

**The psychological experiences of women who survived HELLP syndrome  
constructed online**

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Submitted in accordance with the requirements for the degree of

Master's in Psychology in the Department of Psychology

at the University of the Western Cape



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Keywords: HELLP syndrome, maternal health, psychological experiences, high-risk pregnancy, online social support, thematic deconstruction, social construction, social suffering theory, qualitative methods, internet mediated research

**November 2017**

## **Abstract:**

This thesis is about HELLP Syndrome (hemolysis, elevated liver enzymes, low platelet count in pregnancy). HELLP syndrome is considered one of the most devastating complications in pregnancy. Once set in motion, the symptoms rapidly progress resulting in organ failure which can lead to the deaths of both the mother and the fetus. The only intervention found to be helpful in saving the mother is immediate termination of the pregnancy.

The last couple of years have seen a proliferation in the way people express their feelings, emotions and thoughts utilising online platforms. The internet as a site has thus become an important area of research as it provides valuable information regarding how users write about their own health related experiences. The primary objective of this thesis was to explore the psychological experiences of women who survived HELLP syndrome as constructed online. Through identifying these psychological expressions on line these experiences could be deconstructed.

A social constructionist epistemological framework was used as well as social suffering theory. In conventional terms “social suffering” would refer to political relevance only, however the term has theoretical standing as it deals with the core essence of social experiences and takes into account the psychic, social and cultural dimension that make up these experiences.

An internet-mediated method was used to conduct this study. The data was collected over a one month period on an online platform which had 3720 members. During that month 87 postings and 228 interactive postings were recorded. Electronic copies of the consent form, information sheet and the ethical clearance letter were posted onto the online platform where it could be accessed by all members. Ethics approval was obtained from the University’s Senate Research and Ethics Committees to proceed with the research study.

A thematic decomposition analysis of the data revealed that the main themes were: mourning and loss, memorialization of the loss, experiences of medical staff, intuition, religion and spirituality and social support found online. I attempted to produce a thorough description of the way women construct and make meaning through these experiences. This thesis revealed through its main findings as well as the literature reviewed a large part of pregnancy is seen as natural; my thesis however contradicts this linear process and emphasises the risk that could encapsulate the entire process.

**Declaration:**

I declare that *The psychological experiences of women who survived HELLP syndrome constructed online* is my own work, and that it has not been submitted before for any degree or examination at any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

*JL Cupido*



## **Acknowledgements:**

*“Thank you’ is the best prayer that anyone could say. I say that one a lot. Thank you expresses extreme gratitude, humility, and understanding.” - Alice Walker*

First and foremost I would like to express my gratitude to God for blessing me with this opportunity of learning and for being so gracious upon my journey.

To my supervisor, Prof. Michelle Andipatin, thank you very much for not only being a supervisor but also a guiding light and motivation on the days I doubted myself. I thank you for all your support and guidance.

To Prof. Priscilla Daniels and the Community Engagement Unit, thank you for affording me the time to work on my thesis and for supporting me throughout this journey. Thank you for all the words of motivation and encouragement.

To my fellow Masters colleagues of 2015 and my friends, thank you for always being my sound board while conceptualizing this study. Thank you Kyle Jackson and Abigail Simons in particular, my special cheerleaders, your friendship and support means the world to me.

Thank you to my participants who afforded me this opportunity by sharing their lives with me. You are warriors and I have learnt so much from you. I give each of you the gift of acknowledgement. Your story matters.

To my wonderful parents and my siblings... my people. Thank you for being my unconditional support system and my biggest source of inspiration. Everything I am I owe to you, for all your sacrifices I say thank you.

Last but not least, to my amazing husband, Chad Masters: Thank you for being the most supportive and tolerant partner in the world. Thank you for motivating me to chase my passion fiercely. Everyone deserves someone like you to do life with.

*“Be around the light bringers, the magic makers, the world shifters, the game shakers. They challenge you, break you open, uplift and expand you. They don’t let you play small with your life. These heartbeats are your people; these people are your tribe.” - Unknown*

Thank you my tribe, you all know exactly who you are!

I dedicate this thesis to all the HELLP syndrome infants and mothers who did not survive and who never got to tell their story.

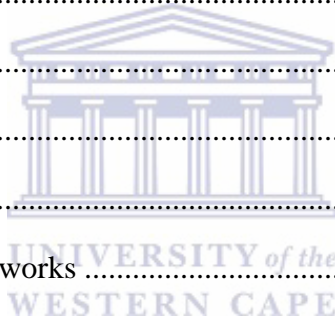
Most of all I dedicate this thesis to my mother.

*“The healing power of even the most microscopic exchange with someone who knows in a flash precisely what you're talking about because she experienced that thing too cannot be overestimated.” — Cheryl Strayed*

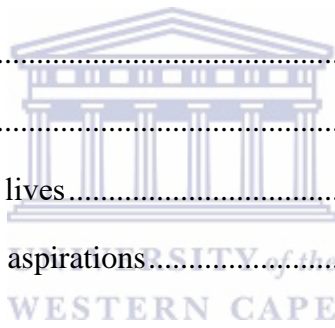


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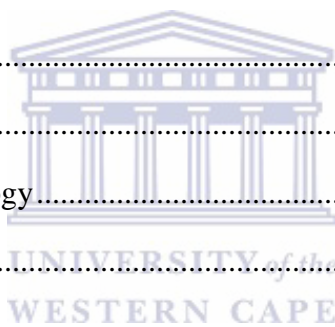
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# Chapter One

*“Hello fellow warriors...just a reminder that we’re all here due to a common condition but our journeys are far from identical. In that respect, so is our healing. Let’s keep it kind and delicate as we cannot always fully comprehend where others are standing and this group is amazing for giving and receiving support at all stages. Your admin all love you and are here for you and it warms our hearts to see the kinship formed and relationships forged. Thank you for helping us keep this group a safe and an inviting place to just simply be”- HELLP syndrome survivor.*

## 1. Introduction

The primary purpose of this thesis was to explore how women who survived HELLP syndrome constructed their psychological experiences online. HELLP syndrome is characterized by haemolysis, elevated liver enzymes and low platelet count (Roomaney, Andipatin & Naidoo, 2014). According to Andipatin (2012) high-risk pregnancy is a field that has been researched yet HELLP syndrome is hardly ever mentioned. In this section, I will be introducing the role of the internet in health related incidents including HELLP syndrome, followed by an overview of maternal health. This section also explores high-risk pregnancy and HELLP syndrome briefly. The latter part of this section looks at the aims and objectives of this study as well as the rationale.

### 1.1. Background and Rationale

#### 1.1.1. The role of the internet

The last few years have seen a proliferation in the way people express their feelings, emotions and thoughts online. According to Haverinen (2014), people share many elements of their lives with each other on social networks and other online sites including the stories of joyful times as well as the more unfortunate events in their lives. The internet is not only used for gathering information, it has also become a site for self-expression and seems to serve quite a therapeutic function for many. For these reasons mentioned, the internet has become an important site of investigation as it enables glimpses into how many users experience, write about and make sense of many health related issues.

Davison, Pennebaker & Dickerson (2000), stated that support groups in health were initially characterized by physically meeting together at a particular time in a particular venue. This phenomenon has however changed throughout the years and the internet has become a critical role player in areas of support regarding health. According to Fox & Duggan (2013) the internet is used by patients to not only conduct further investigations regarding their health concerns, but also to gain support from other users who are experiencing similar concerns. They also suggest that the internet has become a measure of support and this notion is supported by Huh & Pratt (2014) who found that online communities are a measure of support in diverse spheres of health such as cancer, diabetes, rare disease and HIV/AIDS.

Huh & Pratt (2014) found this type of support to be a source of connecting and distributing knowledge and experiences that lead to a shared social identity. These authors further maintain that health professionals cannot always deal with patients in the way that other patients can who are experiencing the same issues in terms of meaning making, psychological experiences and dealing with the illness. Furthermore, Potts (2005) suggests that these online spaces are often overlooked. According to Davison et al. (2000), the study of online support communities offers a gap for researchers to examine the kinds of experiences that patients grapple with ranging from issues such as misdiagnosis to confusion and perceived ill treatment from health professionals.

A cursory glance at internet sites revealed that many women are using it as a site to explore and understand maternal health or ill health because the internet has provided mothers with a space to adjust and feel empowered. In addition, it also allows for a virtual connection and social interactions for mothers (Kim, Lee and Oh, 2015).

### **1.1.2. Maternal health**

The World Health Organization (2014) reported in 2013 that approximately 800 women lost their lives daily due to maternal causes globally and 99% of these deaths occurred in developing countries. Most of these deaths could have been avoided as medical interventions are available, however, the accessibility of medical services before, during and after giving birth poses huge challenges for many women in developing countries (WHO, 2014). In high income countries, 99% of women are attended to by qualified professionals, while in low income countries only 46% are attended to during child birth, increasing the risk of obstetric problems. (WHO, 2014). Due to the

lack of professional care, especially in low income countries women's experiences of pregnancy and birth vary considerably hence the way these experiences are dealt with is multi-faceted. Meaney, Lutomski, O'Connor, O'Donoghue and Greene (2016) explored the way women internalize maternal morbidity and found that four responses were prevalent throughout the study. These responses were: powerlessness, morbidity management, morbidity treatment and the corresponding socio-behavioural responses to these morbidities (Meaney et al., 2016). In other words, Meaney et al. (2016) argued that many women relinquished their power "handing it" to medical staff while receiving treatment, in order to secure the safety of both themselves and their baby. Yet these very participants reported feeling frustrated and anxious concerning the debilitating nature of the morbidity. These authors thus suggest that maternal morbidity not only impact the mothers at the onset of the experience but can still be observed long after the delivery (Meaney et al., 2016). Furuta, Sandall & Bick (2013) concur with Meaney et al., (2016) and maintain that women's experiences of maternal morbidity can be grouped into three main areas: the experience of the event, thereafter the immediate reaction and this is followed by the aftermath. These three areas can be operationalized as the actual physical experience, the belief about the event and the way in which the mother interprets what had happened. The issue of maternal loss is not widely discussed hence the lack of awareness and the psychological experiences of the trauma are silenced, despite the importance of the dire needed trauma treatment.

### **High risk pregnancies**

A pregnancy can be defined as high risk when there is an elevated chance that the baby or the mother's health can be compromised (Daflapurkar, 2014). The term high risk is used when various risk factors are evident during the pregnancy; in other words, either pre-existing conditions or complications as a result of being pregnant (Daflapurkar, 2014). There are a few conditions that are associated with the aetiology of high-risk pregnancies such as diabetes and other health difficulties, physical conditions, environmental factors and also preeclampsia of which HELLP syndrome is one of the variants. (Lee, Ayers & Holden 2012; Vafaeimanesh, Nazeri & Hosseinzadeh, 2014).

### 1.1.3. HELLP syndrome

HELLP syndrome is considered one of the most devastating complications in pregnancy because it increases the maternal and fetal mortality rates. Maternal mortality rates have been pegged at 1.1 to 25% of all high-risk pregnancies, while fetal mortality rates range from 7.4% to 34 % within high risk pregnancies (Darby, Martin, Mitchell, Owens & Wallace, 2013; Vafaeimanesh et al. 2014). Despite these alarming statistics, the psychosocial aspects of this syndrome remain shrouded in silence, under researched and hence poorly understood. According to Aydin, Ersan, Ark & Aydın (2014), the prevalence of HELLP syndrome ranges between 0.5–0.9% in all pregnancies and 2–30% in cases where there is severe preeclampsia. Preeclampsia can be defined as a ‘hypertensive, multisystem disorder of pregnancy’ which is affirmed by Postma (2014). The third trimester is concomitant with the peak time of diagnosis of HELLP syndrome and giving birth to the baby is generally considered the safest route, in an attempt to minimize harm to either the mother or baby (Vafaeimanesh et al., 2014). Due to the severity of this medical condition, time is of the essence.

### 1.2. Rationale of the study

Hinton, Locock & Knight (2014) argue that in order to improve the experience of childbirth it is important to understand the subjective perceptions and experiences of the event. The majority of the studies investigating HELLP syndrome reviewed mainly focus on the medical components of the disorder and very little research was conducted on the psychosocial aspects (Roomaney, et al. 2014). The few studies that have examined the psycho-social aspects of HELLP syndrome focused on conventional methodologies using face to face interviews such as those done by Roomaney et al. (2014) and Andipatin (2012). As time progressed, the internet has become a crucial part of our worlds and it is necessary for us to acknowledge the role it plays within highlighting our experiences. Not many studies have been conducted using internet mediated designs and consequently there is an abundance of information on women’s experiences that have not been explored. The social support structures that are housed within the internet and the assistance it seems to provide for users deem a need for greater understanding. The use of an internet mediated platform allows many women a voice as St John, Cooke and Goopy (2005) affirmed that in a traditional setting women feel that they lose their status as a mother once they have lost their baby or survived the ‘abnormal’ circumstances involving the pregnancy or birth. Due to family and

friends not validating the grief or loss, women feel isolated and are left in a space of silence (St John et al, 2005).

### **1.3. The Aim and Objectives**

Given the above, this study's primary aim was to gain an understanding of how women globally who survived HELLP syndrome construct their psychological experiences online. For the purpose of this study psychological experiences were defined as emotions, feelings and thoughts (Andipatin, 2012). Based on the general aim the following objectives were constructed:

- To explore how women who participate via various social media platforms express their psychological experiences of HELLP syndrome online.
- To deconstruct these psychological experiences as they were expressed online.

Based on the aim and objectives of the study a social constructionist framework was selected to frame the study as it views people's experiences as a product of social processes. Furthermore, the social suffering theory states that illnesses are not unanimous and people experience illness in relation to the culture, society and time. Hence, this theory was used to gain a deeper understanding of the online community and the rare illness called HELLP syndrome.

This is particularly important as the participants construct meaning from their own HELLP syndrome experiences and this is shaped as legitimate through various discourses or through silence.

### **1.4. Conclusion**

The introduction contextualizes the research study and defines all the concepts under exploration. The significance of the study in relation to internet-mediated research is introduced and discussed focusing specifically on addressing the aims and objectives of the research study. The following chapter will thus focus on a review of the relevant and related literature pertaining to high risk pregnancies in general and HELLP syndrome in particular as well as how these issues are addressed on online platforms. Below follows an outline of the chapters that follow.

## **1.5. Outline of thesis chapters**

### **Chapter Two – Literature Review**

This chapter reviews literature relevant to maternal health focusing on HELLP syndrome. It provides the reader with insight into the literature relating to high risk pregnancies. In addition, chapter two introduces the social constructionist framework and social suffering theory that were used and details the underpinnings that make the framework suitable for this study.

### **Chapter Three – Methodology**

The methodology implemented in the study is described in this chapter. The research design, procedure, data collection and analysis, reflexivity and very importantly, the ethical guidelines of the study are explained.



