to make sense of their passage into motherhood, the ensuing section examines the meaning-making process in general for these participants.

## **8.8. Making meaning of the experience of HELLP syndrome**

At the end of the interviews participants were asked how they made sense of the entire experience. All of them drew on discourses of religion and spirituality, while some of them (Maya, Miriam, Kayla and Micha) drew on existentialist discourses. Breen, Price and Lake (2006) argue that it is not uncommon for spiritual needs to emerge when people are confronted with illness or a potential threat to life. This could be due to the potential loss of identity, meaning and purpose. Stainton *et al.*, (1995) contend that this may be particularly relevant to pregnant women experiencing medical complications, given that women's identities and life purpose are often connected to their family roles, including parental roles. The birth of a child frequently signifies the formation of a family identity or a new family unit. The ensuing section highlights some of these issues.

### **8.8.1. Discourses of religion and spirituality**

Participants were of different religious persuasions. Some classified themselves as Christian, Hindu and Muslim. In drawing on religious discourses there seemed to be a discourse of supplication as in Xoliswa's case, while with Yvonne there seemed to be more of a questioning of God's will. Prayer also appeared to be central to the participants during this time.

*I'm a churchgoer. Every time I've got a problem I just pray to God to take that away that em and I believe He can do anything. When I had HELLP syndrome I just tell God He must keep my child alive because every time I just tell my God, please God just keep this baby because I want this baby(Xoliswa).*

For Xoliswa, God is positioned as the helper in times of trouble or need. Her prayer centred on asking God to keep her child alive. Research conducted by Lobel *et al.*, (2002) and Yali and Lobel (1999) identified the use of prayer as an important coping mechanism for women

who experienced high-risk pregnancies. While these authors acknowledge the significance of prayer as a coping mechanism, prayer remains undefined and they do not provide a detailed analysis of why prayer is used so regularly by women to cope with their situations.

*I think one side what has helped me heal was my spiritual side. Knowing that we believe, Hindus firmly believe that the baby takes, your soul takes rebirth. And um... knowing for that fact ...um like my priest told me, that you must be lucky your womb was selected, chosen for the soul to pass through the passage so it can take rebirth in the next life (Kerishne).*

Kerishne's talk highlights the Hindu belief in reincarnation. What is interesting is the priest's assertion that her womb was chosen and that this should make her feel good. She contends that it was her spiritual understanding that provided the impetus for healing to occur.

Yvonne seemed very angry in her questioning of God and wondered why she could not be granted a child, while other women who were unable to care for children (in her opinion), were granted children. There seemed to be a sense of unfairness and injustice in this divine distribution of granting children that resulted in anger for the participant. Layne (1997) articulates this sentiment when examining the narratives of participants in pregnancy-loss support groups. She argues that pregnancy-loss support groups witness a number of areas of doubt concerning the believability, reasonableness and justice of a religious system in which some old man has first rights to your children.

*I will always say that why does God give women who doesn't want children, children, but yet the women that really want that can even look after children. Why can't we just have a normal pregnancy and have normal children?(Yvonne).*

So you see God as the absolute giver of life the one who can take life away? (Interviewer).

*Takes life away, ja... He knows His reasons. I cannot question Him because I will not get an answer. I just have to leave it in His hands and just hope and pray that He gives me at the right time(Yvonne).*

Religion was found to play very significant roles in women's lives where there were miscarriages, premature births with medical complications and stillbirths (Black, et al, 2008; Keane, 2009; Layne, 1997, 2003). For example, Black et al.,(2008) report how

mothers in their study regularly referred to a reliance on faith and religion, endeavouring to discern meaning or a greater sense of purpose for what was transpiring. These mothers attempted to seek and impose order on what they recognised as the dishevelled nature of their experience and often did so through understanding their experience in the context of faith or religion.

While religious discourses are vital to women trying to understand and make sense of their experiences, it does seem that (particularly in Yvonne's case) adequate answers were provided. Thus this taken-for-granted notion that religion will be the ultimate comfort, in reality was. Yet Yvonne alludes to the fact that as unhappy she was with the entire situation, she cannot question God. In sum, religious discourses serve different purposes for different women. In some cases they provide a channel for supplication, in other cases they serve as a vehicle for venting and questioning, and in other cases they function as a platform for healing.

While some of the participants explicitly drew on religious discourses, others drew on existentialist discourses in order to extrapolate the meaning of the experience.

