Experiences of Women Who Survive

Major Obstetric Haemorrhage

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DECLARATION

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ABSTRACT

Severe post-partum haemorrhage is a major cause of maternal morbidity in South Africa. There is very little information about the experience of survivors of PPH in the local South African setting. This qualitative study investigated, by way of in depth interviews, the experience of 11 women who survived severe PPH at Tygerberg hospital. Several themes emerged, most notable self-blame, guilt and isolation. This information is important to ensure that future care of women with severe morbidity includes a mental health component, with appropriate referral for psychologic counselling and long-term follow up. The other important themes identified were pain and discomfort, near death, fear and loss of control.

OPSOMMING

Massiewe bloeding na geboorte is ‘n belangrike oorsaak van moederlike morbiditeit in Suid Afrika. Daar is min inligting beskikbaar oor die siening en ervaring van erge bloeding vanaf die pasiënt se standpunt in ‘n plaaslike opset. Vir hierdie kwalitatiewe studie is onderhoude gevoer met 11 vrouens wat erge nageboorte bloeding by Tygerberg Hospitaal oorleef het. Die belangrikste temas wat uit die navorsing te voorskyn kom is die van skuld, self-blaam en isolering. Hierdie inligting kan nou doeltreffend aangewend word om te verseker dat daar ook na die geestesgesondheid van oorlewers omgesien word. Dit sluit langtermyn opvolg in asook verwysing vir sielkundige berading voor ontslag. Die ander belangrike temas wat identifiseer is, is ‘n naby-dood ervaring, pyn en ongemak, vrees en verlies van beheer.

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LIST OF ABBREVIATIONS

AP	Antepartum Haemorrhage
CS	Caesarean section
ECM	Electronic Management System
HELLP	HELLP-syndrome related to pre-eclampsia – Haemolysis, Elevated liver enzymes, Low platelets
HIV	Human Immunodeficiency Virus
ICD	International Classification of Disease
ICU	Intensive Care Unit
IUD	Intra-uterine death
IUD	Intra-uterine death
KBH	Karl Bremer Hospital
KDH	Khayelitsha District Hospital
Kg	Kilogram
MAP	Morbidly adherent placenta
NICU	Neonatal Intensive Care Unit
OCCU	Obstetric Critical Care Unit
P	Participant
PI	Principal Investigator
PPH	Post-partum haemorrhage
PTSD	Post-traumatic stress disorder
RBC	Red blood cells
SAMM	Severe acute maternal morbidity
TBH	Tygerberg Hospital

UNDP	United Nations Development Program
UNFPA	United Nations Population Fund
WHO	World Health Organization

1. INTRODUCTION

Little is known about the experiences of women who survive severe obstetric complications. Over the last decade, there has been much interest in the audit of women who survive severe acute maternal morbidity (SAMM) in pregnancy. Essentially, this refers to women who have had severe life-threatening complications in pregnancy where death was a likely outcome but timely intervention could save the life. Near miss obstetric cases strike with urgency, requiring health care providers to act quickly to achieve the best possible outcome. The nature of these obstetric complications can be traumatic for women as there is little time for explanation and provision of information. These events are not only characterised by severe physical changes and the near loss of life, but also cause profound emotional turmoil around the time of the event and thereafter.

Severe obstetric haemorrhage is a life-threatening birth complication and is a large constituent of SAMM. It can have long term consequences for women and their families. Severe obstetric haemorrhage, according to the WHO organ-based SAMM criteria is defined as a woman who experiences haemorrhage that causes cardiovascular dysfunction, coagulation or haematological dysfunction or where a hysterectomy is required (1).

Severe obstetric haemorrhage remains one of the major causes of severe maternal morbidity in both developed and developing countries. It is reasonably easy to quantify, recognisable to the patient and partner as a life-threatening event and is one of the common causes of SAMM. These factors made it a good subset of the SAMM spectrum to evaluate.

This qualitative study will ask the question “What are the experiences of women who survive major obstetric haemorrhage?”

2. LITERATURE REVIEW

Over the last decade, there has been much interest in the audit of women who experience SAMM in pregnancy. The definition that is supported by the International Statistical Classification of Disease and Related Health Problems (ICD 10) is “a woman who nearly died but survived a complication that occurred during pregnancy, childbirth or within 42 days postpartum”. Essentially, this refers to women who have had severe life-threatening complications in pregnancy. Women who die from these complications will be classified as maternal deaths, whereas those that survive will be considered near misses. The World Health Organization prefers the terminology “near miss events”. This reflects the concept that death was a likely outcome, had timely intervention or good luck not been at play.