### **Chapter Four – Interpretation of Findings and Discussion**

This chapter discusses the findings of the collected data in terms of the thematic categories that provide insights that relate to the aim and objectives of the study. In this chapter I make use of deconstructive thematic analysis reflecting the experiences of the women who survived HELLP syndrome.

### **Chapter Five – Conclusion**

The final chapter summarizes the analysis in relation to the aims and objectives. Theoretical implications are discussed and linked to the literature review as well as giving attention to the limitations of the study. In completion recommendations are made for future research.

# Chapter Two

## 2. Literature Review

This chapter commences with a discussion of literature regarding the issues surrounding online networks, and then proceeds with discussions on high- risk pregnancy and motherhood. The review also examines literature concerning the construction of pregnancy and the constructions t surrounding the experiences of the high-risk pregnancies.

### 2.1. Importance of the online networks

Wellman (2001) states that computer networks in contemporary times should be seen as an integral part of peoples' lives and not viewed in isolation. Computer networks are regarded as rightful institutions that link people, organizations and knowledge. Kietzmann, Hermkens, McCarthy & Silvestre (2011) concur that these new, tremendous, and fast growing online networks have taken over the communication platform and currently provides individuals with a variety of scope and functions. Consequently, Potts (2004) argued that online communities have taken on the role of a support group to people who share a common health or social problems. These online social support groups tend to provide members with a mutual support system and with some valuable knowledge surrounding these communalities (Potts, 2004). Furthermore, Potts (2004) indicates that these online social support communities are not only diverse but are also not always related to a specific organization or affiliated to a certain professional body. In spite of many criticisms, the online platforms are regarded as useful as they are specific spaces whereby individuals can share experiences without the traditional boundaries of time and space (Potts, 2004). These online communities are further characterized by disinhibiting behaviours of individuals in light of various interactions and a certain form of intimacy that is formed by the community members (Potts, 2004).

According to Durante (2011) it is important to note that the online construction of a personal identity is co-created both by the writer and the reader in a space of trust and privacy. Furthermore, he states that the difference between online reality and the 'real' world, ('real' referring to the physical), is not entirely dependent on the differences between the two but rather a way of rethinking and overcoming differentiation. In other words the disparity between the physical world



and online reality is not mutually exclusive domains and can be used in conjunction with one another. Durante (2011) is also of the opinion that the online space should not be seen as a 'second reality' but rather a pathway to a component of the individual's personality constructed on a virtual platform. Durante (2011) thus argues that those who do not acknowledge this construction of the individual on online networks are restricted in a space of belief that a 'second identity' exists.

Previous research established that certain social cues, such as self-disclosure in terms of breadth and depth is what characterizes good relationships (Hollenbaugh & Everett, 2013). However, with the on-going growth of online platforms substituting for face to face interaction it is necessary to understand how these conventional assumptions are revisited (Hollenbaugh & Everett, 2013).

There are six orthodox factors that are generally associated with online disinhibition namely: dissociative anonymity, invisibility, asynchronicity, solipsistic introjection, dissociative imagination and the minimization of authority (Suler, 2004). According to Suler (2004) dissociative anonymity speaks to the fact that when online, a name or username does not reveal much about the individual, thus therefore the 'online self' stands in isolation to the rest of the individual's life. Invisibility refers to text driven online communities where individuals cannot see one another, hence allowing a space where individuals can be more courageous and honest about what they are writing (Suler, 2004). Even on a platform where they use their real names a certain sense of invisibility still applies as there is no face to face connection. Asynchronicity refers to the delay in response on an online platform, which is different to that of physical face to face conversation. Solipsistic introjection refers to the cues that would normally be combined with speaking, such as facial expressions or tone of voice. These cues are missing from text communication and therefore the reader is reading what was written from their reference as they thinking about it. Therefore, the reader decides what the tone of the text communication is. The dissociative imagination effect also surfaces in text communication when the reader forms an image of what they think the writer is like, which adds another dimension to the online reality. Lastly it is the minimization of authority that the online environment controls for, as everyone starts out on an equal setting despite any social standing. Suler (2004) identifies this online disinhibition as a shift to a pattern that differs from the face to face interactive self-structure.

Thus the disinhibition associated with online platforms can be categorized into benign disinhibition and toxic inhibition (Suler, 2004). Suler (2004) identifies the aforementioned as the



less restrained and more expressive kind whereas the latter is linked to a platform that individuals would not necessarily access in person, such as pornography sites. Suler (2004) states that the above mentioned factors such as anonymity, contributes to the disinhibition that individuals are prone to as their identity can be protected to a certain extent. However, Hollenbaugh and Everett (2013) found that there was a correlation between age and the amount of disclosure on online platforms as younger women tend to disclose more than men and older individuals in general. Furthermore, Hollenbaugh and Everett (2013) identified that people who were visually identifiable disclosed less information about themselves. By contrast to the above Suler (2004) does allude to the fact that individuals are complex and this thus determines disclosure in relation to underlying feelings and the personality of the individual.

According to Carroll & Landry (2010), a trend has emerged where social networks are used as a place to grieve and memorialize the death of individuals. Furthermore, these authors propose that this discursive site/s serving as a platform for grieving and memorializing, is the next step in the evolution of social/online networks. Wellman (2001) is of the opinion that internet technology is a powerful force that could lead to very important interventions. One of the most searched topics on the internet is information regarding health and this allows for opportunities to move from the conventional methods of patient-health related relationships whereby the patient has to go see the Doctor to internet mediated health interactions where patients make use of the internet as resources for health related issues (McMullan, 2006). This therefore provides researchers with the opportunity to access information through a different platform where the patient is an active participant instead of a passive receiver (McMullan, 2006).

A review of internet mediated research revealed various studies that have been conducted on health related matters. For example, a study by Chen (2014) examined anorexia; cancer related internet mediated research conducted by Cooper, Mallon, Leadbetter, Pollack & Peipens (2005). These authors focused on the way cancer patients search the internet for health information. Another study conducted by Fogel, Albert, Schabel, Ditkoff & Neugut (2002) focused specifically on the internet usage of women suffering from breast cancer. Mazzi & Kidd (2002) used internet research to examine diabetes management. These are only a few of the studies conducted using the internet as a platform for health related research. Another major area on the internet where women seek information is pregnancy related issues (Newby, Brodribb, Ware & Davies, 2015). In Newby et

al's. (2015) study they examined new mothers utilize the internet for information regarding optimal nutrition during infancy as well as other health related information. Furthermore a literature review was conducted by Plantin and Daneback (2009) where they explored addressing the question regarding how parents make use of the internet regarding their children, health and family life. The findings of their study revealed that the majority of parents use the internet as a resource to find information or support. .A recent study examining Korean mothers' use of technology, specifically their internet usage, found that these mothers seek the vital and informed social support systems on the internet. This behavior is related to the fact that women who become mothers are expected to adopt and adapt to new social roles (Kim, Lee and Oh, 2015). )

## **2.2. Motherhood**

De Beauvoir (1949; 64) stated that, "Childbirth itself is painful; it is dangerous. This crisis according to her suggests that the body does not always meet the needs of both the species and the individual; the child sometimes dies, or while coming into life, it kills the mother; or its birth can cause her a chronic illness."

Childbirth is not just an important biological event, but also an important social and cultural event (Prosen & Krajnc, 2013). Carvalheira, Tonete & de Lima Parada (2010) argue that motherhood is a process that starts long before the actual conception through women's early relationships, adolescence and other identifications. The desire to someday be pregnant and have a child is central for many women mainly due to the way they were socialized since a young age. These authors add that having a child, is regarded by many as the ultimate outcome of various conscious and unconscious motives. According to Andipatin (2012) pronatalist societies construct having one's own biological child as a requirement and therefore women feel pressurized to become mothers. Thus, one can infer from the above- mentioned statement that childbirth is constructed in such a way that it is experienced as the only process that gives women access to becoming mothers; and motherhood in turn is constructed as equivalent to womanhood in these types of societies (Kantor, 2006).

Van den Akker (2011) concurs that pregnancy is constructed in a way that suggests that it gives women a rite of passage to a new identity as a mother.

Kantor (2006, p34) identified that women who could not have children positioned themselves within a discourse of “the deviant other” as she argued that “in a world of mothers and babies there are continual reminders of how women without children stand in contrast to the norm”. Kantor (2006) further states that literature reflected how women who are unable to have children find themselves as the castaway of the social context they are living in, and she argued that they were “outcast, alienated and ostracized...” (Kantor, 2006, p35).

Based on the above, it is evident that motherhood is central for many women, thus being pregnant when there are medical complications severely compromises the passageway for women who are in the process of becoming mothers.

### **2.3. The Constructions of Pregnancy and its Concomitant Loss**

There are various ways in which pregnancy is constructed ranging from societal constructions to medical constructions to constructions posited by Feminists, such as De Beauvoir. Below follows an overview of some of these constructions.

Pregnancy was constructed in a very particular way by Feminists such as, De Beauvoir. She (1949; p64) describes pregnancy in the following way : “In the early months, it often brings with it appetite loss and vomiting that is not observed in any other domestic female and shows the body’s revolt against the species taking possession of it; the body loses phosphorus, calcium, and iron, the last of these losses being very hard to overcome later; the metabolic hyperactivity excites the endocrine system; the negative nervous system is in a heightened state of excitability; the specific weight of the blood decreases, and it is anemic, like “that of people who fast, who are starving, or who have been bled many times, and convalescents.”.” This quotation thus depicts pregnancy in a very negative way positioning the pregnant woman as subjected to various biological processes over which she has very little control.

However, pregnancy is also socially constructed in particular ways and through many stereotypes. According to Schetter (2010) stereotypically pregnancy is seen as ‘happy and joyful’ complication free time, as reported by popular culture through magazines, social media, television and entertainment. In popular culture, pregnancy is often constructed as beginning with a bump and progressing until the healthy baby is born. Pregnancy is hardly ever constructed as a time where there is a lack of resources whether this be socio economic, physical or psychosocial where there

are other stressors present (Schetter, 2010). Due to the fact that the body of a woman is constructed socially during pregnancy, experiences are vast and very different depending on the context within which the pregnant woman finds herself in (Van der Sijpt, 2010). These experiences will be guided by the context, such as, low socio economic circumstances would allow the pregnant mother basic or limited care and very few of the modern day pregnancy associations like maternity photo shoots. In addition, someone with a better socio economic status could afford better health care, there would be a higher likelihood for the latter to accommodate the current popular culture trends. The social construction is influenced by the popular culture, discourses of loved ones and the resources of the country. If the woman is from a rural, culturally background her experience of pregnancy would be guided by the cultural practices of the community she forms part of. However, if the woman is from a big city she would find herself guided by the practices of the city. In any context loved ones impart indigenous knowledge picked up and passed over from their own experiences or what they have seen and this is then handed over to the expecting mother. Referring to the latter, the resources of the country have an influence on the medical discourses.

Pregnancy is also constructed in medical terms within a risk framework as a woman is only considered out of danger when she has given birth to the baby and there are no complications. One can therefore infer that in pregnancy a distinction can be made between low and high risks with low risks being conceptualized as common to all pregnancies and high risk as characterized by severe medical complications (Hammer & Burton-Jeangross, 2013). According to Hammer and Burton-Jeangros (2013) pregnant women's experiences are constructed by the extent to which risk is associated with the expectance of a baby. Women who are pregnant are encouraged to take better care of themselves and to eliminate behaviours that would endanger the mother or baby, who could be at risk from the onset of the pregnancy (Rothman, 2014). Hammer & Burton-Jeangros (2013) concurs with Rothman (2014) that there are many prenatal procedures put in place to avoid harm and routine checks are important to ascertain that there are no problems with the fetus and the mother. Furthermore, Hammer and Burton-Jeangros (2013) stated that the sociocultural prospects toward upcoming mothers have an influence on their experiences of surveillance during pregnancy. In other words, the societal and cultural influences have an impact on the way mothers feel with regards to the different ways in which their bodies are subjected to surveillance during their pregnancy.

Medicine also privileges logic over intuition and this is witnessed in a study conducted by Gaskin's (1996). She discusses her midwifery training and the vital lesson her mentor taught her with regards to the importance of paying attention to the pregnant women and what they had to say about their baby. Gaskin (1996) explained that her mentor also had not been taught this in medical school, but had been trained by their mentor. This is not unusual as the voice of the woman is not seen to be as important in relation to the empirical evidence medicine uses to make decisions for treatment. Greenhalgh (2002) speaks of intuition and medicine as not complete opposites for medical doctors that are more open to it. However, in her study the focus is mainly on the intuitive sense of the medical doctor and not that of the patient. When searching for literature on the role intuition plays within pregnancy it is not a common subject that many researchers write about. However, if the balance can be found between intuitive thinking and feeling as well as medical bio-science this might mean that pregnant women could be of use to doctors when diagnosis has to be made and more than just a passive bystander to what is happening within their body.

Northrup (1995; pg. 59) is of the opinion that intuition is "independent of any reasoning". Northrup (1997) further states that humankind has been taught to believe that the medical profession knows more about our own body than we do. Furthermore, Northrup (1997) calls for women to take back their inner guidance; that is to own to their bodies.

A negative experience of pregnancy and even childbirth for most women may cause post-traumatic stress disorder, avoidant behaviour or even flashbacks to the traumatic experience (Waldenstrom, Hildingsson, Rubertsson and Radestad, 2004). Waldenstrom et al. (2004) found that a lack of control was a major contributing factor to a negative birthing experience for their participants, and this included fear of death and physical damage to their bodies. Cooper and Beck (2014) concur that the lack of control leaves the women with long-term feelings of distress. Therefore Andipatin (2012) argues that this process is compromised and fraught with difficulties for women who face severe morbidity.

Religion also constructs pregnancy in very specific ways. Willard (1998) states that the 'soul is regarded to be part of a person that does not exist without the person and that the person does not exist without the soul', therefore the soul and body is seen as equally important. Griffith (2004) is of the opinion that a human fetus is a member of the human race from the moment of conception. According to this view, the soul is central to our being and central to our life (Hall, 2006; Griffith,

2004). The developing baby communicating its ‘personhood’ through connecting with the mother’s spirit, is seen as a connection to the mother with the unborn fetus (Hall, 2006).

Due to the various constructions discussed above a concomitant loss occurs when a pregnancy does not meet these norms as set out by the many constructions. According to Naidoo (2012, pg. 1) “there is a conspiratorial silence around the way loss is experienced due to the constructions surrounding pregnancy”. According to Corbet-Owen & Kruger (2001) due to the various constructions of pregnancy, woman experience loss in different ways when a pregnancy is not carried to term and is surrounded by negative experiences. Furthermore Callister (2006) states that when this loss occurs women grieve and mourn the hopes, dreams and expectations that they had for the baby.