### **8.8.2. Existentialist Discourse**

For Maya, Micha, Kayla and Miriam the time after their HELLP syndrome experience ushered in a period of deep questioning and re-evaluation of their existence. What is evident is the deep search for meaning within themselves, which subsequently led to a changed understanding of themselves, their families and their lives.

*...but, but, but, the other thing that happened. I, I think for me having sort of survived, pretty much from what I was told, against medical opinion you know like it was a surprise that I that I survived and then recovered. That set up something else for me about um what did that mean for me, for my life um... that I was spared the sort of sense of being spared. And you know I I sort of went through quite an existentialist sort of period for about the next year. I suddenly thought maybe I must change my life. Maybe I must... I mean I went through a stage thinking maybe I must sell my goods and go off to you know um um Zaire you know, do something radical. I never sort of activated any of those plans but I was looking for some great, what the Universe wants me to do you know(Maya).*

*As I said, that experience for me heralded the beginning of a totally different new era and at that particular point in my life, I underwent serious evaluation of my life, of where I am, what am I doing here, going through a very deep questioning of yourself and where you are. I definitely think that was the part in my life where I seriously started looking at things and started embarking on a whole new journey and the thing that remained with me after that was, would I ever be able to have another baby? (Micha).*

*No it's just em, I think that was just like a wake-up call. Wake up to 'hey girl' take things a bit easier. You can't just run a company, do this, still cook up a storm. You need to relax, you need to... okay I blame that and I said okay right. Now that I've said 'you'll stay at home, you going to rest' now I thought somebody said ...I'm going to do that now, my body needs rest. I mustn't eat these things. And I 'm going to listen. Now I'm listening big time. I can die, the baby can die. Em so it's just like er, a little bit of a 'listen you are not in control here, you going to do what's right, what's required (Kayla).*

*I don't feel guilty anymore because I guess I've become fatalistic now. That it is meant to be. It's something that was meant to be...and that as people we are not in control...there is a Higher Power that is in control and you are not always in control(Miriam).*

The excerpts from the interviews highlight various issues for these women. For Maya it was about what she should do with her life after her experience. For Micha the experience signalled a change in course for her life. Kayla's talk focused on her need to take things a bit easier, slow down and generally look after her health. Miriam's experience brought her to the understanding that there is a Higher Power in control and that as humans we are not in control. She uses the word 'fatalistic' to describe her understanding of what all of this meant, particularly given the fact that she almost lost her own life.

What is interesting to note is the source of women's explanation in their meaning-making process. When looking at their educational levels, it appears that those without tertiary levels of education drew on more religious discourses to frame their understandings. Those participants who drew on more existentialist kinds of understandings had tertiary level education.

Complications in pregnancy herald a very stressful and uncertain time for women. Research, as well as the participants in my study, supports the fact that women experiencing high-risk pregnancies experience a host of emotional issues, including stress, fear, anxiety and guilt. While very few studies have focused on women's spiritual experience, the available literature does report that a large number of women use spiritual beliefs and practices as a means of coping. It has been shown in some studies that spiritual beliefs and practices can alleviate stress and anxiety and aid in establishing a sense of security and hope. Lobel *et.al.*, (2002) report on the link between stress reduction and positive health outcomes for mother and baby.

### **8.9. Conclusion**

In the HELLP syndrome experience it appears that motherhood, when it does materialise, comes at an enormous cost. The uncertainty and unpredictability of this experience places incalculable demands on women physically, emotionally and psychologically. Given the primacy of motherhood in South African society, such experiences challenge women immensely as the threat exists that some women who have had HELLP may never have a biological child of their own. This chapter demonstrated how powerful these dominant discourses of motherhood are and how women constantly defined themselves in terms of these notions. This was no different for the participants in my study. However, given their risk situations these traditionally held notions of motherhood certainly seemed to exacerbate the situations and many of them felt extremely pressured to deliver their infants. With engagement around motherhood issues increasing, my analysis highlights the need for this engagement to be extended to those mothers whose pregnancies are at risk. The concluding chapter therefore attempts to call to attention the need for this type of engagement.

## CHAPTER 9: CONCLUSION

In this thesis I have examined the meaning-making process for women who have had HELLP syndrome: a high-risk condition of pregnancy. This entailed exploring their emotional/psychological and physical experiences, attempting to understand the role which frameworks of intervention and biomedical discourses play in their experiences, and finally, exploring their subjective experiences in becoming mothers in the light of the dominant discourses prevailing on motherhood, when there were such tangible threats to themselves and their infants. This exploration was based in a feminist-poststructuralist epistemology, and a material-discursive theoretical framework was used to theorise the HELLP syndrome experience. In this final chapter, I will provide a reflective overview of the core findings of my study, examine the broad implications of these findings for scholarship, discuss the utility of the theoretical framework, reflect upon the methodological strengths and limitations of the study, and provide some recommendations for future research and for healthcare personnel.