South Africa uses the term Severe Acute Maternal Morbidity in keeping with a pilot study pioneered by Mantel and Buchmann from South Africa that tested the application of a clinical definition of SAMM in 1998 (2). They found that audits of SAMM identified nearly 5 times as many cases of morbidity as maternal deaths. They also concluded that their criteria constitute an effective audit system of maternal care because it is based on clinical signs and the cases identified reflect the pattern of maternal death.

The prevalence of SAMM was studied by the World Health Organization (WHO) in conjunction with the UNDP, UNFPA and World Bank by performing a meta-analysis on studies reporting on maternal mortality and morbidity (3). Using organ-based criteria, the prevalence of SAMM was found to be 0.38% to 1.09% worldwide.

In South Africa, the pilot study by Mantel and Buchmann identified 147 women out of 13,429 deliveries in a one year period in the Pretoria Health Region (1). Using organ-system based clinical criteria, the primary obstetric factors in maternal near misses were found to be hypertension (26%), antepartum haemorrhage (9.5%), postpartum haemorrhage (16%), pregnancy related sepsis (7%) and sepsis related to termination of pregnancy (13%).

A follow up study in South Africa concluded that a SAMM audit gives a different disease pattern to that obtained from maternal death audit, is useful in highlighting inadequacies in the health system and is a valuable addition to data collected by audits of maternal deaths. The study showed hypertension and haemorrhage to be the most common causes of SAMM in South Africa (4).

A recent audit of SAMM in the Metro East, Cape Town found that 15,623 women delivered in the Metro east in Cape Town between 1 November 2014 and 30 April 2015 (Anke Heitkamp, personal communication). During this time, 209 cases fulfilled criteria for SAMM making the incidence of SAMM for this time period 1.34%. Ten maternal deaths occurred in the same study period. The audit concluded that hypertension and haemorrhage were responsible for the majority of causes of SAMM.

The 10th Annual Scottish Confidential Audit of Severe Maternal Morbidity (SCASMM) in 2014 represents a 10-year audit of SAMM in Scotland. It demonstrated that the maternal morbidity rate rose steadily from the report's inception in 2003 mainly due to an increase in the number of cases of haemorrhage. Major obstetric haemorrhage accounted for 80% of events in 2012 (5).

Few studies have tried to shed light on describing women's experiences of coming close to death in a life threatening obstetric emergency. The non-physical aspects are an important and often downplayed aspect of severe obstetric complications. As highlighted by a study by Souza and co-workers, not only does a women experience severe pain and other major physical affects, but also the imminence of death, fear, frustration and grief during an emergency event (6). Souza reported that women who experience SAMM felt extreme pain and dyspnoea, which made them feel like they were going to die. They concluded that fear was the driving force that made the women believe that death was imminent.

Similarly, according to Ryding et al, who looked at experiences of women who have an emergency caesarean section, fear was noted to be a dominant feeling expressed by women in relation to impending death or serious injury as a result of having a caesarean section (7).

Religion and spirituality also play pivotal roles during a severe obstetric emergency. Women in the study by Souza et al elaborated that religion and spirituality was helpful to them during their crisis (6). Similarly, in a study by Elmir et al, women took comfort in their faith and felt that it was an important aspect that allowed them to keep calm when they sensed imminent death (8). It has been found that people who experience coming close to death have a spiritual awakening and people can sometimes develop strong religious beliefs following a close encounter with death (9)(10)(11).

An Australian study by Elmir and co-workers described women's experiences of having a severe obstetric haemorrhage that resulted in a hysterectomy (8). The major theme elicited was that of "between life and death". The study reported that women felt an overwhelming

imminence of death. Furthermore, they were distraught at the amount of blood they saw. The participants reported feeling uncertainty as to whether they would survive. This was accompanied by concerns as to who would be left to raise their children. The devastation and realisation of almost losing their life and having had a hysterectomy continued to affect some of the women in the form of flashbacks.

Kadir et al found that the sight of large quantities of blood evoked severe shock (12). Similarly, the study by Elmir et al found that women could sense the imminence of death and felt utter despair at the amount of blood that they were losing (8). In addition, Elmir reported that women felt a sense of loss of control and disconnection from their bodies after seeing the extent of the blood loss and the amount of blood being transfused.

Due to the fact that obstetric complications strike with urgency, with little time for health care providers to fully explain what is happening, many women felt that there was a breakdown in communication. A study by Mapp et al noted important themes of verbal and non-verbal communication. Women felt that they were left on their own to make sense of what had happened to them (13).