Kohn and Moffitt (2000) explains that when the woman finds out that she is pregnant she starts thinking about how she would include the baby in her life and her existence at the time, with the expected outcome of a healthy baby. When this outcome is not met mothers often make sense of the unexpected outcome through various discourses. According to Naidoo (2012) the women in her study on miscarriage made use of three main discourses. The first is motherhood discourses, such as instinctive motherly attributes being disregarded, in terms of the mother having a natural feeling about certain things, which increases universal ideas of constitutes ‘good mothering’ (Kruger, 2006). They used discourses of failure, not seeing themselves as a good mother who could carry a baby full term or feelings that their body or medicine had failed them. Thirdly, they made use of religious discourses to find peace that what happened to them had a divine reason (Naidoo, 2012). In other words, religion becomes a meaning making mechanism for the mothers.

#### **2.4. High risk pregnancy**

As seen in the Andipatin (2012) study ‘high-risk’ pregnancy is not a very old term as it was not yet used in the nineteenth century (Shorter, 1982). Rather than ‘high-risk’ pregnancy, medicine used discourses such as ‘complications’ or ‘risk’ (Andipatin, 2010).

According to Andipatin (2012) it is important to examine risk factors that constitute a high-risk pregnancy as this is useful in gaining an understanding of what is associated as ‘high-risk’. Ganesh



(2008) states that risk factors are characterized by things such as age and weight or pre-existing conditions or complications (Daflapurkar, 2014) as a result of being pregnant. Furthermore,- there are other conditions that can be associated with high-risk pregnancy such as physical conditions (Anemia, weight gain, urinary tract infection etc.), health conditions (High blood pressure, diabetes, auto immune disease etc.) or environmental conditions (Cigarette smoking or alcohol use etc.) (Lee, Ayers & Holden 2012; Vafaeimanesh, Nazeri & Hosseinzadeh, 2014).

Zanette et al., (2014) define cases where organ damage or other severe obstetric complications are present as high risk. Zanette et al's. (2014) study focused on the significant correlation between hypertensive disorders and severe obstetric complications as this demonstrated severe maternal results such as, near miss or maternal deaths. It is important to note that hypertensive disorders were linked to 70% of the participants in the Zanette et al. (2014) study. Furuta, Sandall & Bick (2014) maintain that maternal morbidity rates are increasing due to the health and obstetric needs of women in high and middle- income countries.

According to Kidner & Flanders-Stepans (2004) events with a life threatening nature such as experiencing a high risk pregnancy can have a major impact on the psychological condition of the woman. Furuta et al. (2014) found that the intervention after a high- risk pregnancy is very important in both the physical and emotional area to minimize severe long- term effects to the mother as well as the extended family affected. Due to the severity of high- risk pregnancies women often experience various emotions, feelings and thoughts. Below follows a review of the studies that were conducted examining various aspects of high- risk pregnancies such as the psychological experiences, religion and spirituality as well as intuition.

## **2.5. Psychological experiences of High-Risk pregnancies**

Due to a lack of research on HELLP syndrome, the high- risk pregnancy literature was reviewed to gain an understanding of how psychological experiences are constructed. According to Schetter (2010) there is great variability in the experiences of pregnant women and many factors interplay hence no single experience is exactly the same for every woman. There are many confounding factors that influence the construction of psychological experiences of the mothers during a high-risk pregnancy.

Turner (2006) suggests that human behavior is guided by a set of expectations that is socially constructed. Therefore, individuals compare themselves with the societal norm of how an experience is supposed to be. It is therefore not uncommon when pregnancy and motherhood are associated with social norms within a social context (Kim, Lee and Oh, 2015). Within many social contexts pregnancy is seen to be an uncomplicated nine months that eventually leads to the birth of a healthy baby. Pozzo, Brusati, Cetin (2010) note that the transition from a seemingly “normal” pregnancy to a “high risk pregnancy” is a critical moment for mothers and may lead to diverse emotions. Roomaney et al. (2014) states that there are various pressures and tensions that accompany and contribute to the construction of a high- risk pregnancy. These areas include means of coping, stressors, and experiences regarding medical decisions as well as feelings and emotions.

Women’s experiences of maternal morbidity can be grouped into three main areas: the experience of the event, thereafter the immediate reaction and this is followed by the aftermath (Furuta, Sandall & Bick, 2013 and Meaney et al., 2016). These three areas can be operationalized as the actual physical experience, the belief about the event and the way in which the mother interprets what had happened.

**The experience of the event:** Kidner & Flanders-Stepans (2003) specified that women in their study on HELLP syndrome felt overwhelmed by the lack of knowledge and ultimately felt that they had no control. They further maintain that some women do not completely understand their diagnosis, they are either struggling to understand the explanation given by health professionals or they do not understand the medical terms. Roomaney et al. (2014) concurs with this in their study done in the South African context. Some of the participants in the Roomaney’s et al. (2014) study only understood their diagnosis after conducting their own research on their illness. Furthermore, women acknowledged a sentiment of betrayal due to misdiagnoses early on by medical professionals but also by family members who agreed that it could not be anything serious. Fear, frustration, anger and guilt were feelings that were consistent within the women (Kidner & Flanders-Stepans, 2004). McCain (2006) who conducted a study on the experiences of high- risk pregnancy for both parents noted that feelings ranged from fear of caring for a premature baby to the complicated and life threatening event.

**The belief of the event:** According to Pozzo et al. (2010) the uncertainty of the birth of the baby and when it will happen adds to the anxiety. Bed rest and the inability to do tasks for themselves



brought about feelings of frustration and anger within some of the women in the, McCain (2006) study where they examined the experiences of high-risk pregnancy for both parents. Due to these and many other restrictions and confusion caused by the high- risk pregnancy women's experiences are constructed in terms of threat and diverse difficulties.

**The way the mother interprets the event:** Some mothers drew on medical discourses to make sense of their experiences. Andipatin (2012) argued that women in South Africa make use of biomedical discourses and the structure of health care to derive meaning of their experiences. This is also seen in the Hammer and Burton-Jeangros (2013) study conducted in Switzerland where biomedical discourses played a major role in how women constructed the experiences for themselves. In other words, women made use of the biomedical discourses as a framework to make meaning and gain understanding. Andipatin (2012) elaborates that different kinds of discourses and metaphors such as 'medicine as science, body as machine, doctor as God, and the fetus as super subject', were drawn on in her study within dialogues with the participants which gave meaning to the way the women experienced the event. The metaphor 'medicine as science' refers according to Andipatin (2012), to the split between mind, body and the increase of medicine. Furthermore 'body as machine' refers to the approach that the body is separated into different parts and as a result only the broken part can be fixed. The term 'Doctor as God' reflects the patriarchal and the hierarchy within the medical model. The doctor is positioned as the one who is omnipotent and all knowing.

According to Rodolfsdottir (2000) the 'Fetus as super subject' is often the way literature positions the pregnancy. As a consequence, this understanding transforms the body of the woman into a container or incubator (Andipatin, 2012).

Due to further studies done there has in recent years been an increase in giving a voice to the women who experience high- risk pregnancies. Some mothers draw on religious and spiritual discourses. Various studies focused on illustrating the role of religion and spirituality in traumatic events. Horton (1960) suggests that religion is a multifaceted term lending itself to various understandings. Horton (1960) defined religion as a resource that informs and directs human behaviour. An example of this is where children are born into a religion and are expected to accept this religion as 'the truth'. Furthermore, the second definition according to Horton (1960) refers to religion as metaphorical statements and actions that guide the social relationships and allows for

social status. An example of this is the hierarchy of leadership within religious institutions. The third definition refers to religion as a term which class a certain group of objects together such as 'spirits' or the 'supernatural'

This opinion is agreed upon in a study done by Zinnbauer et al., (1997) who found religion to be associated with high levels of family attendance at church, inherent religiousness as individuals naturally take on a religious means of understanding behavior or use religion as a way of making sense. Furthermore, Zinnbauer (1997) associates totalitarian behavior with religion as individuals assess their behavior through guidelines provided by their specific religion. Due to the many definitions of religion, spirituality and religion, are often used interchangeably even though the two concepts are different (Tanyi, 2002).

Zinnbauer et al., (1997) argues that spirituality in contrast is constructed around a modern belief and practice system where the individual has a broad framework by which they enquire about the meaning of life Tanyi (2002) concurs that spirituality can be defined as an internal component of being human that is 'naturally' present. This component is completely subjective and multidimensional. Therefore, it is clear that spirituality is about the human being's search for the meaning in life whereas religion is more structured in terms of rituals and structures that focus on one higher power. Spirituality due to its subjectivity can therefore be related to religion however certain individuals do not relate it to religion at all (Tanyi, 2002). Even though religion and spirituality are different concepts, they both are a structure by which individuals either find support or make meaning.

Powell, Shahabi & Thoresen (2003) conducted a study that provided evidence that religion or spirituality acts as a protective resource that has a significant impact on physical health as it constrains disease in people. The Powell, et al., (2003) study observed a change in the attitude and behavior of individuals that made use of their religious and spiritual belief systems as a resource while they were ill. Furthermore, religion or spirituality is considered to be a measure which is used to cope with health issues (Powell et al., 2003). This method of coping is acknowledged through prayer, worship and reliance on God. This generally allows people going through a traumatic physical or emotional experience to find inner peace (Khoshtinat, 2012).

Issues regarding the spiritual nature of pregnant women has according to Hall (2006) been explored over the years. A study done by Carver and Ward (2007) explored the experiences and needs regarding spirituality during pregnancy. The majority of the women identified spirituality as an important aspect in their life, through religious practices as well as alternative spiritual techniques such as tarot and crystals (Carver & Ward, 2007). Pregnancy and birth have been recognized to be a state in which women have a heightened spiritual atmosphere hence becoming more in touch with their bodies and intuition (Hall, 2006). These participants had expressed the need for the medical professions to respect their beliefs and practices (Carver & Ward, 2007).

**The aftermath:** According to Keane (2009) pregnancy loss memorialization is contextualized within the ideology of intensive mothering. This positions the child as 'sacred' and the mother dedicates time and energy to the unique relationship shared throughout the pregnancy. The relationship surpasses time and space and speaks to a pregnancy loss discourse which focuses on the unwavering love between mother and the child (Keane, 2009). Earlier the social construction of pregnancy was discussed and Keane (2009) identifies consumer culture as one of the key components of the social construction. A mother who is viewed as caring according to society will ensure that her child has the safest equipment such as prams, the most natural food as well as the best day care that would be most nurturing (Keane, 2009). Layne (2004) states that pregnancy memorialization to a certain extent relies on these commodities to represent a lost experience or child. The commodities are also proof of the reality that motherhood was denied for this person.

According to Layne (2003) personhood is not viewed as an inherent attribute found in all pregnancies, it is rather measured by those who are mourned and memorialized. This opinion works on the assumption that the babies who are mourned and memorialized were wanted and could be categorized as 'real babies' (Layne, 2003). Keane (2009) however states that applying the notion of personhood to pregnancy limits memorialization to a fetus only, whereas many times that which is being memorialized is the loss of what was idealized for the child, despite gestational age. The loss is real; yet due to the dominance of inherent biological personhood it is difficult to meet the requirements for the loss to be noted as an embodied existence. Furthermore these social identities remain disembodied and precarious (Keane, 2009).

Keane (2009) further states that the internet has been a key component of pregnancy loss discourse and memorialization. The internet has become a space that is used for memorializing the dead and

these interactive platforms of memorialization may continue to progress as years go by (Veale, 2004). According to Keane (2009) the experience of these platforms is both disturbing and emotionally moving as it is a virtual space filled with intimate, tragic and private experiences written by the person who had experienced the trauma themselves. Mortazavi, Mousavi, Chaman & Khosravi's (2014) findings concludes that there is a gap for interventions to promote psychological well-being as this increases the quality of life.

## **2.6. Theoretical Framework**

Due to the nature of this study a social constructionist epistemological framework was used (Burr, 1995). Considering that this study focuses on women who survived a traumatic experience in the context of a biomedical institution, the study also draws on social suffering theory (Kleinman, 1997). In conventional terms “social suffering” would refer to political relevance only, however, according to Renault (2010) the term has theoretical standing as it deals with the core essence of social experiences and takes into account the psychic, social and cultural dimension that make up these experiences.

Wilkinson (2013) is of the opinion that ‘social suffering’ requests of the social science researcher to adopt the pursuit of social understandings of human suffering, whether this be as a result of institutional political injustice or of illnesses. Furthermore, Wilkinson (2013) suggests that “social suffering” represents the marginalized in terms of gender and high- risk pregnancy. Therefore reflecting attention to the lived experiences of those in need of understanding and focusing on the realignment of these issues in relation to social context is vital. Wilkinson and Kleinman (2016) alludes that the focus on “social suffering” has broken away from suffering being a problem for an individual but rather a social concern.

In terms of Social Constructionism the foundations are found in postmodernism. It suggests that the world as it is experienced is a result of social processes with no ‘one’ true reality (Schwandt, 2007). These realities could take a wide variety of different associations as it is conceived on an individual level, therefore one can refer to numerous possible ‘social constructions’ in the world (Burr, 1995). In addition, subjective reality is constructed inter-subjectively through the meanings and understandings developed socially and experientially (Guba & Lincoln, 1994). The theory of social suffering finds synergy with what Guba and Lincoln (1994) asserts as Renault (2010) argues

that ‘social suffering theory’ is cognizant of both political and social positions of people. Knowledge is thus constructed through our lived experiences in conjunction with our interactions with other members of our society. Burr (2015) suggested that with social constructionism there is no such thing as an objective fact therefore researchers cannot view the world in a ‘taken for granted’ manner.

Burr (2015) summarized the key aspects of her approach on the social constructionist framework through the following:

Firstly, when using a social constructionist framework Burr (2015) alludes that main stream psychology moved away from what used to be seen as discovering the true nature of people towards the idea that knowledge comes in all forms. Burr (2015) is of the opinion that the way we understand our world comes from interaction with other people and therefore our reality cannot be boxed into preconceived ideas. This philosophical belief that individuals construct meaning based on their interaction with their surroundings was noted by Guba and Lincoln (1989) earlier on and was concurred by Burr (1995;2015). In light of what Guba and Lincoln (1989) as well as what Burr (1995) states, Victora (2011) suggests that within social suffering theory illnesses are not universally unanimous and therefore it is experienced in a person specific way in relation to different cultures, societies and times. The participants in this study via an online platform are therefore actively living their experience as a portrayal of how they construct their experiences in relation to their contexts and popular discourses.

Secondly, historical and cultural specificity of knowledge; herewith Burr (2015) recognized that knowledge is specific to cultural and historical perspectives and that the researcher should take into account the social practices by which constructs are created. This had been spoken to in previous work (Burr, 2003) suggesting that social constructionism is concerned with “social, historical and collective nature of human consciousness” (Durrheim, p176, 1997).