### 9.1. Summary of the core findings

In exploring the emotional/psychological experiences of women with HELLP syndrome I drew on a phenomenological analysis in which I attempted to generate a structural description of the experience. However, the women's experiences were diverse and differed substantially depending on the severity of the disorder and the gestational stage of the pregnancy. These lived experiences were described by participants on bodily, psychological and emotional levels as difficult, a disaster and an extremely painful experience. Because the syndrome is insidious and difficult to diagnose, events culminated in a whirlwind experience in which there was very little time to prepare for what lay ahead.

Many emotions were experienced ranging from shock, disbelief and surprise at the onset of the disorder to anger, helplessness and powerlessness, fear, guilt, feeling robbed and cheated, and culminating in profound sadness in some cases, particularly when these mothers lost their babies. Psychologically almost all participants at one time or another contemplated dying since the condition is potentially fatal for mother and baby. In addition, due to the rarity of the disorder, it remains relatively unknown and therefore the participants grappled with their situation as they had very little previous knowledge of this disorder. Blame was also a huge issue for many of the participants as they tried to make sense of their situations.

On a bodily level, differing degrees of pain were experienced and this pain served as a messenger for some of the participants. Other participants examined the role of their bodies and expressed a sense of body failure and betrayal, creating a kind of dualism in their own understanding. This experience highlighted many issues for the participants that would otherwise have been taken for granted, one of them being the role of their bodies. Only once their bodies ‘malfunctioned’ (Martin, 1992) did some of the participants seriously contemplate the role of their bodies in reproduction. In one case, the body became the source of absolute abjection.

In trying to locate and demonstrate how these voices and experiences are linked with ideologies, dominant discourses and power relations, I examined ideologies of patriarchy, technology and medicine itself. On examining the expressions of participants, it became apparent how patriarchy itself sets women up and disempowers them completely, particularly in the medical context in which HELLP syndrome occurs. Notions of control and power were evident in all the participants’ talk but differed in terms of how they negotiated these forms of power. What played a tremendous role in this regard were the socio-economic positions women occupied in society. Those who were middle-class and had access to medical aid were treated at private hospitals and had very different experiences to their more disadvantaged counterparts.



The fact that both mother and baby were compromised through these experiences tremendous guilt was experienced by the participants, and most of them reported that they blamed themselves. The issue of self-blame was of huge significance, and on closer inspection it became evident that the blame was in large part internalised through discourses of the ‘all-responsible mother’. As documented in Foucauldian scholarship (Dean, 1994; Rose, 1996), self-surveillance becomes the order of the day which is then operated and exercised under the influence of some system of truth which in this case is the medical system, together with dominant notions and social expectations woven into the fabric of this system and the rest of participants’ lives.

The second part of my analysis focused on the role which frameworks of medical intervention and biomedical discourses play in women’s understanding and meaning-making process with regard to HELLP syndrome. Women’s meaning-making of their experiences

was in large part shaped by the structure of healthcare in our country. State healthcare was experienced as extremely stressful and unpleasant by most of the participants. The physical environment, the level of care as well as the attitudes of nursing staff were found to be particularly problematic for those participants who attended those hospitals. What was interesting to note was that while participants attending state-run hospitals described the maternity sections as 'pathetic', the NICU was highly acclaimed in those same hospitals. Therefore within one hospital, care appeared to be very uneven, seemingly privileging babies over mothers.

In terms of nursing care and interventions by physicians, there were huge disparities. 'Caring' was a term reserved for nurses while 'cure' was a term used for doctors. These dualisms seemed to be constructed and utilised in very particular ways. They also seemed to confirm how doctors are trained to focus more on the diseased body, while nurses are involved with the ill person. In addition, these dualisms reflect the gendered differences with doctors being primarily male while nurses were predominantly female. These gendered roles further dictated the nature of the interactions between health personnel and their patients. The participants experienced doctors who were predominantly males as the providers of information and idolised as authorities, whereas nurses, who were mostly women, were expected to be the carers.