In keeping with the urgency of obstetric complications, Fallowfield et al concluded that the reaction to bad news can be distressing for the individual, particularly if it involves major life changing circumstances (14). The manner in which bad news is delivered can impact majorly on the women in the postnatal period (15).

Studies in Burkina Faso looked at women who survived SAMM. With a process of in-depth repeated interviews, they were able to ascertain the magnitude of the aftermath of SAMM. They concluded that not only are “near miss events” characterised by the near loss of life, but often the loss of the baby, loss of normal bodily integrity through injury, ongoing illness and lack of strength. The consequences also include household disruption through high expenditure, debts and loss of productive capacity as well as social identity and stability. In conclusion, they felt that maternal health policy needs to be aimed at not only preventing loss of life, but also with preventing or lessening other losses associated with obstetric complications (16)(17).

Other studies in Burkina Faso revealed that 5.3% of 337 women suffering SAMM died in the 4 years following pregnancy, whereas 0.9% died after uncomplicated pregnancies (18). More than half the deaths after a “near miss” were related to the original pregnancy, but none after an uncomplicated delivery were pregnancy related. Relative’s accounts suggested the causes of death were related to lack of follow up care, high cost and poor quality of health care and inadequate contraception. They concluded that the likelihood of survival over the longer term could be increased by offering more holistic care with emphasis on social causes of death.

A study by Filippi et al found that women who survived severe obstetric complications were poorer and less educated than women with uncomplicated deliveries and experienced significantly higher mortality and infant mortality (19). Women with severe obstetric complications were significantly more likely to have worse mental health outcomes, especially in terms of risk of suicidal ideation and depression. They were also more likely to report that the pregnancy had a negative effect on their lives compared to women with

uncomplicated deliveries. They concluded that women with severe obstetric complications are a high-risk group with a high mortality even after discharge. They felt that efforts targeting women with severe obstetric complications for social and financial interventions would be beneficial.

Ethnographic data from a subset of the above study suggested that mental health problems could arise due to disappointments with the pregnancy outcome, fears about future reproductive uncertainties and increased social tensions (20). Social factors resulted from the financial and emotional difficulties of compromised physical and emotional wellbeing, and general difficulties from poverty.

A study looking at the relationship between severe maternal morbidity and postnatal psychological health symptoms found that there was a higher risk of Post-Traumatic Stress Disorder (PTSD) symptoms among women who experienced severe maternal morbidity compared with women who did not (21). The authors recommended that further interventions during hospitalisation be made to try and prevent these risks. A systematic review of risk factors for PTSD following delivery identified subjective distress in labour and obstetrical emergencies as the most significant (22). A prospective study by Ayers and Pickering found that 1.5% of women suffer PTSD following childbirth (23).

Kaye et al conducted a related study in Uganda (24). On the basis that there is limited research into what happens to women who survive severe obstetric complications, they aimed to understand their experiences and possibly formulate strategies to support survivors. They followed up women who survived uterine rupture following obstructed labour. They

concluded that the results of uterine rupture include loss of fertility, loss of bodily image, poor quality of life and disrupted marital relationships. Furthermore, it placed a severe economic burden on survivors.

Near-miss events can be traumatic for the patient, but also for the partner. Hinton et al performed a qualitative study focusing on patient partners (25). The long term emotional effects were severe with some partners experiencing depression, post-traumatic stress disorder and flashbacks. These effects had an impact on the entire family unit. They concluded that little support was available for the partner's stress.

It is clear that an audit of SAMM identifies a group of women at high risk for further complications, mental health problems including depression and PTSD, economic disadvantage and social stigmatism. These aspects are often overlooked by medical teams.

Major obstetric haemorrhage is a complication that is reasonably easy to quantify, recognisable to the patient and partner as a life-threatening event and is one of the most common causes of SAMM. It is therefore a good subset of patients to study within the SAMM spectrum.

Major obstetric haemorrhage, according to WHO organ based SAMM criteria, can be defined as a woman who experienced any of the following:

- Cardiovascular dysfunction: Shock, cardiac arrest (absence of pulse/heart beat and loss of consciousness), use of continuous vasoactive drugs, cardiopulmonary resuscitation, severe hypo-perfusion (lactate >5mmol/l, severe acidosis pH <7.1);

- Coagulation/haematological dysfunction: failure to form clots, massive transfusion of red cells (≥5 units), severe acute thrombocytopenia (<50 000 platelets/ml);
- Hysterectomy secondary to haemorrhage.

It is clear that childbirth can be accompanied by life threatening complications. The limited literature available suggests that these women are overcome with shock, fear and anxiety when placed in a position of coming close to death. Furthermore, the impact of SAMM is not only felt at the acute event, but cascades onto other aspects like the partner, the family, other children and can impact greatly on the social circumstances of the women.