Burr (2003) identified language as a critical component of social constructionist framework. Burr (2003) noted that human beings are the only species who make use of language to bring about meaning. Other species use scent, sound, gestures and many other meaning making communicative symbols that are fixed and stable. Language is however not fixed and its interpretation is dependent on the context of the user (Burr, 2003). It is viewed as a pre-condition for thought. We are born

into a certain cultures and make sense of language use through the framework it was introduced to us and carried forward by us (Burr, 2015). The way language is structured is therefore a determinant of the experience and also of the consciousness of the person (Burr, 2003). Language is considered a central aspect as it is seen as a form of action and some social constructionist researchers focus on language as their main interest. It is through language that the opinions and understandings of individual experiences are expressed and the manner by which new meanings are generated (Gergen & Gergen, 1997). Language and individual experiences were of importance in this study as it generated the manner by which the women who had survived HELLP syndrome felt and dealt with the trauma they had experienced.

This theoretical framework consists of two inter-related lenses by which this study will examine the experiences of the women who survived HELLP syndrome, was deemed ideal. It allowed the researcher a distinctive method by which to emphasize the meaning that the HELLP syndrome survivors attach to their experiences and the way they construct their reality after the traumatic experience.

## **2.7. Conclusion**

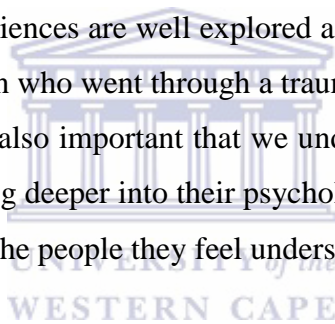
The literature investigated above outlined the dominant research done in the field of internet-mediated research, online support groups, maternal health, high risk pregnancy and HELLP syndrome. In reviewing the literature traditional qualitative studies were predominant. However it is vital to note that internet mediated research is a growing method of enquiry as the use of online networks as a social support system has evolved. Online networks have become a measure of social support and therefore the role it initially constructed has further developed. The construction of health issues online, are similar to the way individuals construct it in the face to face interaction by making use of online resources. Furthermore it has become a space where women can construct their thoughts and feelings regarding motherhood, pregnancy and all other social norms with regards to pregnancy.

It is concluded through the literature that motherhood is not a natural state or need that develops out of nowhere for every single woman. Yet motherhood is conceptualised and institutionalised as a natural occurrence for women from a very young age. This opinion continues in the construction

of what pregnancy is supposed to look like and contains a remarkable position in the paradigm used to view pregnancy.

The idea that pregnancy is always a beautiful baby bump and a healthy mother is connected to the institutionalization of a “normal” pregnancy which is further motivated by popular culture and the standard to which women are held when they are pregnant. However, when the pregnancy does not follow the same route as what is expected and the opposite occurs, it is less spoken about and eventually dies down until the next occurrence. The less well-known idea of pregnancy is termed ‘high-risk’ and as seen through the literature, ‘risk’ is the term that defies all pre-existing constructions of pregnancy.

The lack of knowledge, feelings of inability and loss of all that is categorized as a ‘normal pregnancy’ leads to diverse psychological experiences. It is very important as seen throughout the literature reviewed that these experiences are well explored as we can only be of assistance if we thoroughly understand what women who went through a traumatic experience such as a high-risk pregnancy feels. Furthermore it is also important that we understand their social support system that they form online where they dig deeper into their psychological experiences and extend their stories as a means of a gateway to the people they feel understand the other less spoken of side of pregnancy.





# Chapter Three

## 3. Methodology

The aim of this research study was to explore the psychological experiences of women who survived HELLP syndrome constructed online. Therefore, the research study proposed to gather information from an online platform where women globally who had survived HELLP syndrome wrote about their experiences through employing a qualitative research method. This next section will therefore provide the particular research design, sampling and participants, procedure as well as the ethics considerations. I also reflect on the validity and my own reflexivity of this research process.

### 3.1. Qualitative Research Method

This study explored the psychological experiences of women who survived HELLP syndrome. The exploratory nature of the study was informed by a qualitative research approach as it provided an in-depth understanding of the construction of the psychological experiences of women who survived HELLP syndrome (Babbie & Mouton, 2014). It presented me with an opportunity to explore the subjective meanings of a health-related incident such as HELLP syndrome. From the literature reviewed it was evident that motherhood is much more than it appears; it is a lifelong internalization of the role and identity through social and cultural patterning (Prosen & Krajnc, 2013; Andipatin, 2012) where the body of the pregnant women takes on a social identity (van der Sijpt, 2010).

In light of the aims and objectives of this study it was important to utilize a methodology that allows for the perspective of those who have experienced the syndrome to emerge, therefore a qualitative approach was selected. Qualitative research is characterized by the flexibility of interpretation among socially constructed worlds (Merriam, 2002). Qualitative research is also compatible with social constructionist tenants as it allowed for the survivors of HELLP syndrome to be understood within the framework of their specific context.

Kitto, Chesters & Grbich (2008) argued that qualitative research is interested in the methodical gathering of information and adequately describing the understanding of data from conversations,



observation and documenting. Hence, the online nature of this study suited the methodological gathering of the data online perfectly and provided good insight and comprehension of the topic.

According to Skalski, Neuendorf and Cajigas (2017) users of social networking and non-social networking services play an active role in the construction of content. The increase in research opportunities as 'big data' has become available. 'Big data' is the term used by many researchers as they are faced with huge quantities of data sets generated by users' behavior online. Furthermore, Skalski et al., (2017) states that there are different kinds of users on the social networking sites. They are listed below:

**User to user interactivity:** This refers to a social networking site where users can respond on postings such as Facebook and Instagram

**User to system:** This mode of interaction refers to video gaming where the individual is responding to a coded system.

**User to document:** This interaction refers to the hyper textual content that individuals can use, such as accessing documents (Skalski et al., 2017).

Therefore, most content creation is dependent on what a user intends it to be when interacting on the internet. There are three different kinds of content (Skalski et al., 2017):

**User generated content:** This content can refer to tweets, status updates, posting pictures etc. The user has generated this content themselves.

**User selected content:** This content refers to something that was in existence that is either being shared or reposted. An example of this could be someone sharing an article on Facebook that actually belongs to a newspaper or even someone uploading a picture that was taken by someone else and is being reposted.

**Interactive media output:** This content is created based on the way users mediate their way on the internet. This media output collects the web surfing habits of people or the selection they make during video gaming. This content is possible to capture however, it is slightly more difficult (Skalski et al., 2017).

For the researcher the type of content as well as the type of user is dependent on what they seek to explore as this would guide them to which sphere they would link to. In this research study, I made use of user generated content that stemmed from user to user interactivity. The function of the platform selected was to create a space where women who survived HELLP syndrome could pose questions, share highlights, refer to traumatic experiences as well as reflect on current emotional experiences. This platform is therefore a content sharing space within a network for people with similarities, creating a community. The audience of the space where data was collected is differentiated within a separate group from the broader group of undifferentiated (open access to those registered) space on the internet.

### **3.2. Sampling and participants**

At closing on the 6<sup>th</sup> of September 2015 the online platform had 3720 members of which there were 87 postings and 228 interactive postings recorded within the month of data collection. The postings were all written by the differentiated group of women who had experienced HELLP syndrome themselves and were constructing content from their personal experiences. The demographics of participants were not available as it is not a requirement of the online platform to provide any details such as ethnicity, age, marital status or other categories. Due to the nature of the online platform it is accessible to women internationally where access to the online platform is permitted by the country they are in.

### **3.3. Procedure**

This study was conducted at a South African University after obtaining ethical clearance from both Senate higher degrees and the relevant research ethics committees of the university. I made use of a general search engine as Chen (2014) argued that it is necessary to make use of basic search engines that are accessible without having to be a technological expert. Initially I intended to use the Nielsen Net Rating tool which provides an analytic service to find a preferable online platform (Sullivan, 2006; Chen, 2014), however the tool was closed to people who did not pay to open an account. It was costly to subscribe to an account and as I am not a funded student and would only use it for the purpose of the study, I decided to use another method to find the online platform. Therefore, I identified the keywords and made use of one of the most popular search engines to

find the most suitable online platform. A preliminary search had identified two online spaces where individuals were posting on consistently. I decided to use the one platform as it had the most members and had up to twelve active postings per day. Following the ethical considerations of the Association of Internet Researchers (2012) consent was gained from the administrator of the closed online platform. Thereafter electronic copies of the consent form, information sheet and the ethical clearance letter was posted onto the online platform where it could be accessed by all members. This was posted thrice to ensure transparency (See Appendix 1 & 2). In these three identical postings I made it clear that I would not be interacting with any of the participants or probing on anything that they post. I informed all users that my role was to observe. After posting the above, I received resistance from one participant who was a member of the online platform due to her being employed by an organization that deals with high-risk pregnancies. She explained that she was a member of a particular organisation, yet this was not made clear to other members of the group that she was there as an observer the postings for the organizations' own purpose. She stated that her resistance was towards the method used to gain consent (despite the fact that I posted consent forms and followed all online ethical protocol) therefore she did not want any of her postings to be a part of my study. Her request was acknowledged, however, she did not post anything in the phase where data collection was taking place.

### **3.4. Data Collection**

Data collection took place from the 6th of August 2015 up to and including the 6th of September 2015. For a month data was collected every Friday and every Monday. I chose a Friday as I could collect the entire week's data and a Monday as I could collect whatever was written over the weekend. Data was collected using observation as a method and only data written by an individual who had experienced HELLP syndrome themselves was used. I recorded the posts by directly copying the extract from the website and pasting it into a word document, during the above mentioned times and it was stored safely in an encrypted file that was password protected on my private laptop. The time- frame was sufficient due to the amount of postings daily. The method used for data collection allowed participants to freely construct their psychological experiences without being probed or prompted by any outside influence.

### 3.5. Data Analysis

Given the theoretical framework, aims and objectives of this study I decided to make use of a thematic analysis (Braun & Clarke, 2006) in relation to a thematic decomposition analysis (Stenner, 1993). What discursive approaches in different disciplinary positions have in common is a strong social constructionist epistemology (Nikander, 2008). Jorgenson & Phillips (2002) concur that examining discourse is suitable as an analytical tool for social constructionist approaches. Nikander (2006) furthermore maintains that discursive approaches are very important in analysing individuals' constructions and their social processes as well as the way they construct the social world. Thematic decomposition analysis at its most basic level is a thematic analysis, yet it has discursive elements to it that focuses on content (Ussher & Mooney-Somers, 2000).

Due to the nature of the data collected it was not necessary for any transcribing to be done. The analysis was inductively conducted as I worked from the data. All data collected was written in the English language.

**Phase 1:** The analysis of data started by me immersing myself within the data through reading and re-reading the collected data. This was done twice to gain a better and deeper understanding of the data before continuing the analytic process. The reading and re-reading process allowed me to become more familiar with the depth and breadth of the content.

**Phase 2:** The data were coded manually using Microsoft Word documents as the tool. Different fragments of the data that indicated particular patterns were highlighted and a file was created for each code as suggested by van Niekerk (2015). I coded the original postings and also the commentary on the postings and by doing this I was able to identify the interaction between the participants as well as not losing any of the context created (Braun & Clarke, 2006) (van Niekerk, 2015). Furthermore, through this process codes were refined and allowed for the organizing of data into groups that were representative of the elements within a theme. Thereafter the themes were developed.

**Phase 3:** Once all the coding was arranged the data was reviewed and then captured in terms of themes. The process of reviewing the codes and how they interlink into the larger themes was done through visual representation as suggested by Braun and Clarke (2006). The codes were listed in various formats and placed into numerous themes which allowed for visual representation. The

validity of the themes was reflected through the literature reviewed as well as the theoretical approach of the study. Hoijer (2011) stated that metaphors, images, emotions, attitudes and judgments are found in data as a form of social demonstration.

**Phase 4:** I conducted a thematic decomposition analysis in this study as it explored the narratives and discourses that had emerged from the representations in the data constructed online (Sandberg, 2011). After reviewing my themes as done in the fourth phase of thematic analysis I selected dominant discursive themes so that I could trace a deeper understanding of certain ideologies related to pregnancy, childbirth and motherhood. The aim of this process was to see how individuals use discursive tendencies that are associated with pregnancy and how they construct their subjective positions through this. According to Taylor and Littleton (2006) individual's identities are a compilation of ideas, images, associations as well as the social and cultural context of their lives (p.94).

In my study through the thematic decomposition analysis I drew upon language, subjectivity and the co-construction of my participants' experiences. I focused mainly on the language which is dependent upon meaning and that meaning is largely shaped by the common experiences (Stenner, 1993). Furthermore, according to Stenner (1993) investigating the position of the speaker is an integral part of the narratives or discourses as displayed in online postings.

### **3.6. Trustworthiness of the study**

According to Yardley (2008) addressing issues of validity is an essential ethical element of qualitative research as it contributes to the trustworthiness of the study. Yardley (2008) provided six items that could be used to ensure validity of the study. The first item speaks to 'coding' which refers to a second researcher verifying the themes of the main researcher (Yardley, 2008). The codes and themes were checked by my supervisor as a second researcher. Yardley (2008) proposed that data be fed back to participants; in this case it was not possible due to the nature of this study and the researcher not having any contact with those posting on the site. The research findings were contextualized in relation to other similar studies done as stated in the literature review to validate the study (Yardley, 2008). Transferability was obtained by allowing for thick data descriptions as far as possible to be able to ascertain that sufficient conclusions has been drawn (Shenton, 2004). Dependability was ensured by my supervisor as a subject matter expert evaluating

the procedure and the process of the research study (Shenton, 2004). In addition, I drew on the expertise of other postgraduate students who served as sounding boards and provided valuable input at various points of the analysis.

### **3.7 Reflexivity**

According to Willig (2001) reflexivity involves an awareness of the researcher's involvement to the meaning making throughout the research process. Due to pre-conceived ideas, opinions and thoughts that individuals possess it is vital for a researcher to be reflective of their specific bias when conducting a study. According to Terre Blanche and Durrheim (1999) those who make use of a social constructionist framework should be mindful of the role the researcher plays so to not transfer feelings and expressions on to the participant, as the data collected could be seen as co-constructed. In this study I had to observe the participants therefore their writing was purely based on their thought and emotional experiences. I did however become vigilant of my own position during analysis. I attempted to constantly be aware of my personal subjectivity and sensitivity as best I could.

I am a 24 year old, Black, female student intern residing in a middle income community. I am currently completing my postgraduate degree at a South African University. I have never experienced a pregnancy and therefore might not fully be able to relate to the participants in my study. However, I am being supervised by someone who has experienced a high risk pregnancy and specializes within the field of reproductive health. My mother, like many of these women experienced a high-risk pregnancy while being pregnant with me and lost my twin sister at four months. That has been a crucial part of my motivation to do this research within the maternal health spectrum. When reading the data I realized that it could become very overwhelming to familiarise myself with so much heartbreak and sadness. The way the data was written was 'raw' and the emotions were uncensored. In other words, the participants had no reason to sugar coat anything as they were sharing it with people who understood and had some commonalities. For me as an 'outsider' who had no experience of this depth of trauma it was a deep awakening from any fantasies or notions that I had about what pregnancy was like.