The hospital stay reflected two distinct technological cultures, namely the ICU environment and the NICU. Both contexts proved extremely tiresome, lonely, confusing and bewildering at times. Particularly in the NICU environment, mothers had to negotiate their way through a quagmire of power relations, primarily with nursing staff. Nurses were often in charge of the daily running of the nurseries and the participants had to frequently contend with very patronising attitudes. However, in other instances, participants described some of the nursing staff as very helpful and supportive.

Central to their experiences was how they viewed treatment, their bodies, their foetuses, doctors as well as their interactions with them. Various discourses and metaphors could be traced in their talk. Doctors were thought of as individuals with supernatural abilities to cure and to heal. When this did not manifest there was huge disappointment and disillusionment expressed. Other discourses which emerged were: medicine as a scientific truth, body as machine, foetus as 'super subject' and risk discourses. All of these served to structure relationships and highlight power differentials and hierarchies within medical science.

Doctors are positioned as God and women as patients who, according to Foucault, enable disciplinary power to be enacted and render their bodies docile bodies (Foucault, 1977). Particularly in HELLP syndrome women's bodies were handed over and treated, and often the women concerned were too ill to question this. Most of the participants' primary concern was to get better and fully recover therefore many of them accepted any form of treatment unquestioningly. In the final analysis, what transpired in the medical context further shaped the participants' passage into motherhood.

This section of the analysis yielded some of the painful experiences which these women went through. Their experiences in relation to motherhood were determined by whether or not they had a live baby or not. Moreover, when examining their experiences, hegemonic discourses of motherhood were pervasive. What was significant was that motherhood was perceived to be central in most mothers' talk. For some of the participants, to be a mother had always been considered normal and natural. However one of the participants commented that her choice was more unconscious than conscious, and that this may have assisted in her ability to correct perceptions of her own challenging childhood experiences.

In terms of having live babies, for some mothers the NICU experience structured their passage into motherhood. Motherhood in hospital was a challenge for most of the participants as they were ill, trying to recover from their ordeal, and still had to be mothers to their pre-term infants. For those who lost their babies, it represented a time a profound sadness and loss with the notion of motherhood lost, particularly for one of the participants who did not have any children. The loss of their children symbolised broken dreams, severed connections and a powerful taboo.

Discourses in which motherhood was naturalised and normalised, saturated their talk. For many of the participants motherhood was something you become and do without question. Again a recurring theme in the interviews was how women felt responsible for everything pertaining to their foetuses and their infants. The ideology of mother-blame was rampant throughout the interviews.

In trying to make constructive meaning of the experience, participants drew on discourses of religion, spirituality and existentialism. Drawing on religious understandings allowed mothers to talk about faith and how their faith sustained and enabled them to discern meaning or a greater sense of purpose of what was transpiring. These mothers attempted to seek and

impose order on what they recognised to be the dishevelled nature of their experience, and often did so by understanding their experience in the context of faith or religion. For one of the participants, however, religion did not provide the comfort it was expected to provide. In fact, the participant expressed 'deep anger towards God' for having subjected her to such trauma. In sum, religious discourses served different purposes and held a multiplicity of meanings for women. In some cases they provided a channel for supplication; in other cases these frameworks served as a vehicle for venting and questioning; or were perceived to function as a platform for healing.

For some of the other participants, the HELLP syndrome experience ushered in a time for deep questioning and re-evaluation of their existence. What is evident is that they constructed this as a deep search for meaning within themselves, which led to a changed understanding of themselves, their families and their lives.

One of the key findings filtering throughout participants' narratives is how the experience of HELLP syndrome foregrounds the erasure of women's subjectivities while the life of the foetus or infant takes precedence. This was not only demonstrated through their discursive constructions, but was also emphasised in the way in which participants spoke about themselves and their own experiences. In theorising this framing aspect of the experience, Foucault's concept of self-surveillance is useful. While many of the notions the participants held and discussed as givens were drawn from societal beliefs and norms about what should be, most of them internalised these discourses and treated them as fundamental 'truths' on which they based their lives. With the exception of one or two participants, their talk and how they understood the issues were presented as givens. Having briefly summarised the core findings of my study, I now turn to an analysis of the implications of these findings for scholarship.

## **9.2. Reflections on study**

In this section I reflect on what I believe are the implications and significance of my study for scholarship, theory, methodology and practice.