This innocence to what pregnancy and motherhood was for me played a dual role; as a woman it allowed me a glimpse into what is hidden from our everyday bright pictures of the glowing mother

and her thriving belly. As a researcher it allowed me a deeper appreciation of the participant's experiences as I had no judgment to offer and could invest my time and energy into gaining knowledge of their traumatic experiences.

### **3.7. Ethics Considerations**

Ethics approval was obtained from the University's Senate Research and Ethics Committees to proceed with the research study. The Association of Internet Researchers (AIOR) (2012) compiled a set of guidelines rather than ethical codes to use in order to make responsible ethical decisions while doing internet research. The study on HELLP syndrome made use of these guidelines as well as British Psychological Societies (BPS) Inter-Mediated Research Document (2013) to guide the ethics.

The BPS (2013) highlights that the traditional ethical considerations are still considered to be important and the basics are left unchanged. In order to comply with the AIOR (2012) ethical considerations of website access I provided the users on the closed webpage with an online consent form gaining permission from the community to observe their posts as well as an information guide. The consent form and the information guide were distributed on the webpage and if a participant did not want to partake in the study they had to contact me via email to withdraw their participation (See Appendix A).

For qualitative research it is important to protect the identity of the participant. Therefore, the online posts should not be traceable and paraphrasing is advised (BPS, 2013). For examination purposes the real online posts will be used however for publication purposes I will paraphrase the content. In qualitative internet mediated research, high levels of control over technical variables are not very important. However the context of qualitative studies is more sensitive, thus control of possible identification of participants was thoroughly controlled for by not using any identifiable information. The online environment website identity is protected to ensure that the individuals using the platform remain anonymous. Due to any risk that may arise I have decided to refrain from disclosing the name of website.



### **3.8. Conclusion**

In this chapter I provided an overview of my research design namely qualitative design. Furthermore, I provided information on how I accessed the website and selected the postings representing the participants' experiences, the research procedures I utilised, the data collection time period and process and the method of data analysis. In the chapter that follows I present and discuss the findings of the study.





# Chapter Four

## 4. Interpretation of findings and discussion

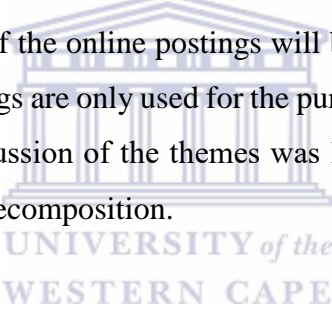
This chapter reveals the ways in which women who survived HELLP syndrome write about their experience online. Following this, the chapter argues that these experiences are embedded within a social constructionist framework with key tenants drawing on social suffering theory. The chapter reveals the following themes as most significant: One broad thematic domain was identified and then divided into themes which described the aims and objectives of the study in relation to the findings.

*Table 1: Thematic domain*

<b>Thematic domain: The emotional experiences of women who have had or survived HELLP syndrome.</b>	
<b>Themes</b>	<b>Sub-themes</b>
<b>Mourning and loss</b>	<b>Loss of the experience</b> <b>Loss of the child</b> <b>Potential loss of women’s lives</b> <b>Loss of future dreams and aspirations</b>
<b>Memorialisation of loss</b>	<b>Memorialising the date of the birth</b> <b>Memorialising a certain time of the year</b> <b>Memorialising certain times</b> <b>Memorialising through items</b>
<b>Experiences of medical staff</b>	<b>Lack of information</b> <b>Lack of empathy</b> <b>Seeking legal action</b>
<b>Premonition and Intuition</b>	<b>Dreams and vision</b> <b>Feelings</b>
<b>Religion and Spirituality</b>	

<b>Social support found online</b>	<b>Support space</b> <b>Advice and suggestions</b> <b>Ambivalent feelings regarding the group</b> <b>Group as a therapeutic space</b> <b>Space to memorialise any form of loss</b> <b>Space to share milestones</b>
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This study was guided by the thematic analysis of Braun and Clarke (2006) as well as the thematic decomposition analysis of Stenner (1993). Therefore, the analysis of the online postings were conducted using the aforementioned modes of analysis. I identified one broad thematic domain, within the domain there are themes and sub themes that spoke to the aim and objectives of this study and then followed up with a discussion of the various themes accordingly. In order to authenticate the themes segments of the online postings will be presented. It is important to note that the extracts of the online postings are only used for the purpose of the thesis in order to protect my participant’s identity. The discussion of the themes was linked to the literature presented as well as in relation to the thematic decomposition.



**4.1. Findings of the study**

All the above-mentioned themes revealed the emotional experiences of the participants who have had or survived HELLP syndrome. The psychological experiences and emotions were portrayed throughout the participants’ constructions of their experiences and are demonstrated in relation to the themes. As previously mentioned, the ethics of this particular study requires pseudonyms to be used. However, due to the size of this particular online community I will not be making use of pseudonyms, however I will be referring to extracts as ‘participants said’ or ‘participant responded to’. Due to the size of the online community, extracts from any particular individual were only used once therefore the extracts do not show conversations neither does it show any interactive feedback or responses.

**4.2. Mourning and loss**

One of the themes that emerged and weaved its way through all participants' writings was mourning and loss. Keane (2009) suggests that there is a restriction placed on this loss as it is not viewed as rational in terms of what is seen as 'real'. As stated previously in the reviewed literature the loss is dependent on the construction of pregnancy as well as the construction of personhood (Layne, 2003; Keane, 2009). Participants often referred to loss in relation to various components of their lives and pregnancy journey. The HELLP syndrome experience is very unique to each woman and therefore loss cannot be spoken of in such general terms.

The variability of experiences as stated by Schetter (2010) impacts the experience hence no experience is exactly the same. .

The loss participants in this study wrote about relates to either the experience, the child itself, the potential loss of woman's life as well as the loss of future dreams and aspirations in the form of a child. The commonality underlying all of this relates to the popular construction of pregnancy which stipulates that once a woman conceives, the result is a healthy pregnancy and a baby (Keane, 2009; Shetter, 2010).

#### **4.2.1. Loss of the experience**

According to Keane (2009) the loss of a pregnancy is a significant experience that results in grief for the participants, yet this kind of loss continues to be largely ignored by the medical profession as well as by society at large. Pregnancy is constructed socially through many normative standards (Van der Sijpt, 2010). Furthermore pregnancy is also constructed medically and through religious discourses (Griffith, 2014; Hammer and Burton-Jeangros, 2013). Therefore one can infer that depending on the various constructions there would be many ways in which loss would be experienced. Disparities were found in the way participants constructed their loss of their baby or fetus. For example, if the baby survived they constructed their loss in terms of the loss of various experiences associated with a 'normal' pregnancy, labour or any other factors they connected with such an experience. In discussing their concomitant losses participants reported feelings of frustration and anger as seen through the following extracts:

*"...so often people chat about their experience of normal and complication free births recently one of them compared a normal 30 labour to what me and my family went through this has some what annoyed me coz I would have given anything to have that rather than my husband*

*being told I wasn't going to make it...saying goodbye to my daughter before I even said hello me and my daughter fighting to get better in hospital for two weeks. They say labour is a pain u forget I wish I had that the pain and memories I have I will never forget! They don't know how lucky they are and don't understand what we went through xxx".*

*"4 years ago today, I had my heart set on a waterbirth. This was after all my 3rd baby and my OB felt it wouldn't be a problem. We took a tour, I got to see the birthing suits, the tubs everything inside the actual birthing center. Little did I know in 7 weeks I'd be flown to that exact same hospital, but for the trauma center, that id be in liver and kidney failure, platelets ok 6k and stroke level BP ending up in PICU for 9 days. I wouldn't have my baby placed upon my chest, I wouldn't even hear her cry. The first time I would get to see her was by a photo on her fathers phone".*

The next participant defined her loss of the experience in accordance to the more modern day constructions according to society that are linked to being pregnant. She speaks of the maternity shoot that she lost which is in the current context of social media and popular culture.

*When I see people who get to have maternity shoots I get jealous and sad...my shoot was scheduled the week before I delivered and I was too sick to get out of bed...I don't want to feel jealous I want to feel happy for them and I do, but I still feel bad".*

Another experience that was deemed as a loss was that of the labour. There was consensus between many women that they had experienced something similar to amnesia or blackout during the emergency C-section. They identified the experience of amnesia/blackout as a time in which they were not conscious and therefore missed out on what was happening around them. The physical time that the amnesia or blackout lasted is person specific and therefore the loss constructed from this is specific to the individual.

*"...my brain just started shutting down...roughly 10 days later I woke in a different hospital, intubated and very confused".*

*“...I expressed my anger that I have no memory of what should be the best day of my life”.*

*“...I went downhill, rapidly. After 24 hours my family was told they may want to make “final arrangements”. A nurse pulled my family aside and told them to demand I be flown to a larger hospital where they were equipped to handle something like this...still in a coma for six months...I was then sent to a rehab for seven weeks to relearn to walk, write and regain all mobility”.*

The loss of various experiences ranging from the loss of experiencing labour to the loss of being in a position to do a photo shoot ushered in many emotions for the participants. The emotions that were prevalent in the extracts were feelings of frustration, anger, envy, sadness and feeling bad. For some of the participants who experienced severe physical symptoms, the loss of their memories resulted in them feeling extremely angry and dissatisfied.

#### **4.2.2. Loss of the child**

This sub-theme emerged from the mothers who had the partial pregnancy experience but their babies had died. This sub-theme seeks to understand the participants’ emotional experiences with regards to the loss of their child. According to Kohn and Moffitt (2000) cited in Ponte (2002) women visualize their lives with a baby from the time that they find out that they are expecting. The mother has a social identity for the unborn child and mourns what they idealized that they would have (Keane, 2009). The following participants lost their babies:

*“I hate when I’m out I see pregnant women and I’m jealous...she was my first child and I was so ready to be a mommy...I didn’t even get to hear my baby cry to see my daughters eyes...Makes me so mad that people do drugs and go to have healthy babies...it is hard to see my friends baby pictures on Facebook...does it ever get easier?”.*

*“Hello everyone asoat of you know I lost my daughter due to hellp October 22.2014. My husbandand I found out we were expecting another little girl due to November 2015. I came to the doctor Thursday morning at 8:30 to be informed that I have developed hellp again. Since I’m only 20 weeks she won’t make it and if I waited any longer to be induced I wouldn’t either”.*

*“A year ago today I had to deliver my twins at 24w 6days because of HELLP. HELLP robbed me of my son, who died later that day. My daughter hung on for 12 days before she died too...my family is thankful that I had the prenatal visit that landed me in hospital, but it is hard for me to feel anything but the loss”.*

The above- mentioned extracts are seen often throughout the loss the participants had experienced throughout the pregnancy journey. Participants reported feelings of anger and loss. Some of the participants described the loss of their infants in very strong terms. The underlying emotions that were expressed were hatred, jealousy, feeling mad, feeling robbed, and an overwhelming sense of loss. What is interesting to note is that one participant described her strong dislike when she is out and sees other pregnant women. The envy she expressed at this situation is palpable.

#### **4.2.3. Potential loss of women’s lives**

The postings revealed that there were many women who wrote about bidding their family farewell either being advised by medical staff or believing that they would not survive the HELLP syndrome experience. As seen through the following extracts this was a common finding and led to feelings of loss of the ‘joyful’ experience of childbirth:

*“My baby boy was born 33 weeks. I said goodbye to my husband. I told him to be happy and take care of my baby. It was the hardest night I ever had”.*

*“...I heard them telling my mom your daughter probably won’t make it through the night call the family and any clergy”.*

*“I listened to them talking to my husband about the ICU and putting me on ventilators... then I listened to them talk about delivering me with no pain intervention...then I said goodbye to my husband”.*

*“You will be having your baby as soon as you arrive, and you may not survive the flight, it’s the only option to try to save either of you...They prepped him so he could kiss me and told him it may be the last time he sees me alive, the baby and I may die on the table”.*

The fact that the participants and their families were informed that she may not make it was devastating to these women. As one participant wrote “it was the hardest night I ever had”. The fear of dying and losing the child was too much to bear. Based on the extracts it is evident how the participants were spoken about, rather than spoken to. The assumption in this case may be that the patient may have been too ill to hear and fully comprehend what was happening to her. The incomprehensibility of this situation for the participants seems a distinctive feature within the HELLP syndrome experience.

#### **4.2.4. Loss of future dreams and aspirations**

Many of the participants reported feelings of anger and sadness regarding the inability to have children after HELLP syndrome or the fear associated with having more children thereafter.

*“What if I can’t get pregnant again. What if it really isn’t safe. So much could go wrong. Should I just be happy with our only child”.*

*“Harder to imagine how badly I want a second child, but too fearful of what could happen to me or the baby”.*

*“So I had my tubes removed, a endometrial eblasion and a mirena put in a few weeks ago and although I don’t regret it, it outs a real no more babies which upsets me a bit...I know if I did have another baby neither would survive as I barely survived y last 3. Just feeling a bit empty and less of a woman!!”.*



*“...they prescribed a birth control bc I am not emotionally ready to be pregnant yet. Although I wish I was still pregnant and none of this happened”.*

The following participant referred to the fears that she had regarding her child’s future:

*“He was born at 26 weeks with lots of complications along the way and the doctor said this has been inevitably played a part. I am feeling so sad and worried for his future, so teary and tired of the years of medical appointments and not looking forward to years more to come. I also feel angry as I feel he’s gone through enough already in his short life and just want things to be easier for him”.*

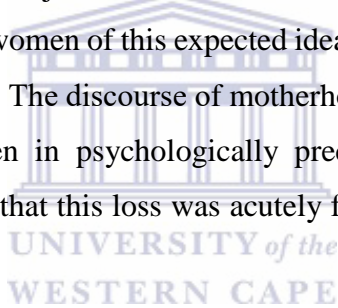
The loss of future dreams and aspirations were expressed at two levels. The first related to the loss felt at the possibility of not being able to have another child, which resulted in feelings of emptiness for one of the participants. In addition, the fear of what may transpire if HELLP syndrome reoccurred seemed to contribute to these feelings of potentially not having another child. Based on the extracts, HELLP syndrome also represents not feeling safe again and the innocence of pregnancy is lost. This is written about in the literature examining pregnancy loss, miscarriage and still birth (Andipatin, 2012).

The second part to the loss of future dreams and aspirations relates to the loss of having a ‘normal child’. With such premature births, children are usually saddled with many complications relating not only to physical challenges, but to psychological challenges as well. This in effect creates major difficulties for both the parents and the surviving child. In the final analysis, having a child presenting with these challenges disrupts the parents’ ideal of having a ‘normal’ child.

Pregnancy is constructed by society as a process that starts at conception and ends with a problem free labour and healthy baby. When the pregnancy deviates from the norm it defies the way the ‘normal’ pregnancy is supposed to go and women feel that they have lost out on various experiences. This loss is housed within a space of public culture, popular beliefs as well as the discourses that outline what a ‘normal’ pregnancy should look like (Hammer and Burton-Jeangros, 2013). In our public culture we find that pregnancy magazines (like “Living and Loving” and

“Your Pregnancy”) portray the experience as beautiful and linear. The magazines are decorated by maternity shoots, baby showers and all the other associated events that contribute to the pregnancy seldom public culture is found focusing on situations depicting pregnancy complications. Hence, the way these participants constructed their experiences is within the reality that they know, witness and have internalised.

As noted earlier, pregnancy is constructed in a sociocultural manner and women are exposed to these constructions long before the actual conception (Prosen & Krajnc, 2013; Carvalheira, Tonete & de Lima Parada, 2010). It is ingrained in women’s early relationships, in their upbringing and is seen as an inherent desire for many women to someday have a baby and be a mother (Van den Akker, 2011). Therefore, as seen through the literature reviewed having a child is constructed within many societal and cultural groups as the ultimate outcome of various conscious and unconscious intentions (Prosen & Krajnc, 2013; Carvalheira, Tonete & de Lima Parada, 2010). When HELLP syndrome deprives women of this expected ideal, they report as one participant did, that “they feel less than a woman”. The discourse of motherhood equals womanhood seems to be activated and places many women in psychologically precarious positions. Thus the above discussion highlights that not only that this loss was acutely felt and experienced, but it was also memorialized by the participants.



### **4.3. Memorialisation of loss**

The survivors of HELLP syndrome attached meaning to various aspects of their lives and related it to the loss that they have experienced through HELLP syndrome. Through their postings they clearly identify the way in which they memorialize the process of loss. Many of the participants had memorialized the birthdays, the estimated date of birth, the day they had lost their baby, the day they found out they were pregnant and any other special dates. This memorialization was apparent in participants whose infants had survived and those whose infants had not survived as seen through the following:

#### 4.3.1. Memorialising the date of birth

Some participants reported that they felt anxious closer to the date their infant was born or supposed to be born. The following participant wrote about the anniversary of their infant's birth, her infant had survived and she wrote about her gratitude that she had a healthy son, yet she memorialized the trauma she had encountered on the date of birth.

*“Exactly 5 years ago at this time I was having my baby. I’m having such a hard time right now. Happy with my healthy sign, but the whole experience was so traumatic”.*

*“6 months has past since I had my twins and hellp. A rainbow appeared on their half bday. Every hard day there has been a rainbow. Lucy's twin Patrick is watching over and telling us it will all be ok. Miss u everyday:( Feeling incredibly sad and blessed at the same time. Lucy is a healthy and happy bubba.” “Is the first year anniversary always this difficult? This week marks the beginning of my endeavour of Hellp and pre e last year... I've been crying off and on all day. Flash backs are vivid. My entire body starts to shake. I can't eat. Just looking at my healthy son, makes me break down.... Lord help me. 😞”.*

The participants reported memorializing the day in various ways. Some of the participants commemorated the day with celebrations with family and posted about it on the online platform. Other participants reflected on their experiences and memorialized the event through other participants' postings by reacting to the posting on the page.

One of the participants reported feeling angry at her family for not remembering her sons first birthday in the same way she had.

*“Today is my hellp baby's 1st birthday. My parents forgot! I have been furiously working towards achieving as much healing and closure as possible, so I'd handle today well. I really can't believe they forgot though...how have your parents reacted? Is this normal? I'm kind of confused at how something can affect me so much, and them so little (they were there).”*

Whereas other participants constructed the day of birth within a reflective space where they could think about the day and all the emotions they had experienced during the birth and thereafter.

*“My little 33week 4lb 6oz HELLP baby is the big 1 today. Even today it's still a miracle that we both survived the most severe case of post partum HELLP the hospital has ever seen. I am so thankful that I found this group you all have no idea how many times the grips of post partum baby blues, birth anxiety, PTSD, jealousy of other moms and many other issues tried to lead me down a dark path but every time I felt the pull I felt a bigger pull from all of you back to the bright side and no one knows except for other survivors what this means to me and my family! Thank you everyone in here.”*

*“Today my youngest HELLP boy is 1! Ive been feeling so good about everything and even ok with our birth. I was put under this time. I was trying for a Vbac. By the time my labs came back I could not get an epidural. The first 24 hours or so are a complete blur. I am thankful I was able to carry my baby full term and that we have made it a full year of breastfeeding despite the lactation consultant telling me I would need to get bottles as my baby had a fast flow preference from being finger fed. Turns out he has a lip tie and it just took us some time to get it down. Anyways last night I was just thinking about it all over again and I had se anxiety about the whole thing. Even went to bed thinking it would happen again. Our birth was not beautiful but we are here.”*

*“3 years ago today I was placed on strict bed rest because my little man was only in the 2nd% at 32 weeks and 4 days, and my care was transferred to the bigger university hospital here in town... Little did I know how sick we both were. I had NO signs or symptoms of HELLP at this point. It's scary how quick this deadly disease can creep up on people. My son was born 3 days later.. But we're celebrating his 3rd birthday today and it brings back a ton of different emotions. From guilt and sadness because my body failed him.. To extreme happiness that we're both here to celebrate another year! Im so thankful for this group, your stories, photos and all the friends I've made though it. So I wanted to take a minute to thank you guys.”*

The next participant had constructed her feelings in relation to the day they were supposed to give birth:

*“A year ago tomorrow I had to deliver my twins at 24w 6 days because of HELLP. HELLP robbed me of my son, who died later that day. My daughter hung on for 12 day before she died too. My HELLP was diagnosed really early, because I was already admitted for Pre-e. I keep reliving the heartburn I had the night before that caused me to wretch like there was something evil in me. I was concerned, but the doctors looked at me, and it resolved with some heartburn meds. I woke up feeling great, that is until they told me my labs indicated a HELLP profile and I needed to deliver immediately. My family is thankful I had the prenatal visit that landed me in the hospital, but it is hard for me to feel anything but the loss”.*

Remembering the date the infant was supposed to be born or the actual birthdate proved very challenging and traumatic for some participants. Memorialising these dates seemed to invoke very difficult emotions which were experienced as flashbacks. These flashbacks triggered many emotions ranging from anxiety to deep sadness, to guilt that “my body failed him”, to extreme happiness for those who had live babies. For some women the overwhelming sadness that one of her twins had survived and the other not, was simply too much to bear. Thus looking at the surviving twin brought up so much guilt that she literally cried out to God for assistance. Drawing on religion is a common coping mechanism as identified by Powell, et al (2003).

The physicality of the reactions for one of the participants was striking. She explains how her body was shaking and she could not eat. Another prominent comment made was “it is scary how this deadly disease creeps up on one”. This reflection thus seems indicative of how HELLP syndrome is thought of and spoken about. In addition to memorializing the birthdates, participants also wrote about the significance of certain times of the year.

#### **4.3.2. Memorialising a certain time of the year**

Despite the fact that many participants reported a significant day, there were a few instances where participants wrote about a certain time of the year that they deemed a very sad time. It was usually around the time that they had gone into labour and experienced the loss of the pregnancy or baby.

*“Hey ladies !!! I know you ladies understand better than anyone how our experiences affect our live everyday so I need to say this here because nobody else gets it...”*

*My birthday is in September rapidly approaching and my HELLP baby boy's birthday is just 3 days after mine.... I really dont feel like celebrating big our birthdays since that was the week everything started ... The day of my birthday I got admited to the hospital with Pre E and 3 days later developed HELLP and delivered my son via emergency CSection...*

*“A couple months ago I was fine and excited about celebrating , but as the day approaches I just feel scared and all I can think about is that that was the week we almost died ... Not much of a celebration reason ...”*

*“My family thinks I should do it and my dad even got mad for canceling the party plans ... I just feel scared ... Has this happened to any of you ?????”*

The excerpts highlight the intense feelings that the participants feel as the time approaches when they experienced HELLP syndrome. In some instances, it coincided with the mothers' birthday and the time served as reminder of all that happened when she had HELLP syndrome. Furthermore, these periods are also filled with anxiety and served as a reminder of the horrifying experience they had been through. Transitioning to parenthood involves many psychological adjustments (Parfitt & Ayers, 2014). Therefore one can infer that a traumatic experience can influence the mental health of the individual even more. Post-traumatic stress disorder is characterised by the replicative thoughts and feelings of the traumatic experience (Soderquist, Wijma & Wijma, 2006). What is also noteworthy with some of the postings is how some participants felt that others who have not been through such an experience would never understand or be able to appreciate what these participants had experienced.

Memorialising the experience and the loss were also commemorated through items.

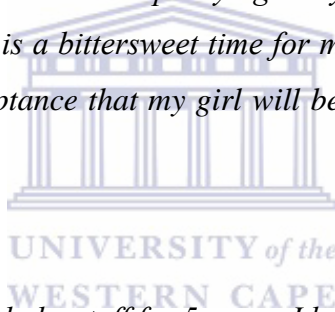
### **4.3.3. Memorialising through items**

As reviewed earlier in the literature Keane (2009) is of the opinion that consumerism is a key component of how pregnancy is socially constructed. There were cases of participants posting the memorialization of items such as toys or baby clothes. According to Keane (2009) these



commodities is a realistic representation of the loss of either motherhood or the experiences regarding the norm for pregnancy. These postings could be differentiated into two main categories. One category spoke to the lost baby; some participants could not let go of their babies' clothes that they had bought in preparation, and even though a year lapsed in some cases they still could not let go of the clothing items. In addition, the second category consisted of the mothers whose babies had survived. They wrote about feelings of anxiety with regards to letting go of their babies' clothing as they felt that these were the only items they had that reminded them of when their infants were small and that they would never be able to recover those memories. Some had also reported holding onto items, as they knew they would never have a baby again and felt too sad to dispose of the items. This is demonstrated through the following extracts:

*“These baby clothes have been sitting in in baskets for months because I just couldn't go through them or fathom parting with them...I kept saying to myself that I needed to hold on to them encase our next one is a girl. This is a bittersweet time for me...im just very proud of myself for finally getting to this point if acceptance that my girl will be my only. Goodbye sweet little tiny clothes”.*



*“I hung on to my little girls baby stuff for 5 years. I kept thinking maybe, but it just wasn't meant to be. She is my miracle and I am so grateful for her”.*

Memorialising through items highlights the ambivalence some of the participants experienced. For example, the one participant expressed that she “could not go through them” nor could she “part with them”. The clothing items thus represented or was associated with the memory of the actual child for whom the items were purchased. Letting go of the items in some way represented letting go of the memories, which were too precious to part with. Letting go of the items also seemed to be associated with acceptance of the loss. One can infer that some of these anxiety provoking memorialisations and flashbacks referred to in this section could have a possible link to Posttraumatic Stress Disorder (PTSD). According to Nichollos & Ayers (2007) vulnerability to PTSD post-childbirth share the same factors as any other traumatic event leading to PTSD. Posttraumatic stress is fundamentally based upon three clusters of symptoms: flashbacks of the event, avoidance of anything that may be associated with the event, and increased stimulation (Di



Blasio, Miragoli, Camisasca, Di Vita, Pizzo, & Piptone, 2015). Di Blasio et al.(2015) characterised child birth related PTSD as linked to premature birth, labour difficulties, stillbirth or other high risk influences. Furthermore Di Blasio et al. (2015) found that writing about the experience can trigger emotions once again and be met by avoidance and opposing thoughts which can initiate secondary trauma.

The time- frame of holding on to these memorialisations was also an important feature of this experience as noted in the posting above. The participant explained that she held on for five years indicating that grieving is extremely personal with no set time- frame attached for each individual participant. While loads of posts spoke to the issue of memorializing many participants used the space to discuss their experiences they had with medical staff.

For the mothers who lost their infant the memorialization is constructed within a discourse where the fetus is not acknowledged as a fully developed person that deserves the same amount of grief that any other infant that is born would deserve. This phenomenon is referred to as disenfranchised grieve as explored by Doka (2009). Doka (2009) states that disenfranchised grief has different tenants namely 1) that the relationship between the mother and her infant is not recognized, 2) the loss is not recognized, 3) the death is therefore disenfranchised and 4) the way an individual grieves is not validated.

Keane (2009) suggests that mothers mourn and memorialize the loss of their unborn baby through constructing the loss within a discourse of fetal personhood. She further suggests that biomedical frameworks do not allow for this construction as the ideology of personhood limits the memorialization of that which is not defined as 'real'. Morgan (1996) argues that these constructions are based within philosophical models of relationality mainly focusing on the western definition of personhood, which deems the birth of the baby as the divider between person and non-personhood. According to Conklin and Morgan (1996) society constructs the status of personhood for those who are the youngest and this determines whether or not they will be accepted into the human community. Keane (2009) concurs by stating that the embodiment of the biological personhood has certain requirements and when these are not met the unborn baby continues in a state of disembodiment. Hence, memorializing the loss of a fetus is constructed within respective communities and what those communities deem as a rightful loss.

#### **4.4. Experiences of medical staff**

The experiences that these participants had of medical staff were regarded as an important topic that many of them had often felt the need to write about. Referring to their experiences with medical staff was one of the themes that received considerable attention and sparked many conversations between participants. The conversations generated primarily focused on the lack of information, withholding of information and a general lack of understanding medical terminology. At this juncture, it is important to note that the women participating on this site hail from different countries, yet they reported shared experiences of medical personnel.

Throughout participants' writings, medical professionals are referred to in quiet abstract terms. The participants report feeling that their understanding of their own body was not considered important. As seen in Andipatin (2012) as well as my study women who suffer from a high risk pregnancy often construct their bodies in relation to biomedical discourses that view medical/scientific knowledge as truth and doctors as experts on women's bodies. Consequently, biomedical discourses tend to disregard the opinions and feelings of women. This disregard seems to be constructed within the unspoken idea that medicine as a science is 'the only truth' and therefore through this provides facts. Participants reported feeling that the medical profession did not value woman's' own innate understandings of their bodies. As Northrup (1997) states, medicine is idolized as the ongoing wisdom and the authority that shapes the body.

Consequently, this notion completely disregards the women as expert of her own body and does not include the women's inherent capacity to know when her body is not well. Women reported feeling confused when the doctors had misdiagnosed them, not knowing what was wrong or withholding information from them. The confusion seems to stem from the way medicine is constructed as always being 'right' and when medicine fails to be 'right' this deviates from the standing of this science in relation to the way this science is idealized within civil society.

##### **4.4.1. Lack of information**

Participants reported a lack of information both from medical practitioners as well as from their own position. Firstly, many participants referred to the fact that many doctors they encountered

had a very limited understanding of HELLP syndrome. However, due to the nature of HELLP syndrome, it is often misdiagnosed not intentionally, but rather as the symptomology is often easily linked to other illnesses. According to Andipatin (2012) “HELLP syndrome may also present with convulsions, jaundice, gastrointestinal bleeding, haematuria, bleeding from the gums and pain in the renal angle, chest or shoulder”.

Therefore making the differential diagnosis is challenging for obstetricians and contributes to the insidiousness of this illness (Andipatin, 2012).