### **9.2.1. Reflections on Feminist scholarship**

I believe my dissertation highlights the need for feminist engagement in an area that has retained a studied silence. Hazen (2006) notes that silences and silencing can be understood both literally and symbolically. DeVault (1999) explains the varied ways that silence is

understood as a metaphor by feminists. Silence may not only mean not talking; it may also mean not writing, not being present, not being heard and being ignored. However, she adds that silence can also entail speaking or writing ephemerally or without authenticity, confidence or authority. Silencing can also refer to “censorship, suppression, marginalisation, trivialisation and other forms of discounting”. DeVault (1999) adds that feminist discourses “do not usually consider the silences of the powerful, often used to maintain control” (p177). Hazen (2006) points out that in numerous research projects which examined women’s work lives, careers and career development, issues of infertility, miscarriage, abortion, stillbirth or infant death were not mentioned at all. Furthermore, the complexities of reproduction and mothering seem largely unspeakable in the arena of work.

What seems to be unspeakable does not only pertain to the area of work, but is much more pervasive in society at large. Drawing on Layne’s (1997; 2003) work, Hazen highlights the significance of these silences around pregnancy loss in society at large. While feminists have critiqued the medicalisation of pregnancy and childbirth, as well as various reproductive technologies, they have been silent around issues of miscarriage and loss.

While engagement around pregnancy loss in feminist circles has now begun, the issue of medically complicated pregnancies still remains largely unaddressed. My thesis thus serves as a starting point for a feminist engagement in this area. While Pamela Klaasen (2001) argues that maternity which includes pregnancy, childbirth and childcare has been one of the most frustrating and provocative challenges for feminist scholarship and practice, my findings point to a need for a feminist engagement when pregnancies are medically complicated or at risk. Given the trauma which the participants in my study experienced, such an engagement is crucial. As Hazen (2006) reports, silences and silencing can have devastating consequences for women – such as depression, severed relationships, derailed careers and missed opportunities for learning and growth.

Locating my study in a feminist poststructuralist epistemology was particularly useful as it enabled a critical analysis of gendered norms. Furthermore, a feminist poststructuralist epistemology allowed me to highlight the complex processes and matrices of power throughout these experiences, not only in the medical context where hierarchies are evident and power is pervasive, but also socially where dominant discourses on motherhood provided the context within which the participants positioned themselves throughout the interviews.

A further benefit of this epistemology resides in the notion that subjectivity is neither innate nor genetically determined. Rather, subjectivities are socially produced in socially specific ways through language and discourse. However, discourses often provide dynamic, different and contradictory subject positions. Therefore it becomes impossible to speak of a coherent, unified and stable sense of self. Poststructuralism thus assumes that the subject is fragmented, contradictory and inconsistent. This was particularly evident in my analysis of the participants' experiences of HELLP syndrome where it was demonstrated how pregnant bodies were experienced. 'The' maternal body and its role during pregnancy constantly shifted, was broken down into component parts, was dichotomised and at times was almost rendered invisible when participants spoke about motherhood. Therefore utilising a feminist post-modern epistemology, allowed the binary distinction between 'the' body and discourse to be punctured and deconstructed. The value of this epistemology allowed for the inclusion of a theoretical framework (material-discursive), which permitted these binaries to be unpacked at all levels in my study.

### **9.2.2. Reflections on theoretical framework**

In drawing on a material-discursive framework my intention was to circumvent theorising in a simplistic, reductionist manner which has been evident in many studies on birth and motherhood. In the majority of these studies, the tendency was to focus on either 'experience' or 'ideology, discourse and macro-systems'. Cosslet (1994) argues that this is largely due to the challenges involved in attempting an analysis that aims to acknowledge and respect women's voices, and simultaneously to demonstrate how these very voices and experiences are often intricately linked with ideologies and discourses and relations of power. In this thesis I have attempted to examine both, but make no claim to have always achieved this. For example, in Chapter 6 where I examine the emotional/psychological experiences of women, I draw on a more phenomenological analysis and attempt to locate these emotions in broader discourses of power and domination. In theorising and attempting to locate the voices of the participants in broader social discourses, I felt at times that the 'lived' experiences of women were getting lost and were downplayed. In this regard, I therefore felt that I had valorised discourses and ideologies of meaning perhaps at the expense of women's subjective experience. I am well aware that this tension exists throughout my thesis.

A further challenge in this domain related to the concept of 'risk' itself which is used quite generically in medicine and its related disciplines, to refer to all births. I agree that the concept is often used loosely and is appropriated to refer to a diverse range of issues such as risk management, accident prevention, health promotion and so forth. However, 'risk' takes on a very specific meaning in my study to refer to situations where either the mother or infant, or both, are at risk for compromised maternal and foetal outcomes. I found the literature and research on high-risk pregnancies in particular, to be problematic, as it was based on an outdated modernist binary mode of thinking which assumes the differences of men and women, and sex and gender. This earlier-dated work on pregnancy in particular, seemed to promote notions of a coherent, unified, autonomous and contained self. In presenting notions of the subject as autonomous and contained has positioned the maternal subject and the foetus as two distinct bodies and thus has allowed her body to be discursively produced in ways that subjugate her to patriarchal and medicalised description and control where her subjective narratives are marginal.

In exploring women's experiences of HELLP syndrome it was evident that high-risk pregnancies could not be separated from the social constructions of motherhood and how motherhood has been constructed in popular and medical discourse. Once again the literature in this regard often culminated in an either/or situation where either women's experiences were examined or discourses of motherhood were explored. In my thesis, the challenge was to be always cognisant of both, while recognising the interface between the two which lines up with a material-discursive view of 'reality'. A material-discursive framework not only served as the theoretical framework for my study, but also informed and became interlaced with the methodological approach to analysis.

This framework was extremely useful to my study as it allowed for the privileging of both sites of knowledge production namely, the subjective and the discursive realms of being. In addition, this study demonstrates the interwoven nature of these dimensions and emphasises how dominant discourses exacerbate the challenging experiences for women with HELLP syndrome, and in turn how these discourses became foundational to their experiences. My study thus displays poignantly how powerful the discourses are in shaping the experiences of women who have had HELLP syndrome. The theoretical framework also served as the basis for the methodological approach in my study. I will now turn to reflecting on some of these issues.

### 9.2.3. Reflections of methodology

In the first place, it was extremely difficult to recruit participants because of the rarity of the disorder. I worked with local state hospitals and in some cases the hospital records were poorly kept, resulting in incorrect participants being recruited. In one instance, I had spoken to the participant and explained the reason for my call, when she responded that she had no idea what I was referring to since she had not had any complications during her pregnancy. A further issue which compounded the recruitment process was the fact that many of the women had to gain permission from their spouses to participate in the study. In some instances, the husbands would not allow their wives to participate, especially in the month of Ramadan (holy month in Islam). This is indicative of the patriarchal control that men endorse and which women tend to subscribe to. One of the participants also reported how she had to convince her husband to allow her to participate using the motivation that such a process would contribute to her healing. While this study did not focus on the partners/spouses, many of the women reported that their partners were not willing to discuss their experiences with anyone, including their female partners. This highlights another silence regarding high-risk pregnancy: one that is gendered and feeds into the idea that women are the talkers and are better able to express their emotions than men.

While all of the interviews were conducted in English, it was not acknowledged that this was not everyone's mother tongue. However, I consciously decided to keep the process open and invite participants across the language spectrum for two reasons. One was that the disorder is very rare and this would have limited participation even more. Secondly, had I only included those whose mother tongue was English, I probably would have ended up with a very middle-class sample. My intention from the outset was to recruit a diverse group of women. In addition, after I met with the head of obstetrics at one of the state hospitals and he informed me that HELLP syndrome seems to be more prevalent amongst people of colour, I was determined to access a greater variety of women to ensure a more heterogeneous sample.

My readings and teaching of qualitative methods made me realise that as qualitative researchers we assume a certain level of verbal articulation, and particularly in psychology, we expect participants to be proficient in emotional and psychological expression. A challenge I encountered in this regard with some of the participants related to verbal expression, especially being able to express themselves psychologically. Some of the

participants struggled to articulate and express themselves verbally. I think this may have been due to the fact that psychological discourse is not a part of the majority of people's daily repertoire. On the other hand, I had one participant who was trained in clinical psychology and she had been in therapy for years. One could clearly discern the difference in the way these participants were able to express their emotions and psychological experiences. I must add at this point that the diversity of expression added to the richness of the study and should not be construed in a negative way. I merely highlight it for consideration, as I think that researchers make assumptions and take many issues for granted.

The interviews were conducted in a fairly unstructured way, but at times I had to probe quite deeply to gain clarity and to encourage participants to reflect. They did not seem to mind, and in fact welcomed the opportunity to reflect. One of the participants (Kayla) commented that the interview provided her with the first formal opportunity to reflect on her experience. I did find her very reflective and I observed many issues being resolved for her. Another of the participants (Jean) thanked me for inviting her to speak about her experience as she said that no-one else had ever asked her about what had happened when she was in hospital. Another participant (Miriam) made it very clear to me that she was participating in the study so that other women could learn from her experiences. Thus it appeared that the interviews in themselves were therapeutic and helpful to those who participated.