Participants wrote about being misdiagnosed by doctors and having doctors disregarding their opinions and feelings both before and after experiencing HELLP syndrome. Some participants reported that they distrusted their doctors’ opinions, which left them feeling confused. In addition, there were participants who wrote about the resentment they harbored towards doctors for misdiagnosing them. Furthermore, some participants also reported resentment towards doctors for shifting the blame onto the patient when they could not find out what was wrong. These postings once again confirm the reasons for why many users are utilizing the internet for health related issues (Plantin & Daneback, 2009; Carroll and Landry, 2011). ).

*"I went to an ER and was sent home. I was told nothing was wrong".*

*"doctors had no idea what was wrong with me".*

*"20 doctors guessing what was wrong with me from gall stones to heart failure".*

*"...so scared to still be recovering from this knowing they misdiagnosed it".*

The above excerpts highlight the challenges faced by both medical staff and the participants themselves due to a lack of knowledge on their side and the difficulty that doctors experience in making a differential diagnosis. The problem with this is the urgency for an exact diagnosis as time is critical when it comes to saving the life of the mother and the baby. Research informs us

that if no intervention is made within 24 to 48 hours of onset, the mother and baby could potentially lose their lives (Raju, Mercer, Burchfield & Joseph, 2014).

Many of the participants reported that they were not informed about their current condition nor future treatment. It was a common occurrence that women who had survived HELLP syndrome spent an enormous amount of time doing their own research.

*"Was starting to develop HELLP and crazy enough my doctor didn't know anything about it. She even told me she didn't know what was going on with me and had to talk to other doctors about me. Didn't find out what was truly going on until I did some research of my own".*

This occurred not only in a short time post the HELLP syndrome experience but also in the long term for other participants. Some of the participants wrote about their experiences and still sought information up to more than ten years later in an attempt to make sense of their experiences.

*"When I had our 22, 19 and 14 years ago there was little to no information available about HELLP syndrome. My pregnancy with our 22 year old was at Chigaco University (which at the time had a grant to research HELLP but completely missed diagnosing me, I went into premature labor on my own at 6 1/2 months), with our 19 year old it took a Family Practice doctor's determination to find out what was wrong with me (it was after her birth that they reviewed my records from my 22 year old and they saw that I had HELLP back then but hadn't been diagnosed). ...We also had twin boys who we lost (I was having the same symptoms but spent 4 months trying to find a doctor who knew about HELLP but couldn't find one). I want to compare my previous pregnancy records to those with my twins. Also, I don't know why but I really want to know how bad it was during all of my pregnancies...I think the birth of my grandson and us almost losing him has hit me hard and suddenly I want to know everything about my own pregnancies...".*

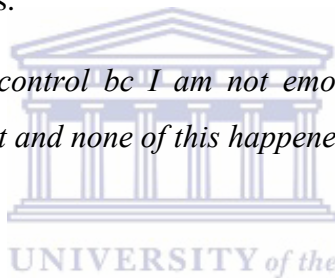
The posting above, was written by a woman who experienced HELLP syndrome multiple times and because it happened many years ago, she was misdiagnosed and did not receive the treatment that she needed. Despite her first experience with HELLP being many years ago, her grandsons' encounter with near death sparked her curiosity again about her own pregnancies. This could be indicative of how deeply traumatic these experiences are.

In sum, many of the participants believed that they were misdiagnosed and thus could not trust the medical system to cure them. The answers which many of them were hoping to find within a biomedical framework, were not forthcoming and this resulted in many of the participants to believing that medical personnel were not empathic.

#### 4.4.2. Perceived lack of empathy

Generally, participants felt there was a total lack of empathy from doctors they had dealings with. This lack of empathy for some of the participants was evident in doctors 'not understanding their need to have another child' despite their HELLP syndrome experience, the way in which medical staff spoke to them about their bodies as well as the fact that birth control medication was prescribed to one of the participants.

*"They prescribed a birth control bc I am not emotionally ready to be pregnant yet. Although I wish I was still pregnant and none of this happened".*



*"I go from feeling normal to feeling this old familiar symptoms and I can't imagine what my dr would say if I told her. She acts like it's in the past and I shouldn't try for another baby but of course..."*

Another participant had reported the lack of empathy from the doctors after experiencing HELLP syndrome.

*"Omg. I wish people wouldn't look at me like I'm stupid when I see them after HELLP. Especially doctors. I know my body and I just want everything checked out."*

This was a common experience throughout for most of the women. Numerous women had reported feeling misunderstood by medical staff or medical staff not taking into account the feelings of the patient. This perceived lack of empathy expressed by some of the participants could be attributed to a lack of understanding biomedical frameworks and what is deemed critical within medicine. The literature highlights how western medicine's view is based on Cartesian dualism,

which splits being into mind and body as western medicine treats the body and components thereof (Andipatin, 2012)). Not understanding the basic tenets of western medicine sets people up for expecting to be treated holistically and this is what many of the participants seemed to be yearning for. This perceived lack of empathy left many participants feeling very disgruntled and one participant went so far as to write that she would like to take legal action.

#### **4.4.3. Seeking legal action**

Seeking legal action had come up once, where a participant had reported feeling that someone should be held accountable. The way the participant wrote about the legal action demonstrates how she felt. She believed that other women who had similar experiences would be the beneficiaries of such action, rather than herself.

*"someone" who stuffed up needs to be held accountable for the death of our son (it should not have happened) and me nearly losing my life also. "I want to take action to make sure that this never happens to another family and their child but if its only about me and my 'injuries' I don't want to pursue it".*

#### **4.5. Premonition and Intuition**

The theme intuition was considered important to explore as there were many women who mentioned either having a feeling that something was wrong or who reported dreaming that this would happen to them.

##### **4.5.1. Dreams and vision**

The extracts below are reflections of the dreams and visions women had written about in the group.

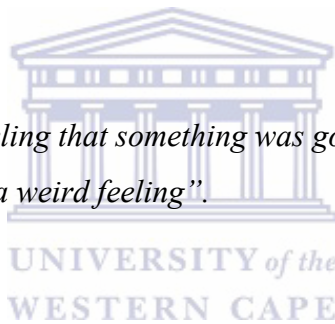
*"I kept having dreams that I was having my baby July 28th when I was due September 10th. I knew my bp was up and knew I had protein spilling. Needless to say I refused going to the hospital on the 28 and was admitted the 29. I had him 3 days later".*

*“I wrote these dreams down in my private journal online and then forgot about them until I finally returned home to live six months after our daughter’s delivery (10 months later). “Look,” I told him. We were warned.””*

*“I did! Years ago, I had a vision, that I was in the hospital, hooked up to all kinds of tubes, and knew I was close to death, but that I was in NO pain, like I had not been in a car accident. I had mentioned to my husband (while pregnant) that I felt like something was going to happen to me (soon). I never put the two things together. In my vision, there was NO presence of a baby, and I think if there had been, I might have been more “alert” as to what was going on. But there, I sat, in the hospital bed, hooked up to all kinds of tubes, in no pain, and no baby in the room, just like my vision (my baby was fine, but on another floor).”*

#### **4.5.2. Feelings**

*“Did anyone one have a feeling that something was going to happen. I had a feeling I was going to be in bed rest...I just had a weird feeling”*



*“I had a feeling before. I even told everyone, “I have a feeling about April 11.” That’s when I feeling I would have issues towards the end, but would be ok.”*

*“I felt this overwhelming sense of doom, it was insane. I literally didn’t want to move. I now wonder if it was my body trying to protect itself or compensate.”*

It is evident through the extracts that these participants had very strong feelings regarding their bodies and what their bodies were communicating to them. In our current society, these “feelings and dreams” are not always constructed as factual and logical information and therefore is not taken into account. One participant stated that even though so many women had accounts of intuitive experiences it was seldom recognized during their antenatal appointments. Another participant spoke to what Northrup (1997) suggests that women should become more obedient to the intuitive side of their bodies. A participant referred to this in her writing where she stated that:



*“...be an advocate for yourself. I too had horrible pain in my upper quadrant and it was dismissed in both pregnancies. I’ve learned if I think there is something wrong, I will speak up.”.*

In a space that is dominated by biomedical discourses it is hardly surprising that intuition is not recognized as an important aspect of the surveillance of mother and baby. Andipatin (2012) argues that western medicine is based upon scientific tenants such as rationality, reason and logic hence the disregard for anything that is defies this logic and rationality like emotions or feelings. As stated by de Beauvoir (1949) female bodies emphasize intuition and emotion as opposed to men who emphasize reasoning, this can be viewed as a binary, and western medicine is constructed in a very static environment that requests logic.

#### **4.6. Religion and Spirituality**

Participants also constructed their experiences in terms of both religious and spiritual discourses. Those who used religious discourses would request prayer, while those drawing on spiritual discourses asked for ‘good energy’ to be sent. It was a common phenomenon that some of the participants referred to themselves as being ‘blessed’ if they had survived HELLP syndrome or became pregnant again which is another form of religious discourse. The following participant had constructed her experience within God being the giver of life and noted her trauma yet she still found gratitude in her religious belief that she was alive and a changed person.

*“...I think thank God I got through it and it changed my life for the better as vile as it was for me”.*

*“I am extremely blessed and grateful. And I am also a symbol of hope for all those ladies who may be struggling. Miracles do happen and “this too shall pass””.*

The participant in the above extract saw her experience as something other women could learn from so to a certain extent it seems as if this made it more bearable. Further on the participant makes use of the word ‘*miracle*’; which is usually used when something cannot be explained by scientific evidence. She had constructed her experience as a miracle. Another participant had used religious discourse to make meaning of her being pregnant again and viewed her pregnancy as a gift from God who she constructed as the giver of life.

*“God decided to bless us with another little one”.*

Some of the other participants requested prayer from the group members when either experiencing the traumatic experience or reliving what they had gone through.

*“Ladies I need some prayer”.*

*“Thank you all again for your prayers”.*

*“Lord help me”.*

Through participants’ writings it seems as if they construct their meaning making within mostly a religious discourse yet it is also important to note the spirituality of some. As stated by Khoshtinat (2012) when people are experiencing something traumatic they tend to find peace within the prayer, worship and reliance on God. Price, Lake, Breen, Carson, Quinn & O’Connor (2007) as well as Andipatin (2012) argued that this is not unfamiliar as individuals tend to draw on spiritual beliefs in time of need. In Andipatin’s (2012) study there was a participant who reacted counter to what is seen in my study. She acknowledged God as giver of life however, she had feelings of anger towards Him. It is therefore important to note that nobody in a community of more than 3000 individuals had ever during my time of data collection disputed religion or spirituality. Therefore, it leaves me with the question of what that unspoken silence would mean if it were to be explored further.

#### **4.7. Social support found online**

Through observation, it is clear that participants saw this online community as a place of safety and a place where they were understood. Various participants stated they had come to participate in this group as they felt that they would be well received and be provided with support from people who had a shared experience. Within this theme, sub-themes of support space, advice and suggestions, ambivalent feelings regarding the group, group as a therapeutic space, space to memorialize form of loss and space to share milestone’s emerged.

#### **4.7.1. Support space**

Participants constructed their writing in a space they associated with support. Many participants referred to the group as a space where they could find support as seen through the following extracts:

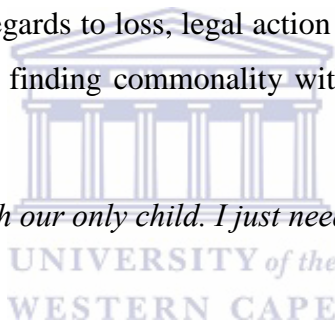
*“I wish this kind of group existed when I had my daughter sixteen years ago”.*

*“I know you ladies will understand”.*

#### **4.7.2. Advice and Suggestions**

The online community played an important role in advising and providing other members with suggestions, whether it was with regards to loss, legal action or any other unanswered questions. This was done mostly in terms of finding commonality with other survivors within the online community.

*“Should I just be happy with our only child. I just needed to get it out to some people who will understand”.*



*“I know you ladies understand better than anyone how our experiences affect our live everyday so I need to say this here because nobody else gets it”.*

#### **4.7.3. Ambivalent feelings regarding the group**

Furthermore, some of the participants reported experiencing mixed feelings about the group as it was perceived by some as a difficult space.

*“I have a love/hate relationship with these boards/groups. Sometimes I have to stay away because I feel as though reading everyone’s stories and experiences keeps it to fresh and makes it hard to put behind and move on...The ability to share this feelings is why I pop back onto the boards every now and then. Thank you ladies for accepting and allowing that and being supportive”.*

*“I have never quite recovered it seems and seeing your recent stories makes me feel selfish for joining since my grief is from so long ago but I hope it’s ok for me to be here”.*

#### **4.7.4. Group as a therapeutic space**

In addition, some participants used the group as a therapeutic space. I had observed this as many of the women advised one another regarding issues that were clinically related such as Post Traumatic Stress Disorder and separation anxiety.

*“I know a lot of you experienced ptsd after hellp syndrome. I’m about to celebrate my daughters first birthday and honestly, I think I am starting to recognize that I may be dealing with some mild ppd or anxiety...I just feel overwhelmed and stupid for waiting this long to admit it. Anyone have similar experiences?”.*

*“How did everyone deal with anxiety when they went back to work? I am having a really bad morning and am supposed to go into work from 2-8 today. I want to call in sick, but am the only one working the desk so they would have no coverage, freaking out right now”.*

*“I feel like I’m going crazy but I know nobody else will understand. My hellp boy is almost 5 and I just had my hellp free baby girl 6 weeks ago. My son spent 18 miserable days in nicu which was amazing since he came at 32 weeks but my daughter came at 39+2 and ever since they handed her to me in the operating room I find myself having trouble putting her down I don’t even leave her with family but for short periods and find myself almost in tears thinking about putting her down in her own bed. I never had this issue with my son even after he came home. I don’t know if it’s me knowing she’s my last baby or if it’s some latent fear that if I let her out of my sight someone will take her from me. It’s insane but that’s how it feels maybe it’s from the way they did when they delivered my son? All I got was a quick glimpse from across the room with the nurse saying here’s your son then they were gone. It’s bad enough that I wouldn’t even let her stay in the*

*bassinet at the hospital after the first night once the catherer came out she stayed in my bed until we were released. ”*

#### **4.7.5. Space to memorialise any form of loss**

The group was also used as a space to memorialize either through being the first person to write about a certain element of memorializing or reporting back on the initial post with their own memorial of their loss. Engaging in such actions served as support and comfort to one another and also provided an opportunity to reflect on their own loss and how they related to it. This can be seen via the first theme where I discuss the different types of loss constructed by the participants.

#### **4.7.6. Space to share milestones**

The online group provided participants with an opportunity to share milestones through pictures of their babies who have grown a bit, those who celebrate their first of anything, who are walking or doing things that are seen as ‘normal’ for other ‘healthy’ pregnant mothers. They share these milestones with people who understand the importance of these milestones after being through the traumatic experience they had all encountered. As noted earlier, the majority of these milestones were depicted through pictures and through similar extracts like the one below.