The analysis was particularly challenging. I constantly found myself challenged when trying to do a purely phenomenological or discursive analysis as I found the relationship between the two dimensions was bi-directional. On a theoretical level I think maintaining and according 'equal' attention to both material and discursive realities was challenging. When attempting to tie up all the loose strands, I felt that I had privileged the discursive, and in a sense wondered if I had lost the more experiential, subjective experiences in the process. This caused some tensions for me as this had been the initial focus of my study. Because I had been through two of my own pregnancies with HELLP syndrome, it was important for me to have these stories told. Moreover, in academia and theorising I recognise the possibility of losing these raw emotional and psychological issues. My fear at some intra-psychic level was also that this part of myself would be swallowed up by the enormous theorising which is expected at this level. However, to satisfy my own need and

desire in this case, I continued to utilise my therapeutic space which has become invaluable during this process, and to journal about my own emotional and psychological processes throughout.

#### **9.2.4. Implications of study for practice**

Having outlined some of the implications for scholarship, theory and methodology, what about the implications for healthcare personnel who are directly involved with women who encounter HELLP syndrome during their pregnancies? The right to survive pregnancy and childbirth is implicit in women's fundamental human right to life. However, women's enjoyment of that right is contingent upon their ability to exercise three other basic human rights: the rights to healthcare, non-discrimination and reproductive self-determination (Cook & Dickens, 2001). In a country like South Africa where major overhauls in the healthcare system have been witnessed, there still remains a steady increase in maternal mortality rates. This raises critical concerns as HELLP syndrome is an extremely treacherous disorder that can be potentially fatal to both mother and baby. Since the medical context is critical in the management of HELLP syndrome, the findings of my study could serve as a starting point to alert medical personnel to the importance of actively listening to women's explanations of the symptoms they are experiencing. As the participants in my study pointed out, when they had strong premonitions that something was wrong, these sentiments were dismissed or ignored by medical staff. Being alert to these warning signals early on could warn doctors and nurses of impending danger and could assist in quicker recognition of HELLP syndrome.

Making medical personnel aware of the intense emotions that women experienced during their HELLP syndrome encounter could also facilitate a more empathic understanding. Participants in my study reported the deep fears they experienced, the lack of control they felt and how powerless they felt. An understanding of these issues by medical personnel could therefore aid women in dealing with such trauma.

Sharing important factual information regarding HELLP syndrome could assist in decreasing the feelings of no control which were expressed. Active decision-making by the patients themselves is important as this will allow women to take back their power. Based on the findings of this study, I believe it is important to convey this information in a sensitive and gentle manner. Women in this situation are faced with such extreme trauma that it may be difficult to absorb the information at the time. However, most of the most

participants felt that knowing what was happening to them assisted them, particularly when they needed to process everything in an attempt to make sense of this experience.

In conclusion, I believe that nurses and doctors need to understand these experiences in order to provide support to these women. This support ideally should continue into the post-partum period so that the long-term effects of trauma are alleviated and the women can move beyond their feelings of loss and fear to deal with possible subsequent pregnancies.

### **9.3. Recommendations for future research**

Research in South Africa on high-risk pregnancies in general and on HELLP syndrome in particular is virtually non-existent. Based on my project, I would strongly recommend that future research focuses exclusively on the emotional and psychological aspects of high-risk or medically complicated pregnancies in general and on HELLP syndrome specifically.

Continuing to work with women across race and class divides, ensures that the complexities in South African society can be understood. I would strongly recommend researchers to be cognisant of this, take it seriously and not merely pay lip service to issues of difference and diversity. If predominantly middle-class samples are used, research in this country will follow predominantly Eurocentric trends and merely be an extension of international research.

My study focused exclusively on maternal experiences of HELLP syndrome. As alluded to research with male partners need to be initiated. This work could serve as a glimpse into work on masculinities which is currently receiving far more attention than in the past.

Methodologically qualitative research is always about depth and understanding, which are necessary if one is to understand the complexities of such trauma and how it is dealt with by individual women. However, what I think is sorely needed in our context is a deeper and more contextual understanding of pregnancy, birth and motherhood in general. Chadwick (2006) in her study also makes this point.

Theoretically I found feminist-poststructuralist epistemology extremely useful in researching and understanding the experiences and meaning-making of HELLP syndrome. The material-discursive framework used to theorise those experiences proved very helpful in the analysis. I think the material, experiential aspects should not be lost in such an analysis. Many of the

participants made a point of letting me know that they were telling their stories not just for themselves or for this academic project, but for the benefit of other women further down the line who might face a similar fate to theirs.

#### **9.4. Final words**

This study makes an important contribution to research in the area in high-risk pregnancy in general and HELLP syndrome in particular. As a reminder, to date, only one study conducted was published in the United States of America. It is an area under-researched both locally and internationally. Moreover, I believe this study attempts to break silences in feminist scholarship where miscarriage and stillbirths have been relegated to the periphery. Studies of this nature compel us to confront these issues and resurrect the proverbial 'dead bones'. While this study heralds the beginning of this type of engagement it certainly is not the last and final word. It is my wish that this study will stimulate other researchers, particularly feminist researchers, to take the baton and carry it forward.

On a personal level this work has served as a growth-promoting process. The stories relayed by the participants were mutually enriching and encouraging. Their hunger for more information regarding HELLP syndrome was voiced and we used this as a basis for further discussions. In sum, through telling the stories of my participants, I believe I have told my own story. Most importantly, I end with the hope that such stories and the unpacking attempted here contribute to a larger scholarship which seeks both to give voice to and critically analyse women's lives in a continued unequal and patriarchal society in which their bodies, especially when pregnant and birthing, are regulated in ways that are not always conducive to their own well-being.

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# APPENDIX 1

## DEMOGRAPHIC DETAILS

**The purpose of this questionnaire is to obtain details about the background and history of your reproductive life.**

Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

Telephone No: \_\_\_\_\_

Current occupation: \_\_\_\_\_

Relationship Status: Single      Engaged      Married      Separated

Divorced      Widowed      Living with partner

Religion: \_\_\_\_\_

Highest Educational level: \_\_\_\_\_

Mother tongue: \_\_\_\_\_

No of pregnancies: \_\_\_\_\_

No of pregnancies with HS: \_\_\_\_\_

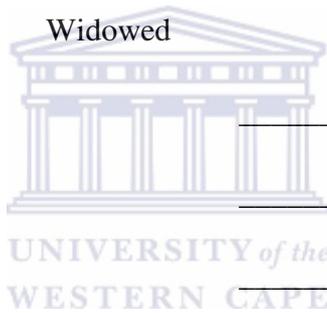
Age with your HS pregnancy(ies) \_\_\_\_\_

No of live births: \_\_\_\_\_

No of infant deaths: \_\_\_\_\_

No of children: \_\_\_\_\_

Any underlying medical condition: \_\_\_\_\_



# APPENDIX 11

## INTERVIEW SCHEDULE

### **Part 1: Motherhood**

- ✓ Tell me about your ideas regarding motherhood
- ✓ What ideas have you grown up with regarding motherhood
- ✓ What ideas do you have regarding pregnancy

### **Part 2: The HELLP syndrome experience**

- ✓ Tell me about your experience with HELLP syndrome
- ✓ Talk about the emotions you went through
- ✓ Talk about your thoughts at the time
- ✓ How did this experience affect you? (Positive outcomes/negative outcomes)
- ✓ Could you make sense of this experience? (How?)
- ✓ How has your HELLP syndrome experience affected your thoughts about motherhood

### **Part 3: The medical context**

- ✓ How did you experience the treatment and care you received
- ✓ How did you experience the treatment and care your baby received
- ✓ What were your thoughts around the medical context
- ✓ What were your thoughts and feelings regarding the doctors and nurses

# APPENDIX 111

## CONSENT FORM

Thank you for considering participation in my study. Please read the following carefully.

A face to face interview will be conducted with you and tape recorded. You will be asked questions which you may consider as very personal and may bring back difficult memories. However, you may wish not to answer some questions or you may want to discontinue the interview. Should any of this take please be assured that this is your right and it will not prejudice any further treatment at the hospital you are attending. Once all my work is completed you have the right to request that your taped interview be returned to you, or alternatively you can request that your taped interview be destroyed.

Should you find questions asked during the interview difficult and you are unable to deal with them later, please contact me so that I can refer you to someone that you can talk to.

To ensure confidentiality, your real name will not be used. All data collected will be protected by storing it in a safe place. The only people who will have access to the tapes are myself, my supervisor, my assistant and examiners should they wish to verify any information. Please also note that the results of my study will be written in the form of a doctoral thesis and may also be published in academic journals-while ensuring complete anonymity.

I understand and agree to the terms set out above.

\_\_\_\_\_  
Signature of **participant**

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of **researcher**

\_\_\_\_\_  
Date

Should you wish to report any problems you have experienced related to the study, please contact:

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