*“...Im so thankful for this group, your stories, photos and all the friends I’ve made through it. So I wanted to take a minute to thank you guys”.*

#### **4.8. Conclusion**

In conclusion, due to the communality found in the traumatic experiences women had suffered an online space provided them with a community that had its own structure and role to play in their lives.

Priya (2012) explored how biomedical claims may contribute to the suffering of humans and through their research suggest that participants reported staying silent due to:

1. Feeling misunderstood by other people.
2. Taking on the responsibility of not hurting a significant other with their opinion or feelings regarding the suffering.
3. Searching for a place where they can make sense of their experience is costly.
4. Finding someone who is actually interested in listening to the experience is hardly possible.

Through the above-mentioned reported reasons of why those in suffering or who survived a traumatic experience stay silent one can see why an online group breaks those barriers. Firstly, the online group allows people who understand each other to partake in the interactive space. There seems to be a mutual understanding as people who have experienced the same syndrome are the individuals reacting to the experience. Secondly the group is a safe space where participants do not have to worry about hurting the feelings of someone who is close to the individual and who may have shared the trauma with the person. The online groups break all barriers of time and space as the individual can literally pop online whenever they need to, and it is also a much cheaper alternative to what they would pay if they went seeking professional assistance. The only cost the participant has is the data cost which is specific to the country that the individual resides in. Due to the mutual experiences found within the group a participant is never in a position where there is no one that wants to listen to the story. Hence, the online support structure refutes any claims of silence that might be constructed in any other setting and allows participants to reflect on their suffering.

Suffering according to Priya (2012) can be categorized into three main categories:

1. Suffering is socially constructed.
2. Suffering linked to physical illness is the awareness of the psycho-social impact of having a disease and receiving treatment for it.
3. Suffering is not always acknowledged with a disease or disorder (Priya, 2012).

According to Davison (2000) the online groups tend to be a place of safety where individuals that have the same diagnosis can gain a mutual understanding and form a support structure. In the Davison's (2000) study, they examined the American On-line (AOL) sites and explored the comparison between face to face support and AOL. They found that for illnesses that are rare or debilitating you would find a higher likelihood of online users. This concurs with the positioning

of my sample, their syndrome is rare and highly misdiagnosed so they find a place of safety and understanding online. As mention previously according to Aydin, Ersan, Ark & Aydın (2014), the prevalence of HELLP syndrome ranges between 0.5–0.9% in all pregnancies and 2–30% in cases where there is severe preeclampsia, this is a true reflection of how rare the syndrome is. Davison (2000) refers to ‘identity by diagnosis’ and this is clearly seen in my findings where the differentiated group reported communality within seeking other patients’ company. My findings thus corresponds with Davison’s (2000) study and purports that an illness does not happen in isolation to the rest of the individuals’ context and that through a collaborative structure patients deal with challenges collectively. Davison (2000) argues that the online support allows patients a feeling of normalcy in a time of crisis and even though his groups were on a different platform to mine there were still overlapping similarities.





# Chapter Five

## 5. Conclusion

### 5.1 Discussion

In my thesis I explored the psychological experiences of women who survived HELLP syndrome and the way they construct these experiences online. This entailed exploring the way they express the psychological experiences online as well as deconstructing these psychological experiences. This exploration was based within a social constructionist epistemological lens and drew on tenants of social suffering theory. The data collected were analysed using a Thematic Decomposition Analysis as guided by Braun & Clarke (2006) as well as Stenner (1993). In the final chapter I will provide an overview of the findings and reflect upon the methodology used to do the study. I will also reflect upon the limitations and strengths of the study as well as provide recommendations for future research.

### 5.2 Summary of the findings

Through exploring the psychological experiences of women with HELLP syndrome constructed online, I attempted to produce a thorough description of the way women construct and make meaning through these experiences. This thesis revealed through its main findings as well as literature reviewed that pregnancy is constructed in popular culture as a linear and problem-free process. A large part of pregnancy is seen as ‘natural’, where the female falls pregnant without any struggle, the big announcement, the beautiful baby bump and glow which then ends with a beautiful and healthy baby. My thesis however contradicts this linear process and places emphasis on the potential and ‘real’ risks that could encapsulate the process for a number of women.

Furthermore, the findings of my study demonstrates that meaning making took place on different levels. Even though there was general consensus within the main categories women made meaning on diverse levels within a category. The way women narrated their loss, memorialization, and their experiences of medical staff were all constructed within discourses of biomedicine and popular culture.

The section on mourning and loss was constructed differently for different people depending on what was felt to be their largest form of loss. One example of this is that of a maternity shoot, which is contextually relevant as this has become a common popular phenomenon on social media. Therefore, the writing is constructed within an extension of popular culture. This was interesting as in another context this might not have been relevant as people's photographs would not be so readily available, if social media platforms were not available and accessible. However, within the online context, people can view each other's photographs and therefore this has become a significant form of loss. For many women it has been their dream to be a mother whether this is considered to be a 'natural occurrence' or a socially constructed need may vary from person to person. Therefore, the loss experienced would also have been constructed within the ideology of what having a child means in terms of their personal needs and is furthermore dependent on social and cultural expectancy. The picture of pregnancy sketched by popular pregnancy magazines as well as discourses around what a linear pregnancy looks like served as another platform on which participants based their construction of their loss. These losses may have been the loss of a full term pregnancy, a certain form of labour, fear whether or not the mother and baby will survive as well as their future dreams and aspirations. Hence the fear, envy, anxiety, anger and hatred experienced by some of the participants were not coincidental as the preparation of what it means to be pregnant seems to commence long before conception. The section on memorialization of loss is constructed in terms of what loss the participant had experienced. Many of the participants had constructed their memorialization in terms of what held sentimental value for them, whether it was a certain date, time or item.

The experiences that the participants had of medical staff were constructed within a discourse of power where the participants wrote about different aspects of the medical staff that left them either powerless or feeling that doctors and medical staff lacked empathy. This was as a result of medical staff either not showing interest in the patient's feelings, thoughts and emotions before the actual incident, during and after it. In some cases it is due to the circumstances after diagnosis that medical staff are so focused on saving the lives in danger that they do not have time to really become invested in what the patient is going through emotionally. This however does not nullify how the participants constructed medical staff.

The section on intuition sparked a considerable discussion and was well received by the interactive group notwithstanding that this topic is not something that is always discussed. It was interesting that participants constructed their writing in such a manner that they could speak about topics that would not always be socially acceptable yet they were allowed a space to make meaning of what they experienced with regards to dreams, visions and feelings. Throughout the discussions of religion and spirituality it was constructed in a manner where religion as well as spirituality was a space where peace was found. It is of interest to me that in a group of more than 3000 participants not one person questioned the role of religion and spirituality in their traumatic experience. As seen in Andipatin (2012) a participant had deferred her anger towards God, however my study revealed the contrary. Their experiences were rather constructed in a manner that made religion and spirituality a discourse of safety, help and guidance. This is not unusual as in many studies it is reported that trauma is related to individuals drawing closer to something that they believe has more power than they do (Price et al., 2007).

The final key finding was the social support offered online to these users. Most participants constructed their writing in terms of the space that an online environment provided drawing on a discourse of social support in shared suffering. They found a space where they had people that could relate to what they experienced and are still experiencing. Not only did the space allow for a therapeutic outlet but it also played a major role in allowing participants to share milestones regarding their children's progress, birthdays and other developments as well as seeking advice or guidance. The greatest role the space played for the participants is that of meaning making. Furuta et al. (2014) found that the intervention after a high- risk pregnancy is very important in both the physical and emotional arena to minimize severe long term effects to the mother as well as the extended family affected. This thus begs the question, is an online space not a means of intervention, even if the community is taking the stance to help each other out of the space of 'suffering'.

In summary based on the findings, my study reveals that the lived experiences of the participants were housed within the discourses of popular culture and biomedical discourses that construct the female body in very particular ways, defines foetal personhood in very biophysical terms completely ignoring the spiritual aspects of being and determines loss in relation to what society deems 'real'.

### **5.3 Reflecting on the methodology**

The methodology used in my study proved useful as it seemed to dismantle the barriers of time and space. It surpassed any challenges of gaining participants or obtaining access to clinical settings. The only challenge was finding a sample that would be able to answer my research question and the inquiry around a differentiated and undifferentiated group. Furthermore, the methodology allowed me entry into a space where these participants were comfortable and open to share their psychological experiences without any probing or investigation from the researcher. The methodology however presented challenges when thinking it through in comparison to traditional qualitative research. Gaining access without breaching any ethical considerations, gaining consent in an unconventional manner with relation to social networking sites' policies as well as not having access to participants' demographic data was daunting.

Even though this methodology had been challenging it is my opinion and in my experience a suitable way of gaining access to more realistic and 'raw', uncensored experiences of women. This method allowed me access into a social structure where women are supported through interactive conversations, they are given guidance by other individuals that know exactly what they are going through because of similar experiences.

This study revealed that there is a space for further online research especially those focusing on designing interventions that could allow people who participate in social online support groups to gain access to professional guidance. My findings on a psychological level alerts medical staff to the role they play in not only the medical aspects of the body but also the psychological components of what women are faced with when going through and also when surviving a high risk pregnancy.

### **5.4 Limitations**

The limitations of my study related mainly to the nature of the internet itself which may have influenced the methodology in various ways. Thus, one of the limitations related to the key words used to allocate the study as this may have elicited different hits as the internet is ever changing. The location of the particular group may also have changed as groups have the option of changing their community status online. Therefore, my findings cannot be generalised to a broader context, however it is important to take into consideration that the particular group was the largest and most

active community at the time that the study was conducted. The time constraints may also be viewed as a limitation as longer time spent in the community may have disclosed richer results, however only one month spent within this particular community yielded 87 postings and 228 interactive postings (which were reactions to the original 87 postings)

### **5.5 Reflecting on the theory**

The social constructionist framework and social suffering theory complimented each other and was extremely useful in this study. It enabled me to theorize the subjective and shared meaning making of a group of participants with a rare pregnancy related disorder on an online social media platform. The strength of these theoretical frameworks lie in their ability to take into account social contexts within which these experiences occur as well as how sense is made of these experiences given the overarching social structures that govern such experiences.

### **5.6 Recommendations**

I would recommend that future researchers be cognizant of the huge influx of online data in social research as this is a growing field with the potential for huge exploration as this area is largely unexplored. It is of utmost importance that we embark on this type of research as this is the space where the majority of people seem to find comfort in their process of making sense of their traumatic experiences as is evident in my study. HELLP syndrome is still an under researched area especially in terms of the psychological experiences thereof. It is however important that future research finds the balance between traditional interventions in hospitals and online facilities. It is important to note the advantages and disadvantages of face to face interviews and psychological interventions as the treatment of an illness as rare as HELLP syndrome is often faced with its own challenges. By exploring internet mediated channels psychological interventions could take on a new identity and become more accessible even in light of an illness as rare as HELLP syndrome.

In conclusion my study employed a social constructionist theoretical framework, and also made use of the social suffering theory in order to draw attention to the key experiences of the participants as they construct it through their own meaning making processes. High-risk pregnancy is painfully invisible in a culture that seeks perfection hence its perhaps unconscious need to render these experiences invisible and keep them silent. In the final analysis my thesis

demonstrates my contribution to the critical conversations regarding high-risk pregnancy and the use of online support groups in contemporary society.



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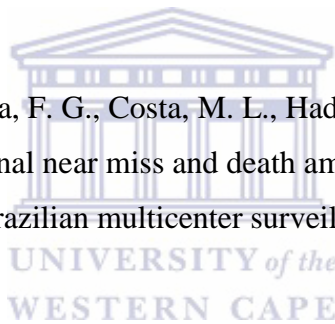
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## Appendix 1: INFORMATION SHEET



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Project Title: The psychological experiences of women who survived HELLP syndrome constructed online.

What is this study about?

This is a research project being conducted by Jill L Cupido at the University of the Western Cape. We are inviting all users of the group to participate in this research project because you have at some stage been diagnosed with HELLP syndrome and have experienced the psychological experience that goes with it. The purpose of this research project is to not only gain an in-depth understanding of how survivors of HELLP syndrome narrate online but also be able to identify the psychological experiences.

What will I be asked to do if I agree to participate?

You will not be asked to do anything or answer any question. Your post/s will merely be observed for the month of June 2015. Every Monday and every Friday the data will be collected to ensure that all applicable post has been attained.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, pseudonyms will be used instead of your name. To ensure your confidentiality, the post will be paraphrased to ensure that none of the findings are traceable back to you or to the webpage.

If we write a report or article about this research project, your identity will be protected.

What are the risks of this research?

Due to the nature of this study participants are aware that when they post and relive their experience that they might experience secondary trauma. However seeing that the participant is not being asked to post it is a risk that the participant is aware of. To minimise any secondary trauma the researcher will not probe or ask any questions.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the psychological experiences of women who survived HELLP syndrome and how they narrate online. We hope that, in the future, other people might benefit from this study through improved understanding of HELLP syndrome and the possibility of online intervention.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized. Due to the nature of this study if you do not post on the webpage you are not part of the study and if you do post it is voluntary. However if you would like to post on the webpage but not be part of the study you are free to contact the researcher and inform them of your decision. Your post will then not be used in this study.

What if I have questions?

This research is being conducted by *Jill L Cupido in the Psychology Department* at the University of the Western Cape. If you have any questions about the research study itself, please contact *Jill L Cupido* at: [jlc1412@gmail.com](mailto:jlc1412@gmail.com)

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department:

Dr. M. Andipatin

[mandipatin@uwc.ac.za](mailto:mandipatin@uwc.ac.za)

Dean of the Faculty of Community and Health Sciences:

Prof José Frantz

University of the Western Cape

Private Bag X17

Bellville 7535

[chs-deansoffice@uwc.ac.za](mailto:chs-deansoffice@uwc.ac.za)



This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

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## Appendix 2: CONSENT FORM



UNIVERSITY OF THE WESTERN CAPE

Department of Psychology

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-9592819, Fax: 27 21-9593515

E-mail: jlc1412@gmail.com

### **Title of Research Project:**

The psychological experiences of women who survived HELLP syndrome constructed online.

I have read the information sheet provided on this webpage and I understand what my participation will involve. I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

If I do not want to be involved in this study but I do however want to make use of this webpage I understand that I am free to contact the researcher and inform them of my choice.

Researcher: Jill L Cupido

Email: jlc1412@gmail.com

Student Number: 3119243

Supervisor: Dr. Michelle Andipatin



## Appendix 3: ETHICS CLEARANCE FORM



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OFFICE OF THE DEAN  
DEPARTMENT OF RESEARCH DEVELOPMENT

19 June 2015

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:  
Ms J Cupido (Psychology)

Research Project:	The psychological experiences of women who survived HELLP syndrome constructed online.
Registration no:	15/4/67

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

A handwritten signature in black ink, appearing to read 'Josias'.

*Ms Patricia Josias*  
*Research Ethics Committee Officer*  
*University of the Western Cape*





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WESTERN CAPE