3. AIM AND OBJECTIVES

3.1 AIM

This study aimed to describe the experiences and the perceptions of women who survived the life-threatening complication of severe obstetric haemorrhage. Emphasis was placed on the actual experiences and views of the participants. Aspects that were explored included experiencing the event of severe obstetric haemorrhage, the immediate reaction to the event (including physical experience, perception/interpretation of their situation and emotion) and the aftermath.

3.2 OBJECTIVES

To describe how the women experienced the severe obstetric haemorrhage.

To describe how the women reacted to the event. This will include the physical experiences of severe obstetric haemorrhage as well as the emotions surrounding coming close to death.

To describe the aftermath of the event focusing, examining feelings and the impact the event has had on their lives.

4. METHODOLOGY

4.1 RESEARCH DESIGN

This study used a qualitative research design with an interpretive analytical approach. Qualitative data was collected through in depth face-to-face semi-structured interviews. Interviews were open-ended thus providing participants with the opportunity to describe their experiences fully.

4.2 SAMPLE

Participants were selected from a recent audit of SAMM in the Metro East, Cape Town, between 1 November 2014 and 30 November 2015 (Anke Heitkamp, submitted for publication for which separate ethical consent was obtained). During this time, 209 cases fulfilled criteria for SAMM making the incidence of SAMM for this time period 1.34%. This databased served as the source of patients identified for the current study.

The audit divided cases into categories, one of which was obstetric haemorrhage. One hundred and three patients were isolated from this category. All possible contact details for each patient in this group were obtained from clinical records and patient registration details in the TBH OpenText Electronic Content Management (ECM) System and the online patient information management system (Clinicom).

Telephonic contact was possible with 22 patients. Each of the 22 patients were informed about the study and invited to become a participant. Two patients refused as they felt it

would be too emotionally traumatic to relive the experience. Four patients agreed to participate but did not arrive for the interview. Three patients were excluded for unrealistic demands, ill health requiring admission and unable to converse adequately in English.

Eleven patients were successfully interviewed. The study was re-explained at the interview venue and informed consent was obtained. Transport and a monetary incentive was issued after each interview (see ethical considerations). Data saturation was reached after 6 interviews; however, the interviews were continued as a minimum requirement for university degree requirements. Each participant was assigned a number (P1-P11) and an alias for ease of reference in the results section.

Table 4.2.1 - Table of Participants

P	Alias	Age	Ethnicity	Home language	Morbidity	RBC	Hyst	IUD
P1	Phumla	38	African	Xhosa	PPH	7RBC	Yes	No
P2	Busi	24	African	Xhosa	AP	5RBC	No	Yes
P3	Anathi	31	African	Xhosa	AP	5RBC	No	Yes
P4	Lindiwe	29	African	Shona	PP, PPH	9RBC	No	No
P5	Nandipha	33	African	Xhosa	PPH	5RBC	No	Yes
P6	Akhona	16	African	Xhosa	PPH	6RBC	No	No
P7	Ntando	36	African	Xhosa	PPH	6RBC	Yes	No
P8	Lee-ann	38	Coloured	Afrikaans	PPH	5RBC	Yes	No
P9	Jolene	32	Coloured	Afrikaans	PPH	6RBC	Yes	No
P10	Lwazi	25	African	Xhosa	AP	6RBC	No	Yes
P11	Felicity	30	Coloured	Afrikaans	AP, PPH	5RBC	No	No

P: Participant number, RBC: number of units of red blood cells transfused, AP: abruptio placentae, PPH: post-partum haemorrhage, Hyst: hysterectomy performed, IUD: intra-uterine death, PP: placenta praevia.

4.3 INCLUSION CRITERIA

Inclusion criteria required that participants experienced a severe obstetric haemorrhage as defined by WHO organs based SAMM criteria. This included one or more of the following;

- Cardiovascular dysfunction: Shock, cardiac arrest (absence of pulse/heart beat and loss of consciousness), use of continuous vasoactive drugs, cardiopulmonary resuscitation, severe hypo-perfusion (lactate >5mmol/l, severe acidosis pH <7.1);
- Coagulation/haematological dysfunction: failure to form clots, massive transfusion of red cells (≥5 units), severe acute thrombocytopenia (<50 000 platelets/ml);
- Hysterectomy secondary to haemorrhage.

Furthermore, the participants must have been willing to participate in the study, and be able to converse in English. Only English speaking woman were enrolled so as to avoid the use of a translator. Due to the personal nature of this study, translation may have caused limitations in the form of loss of data or meaning. For the purposes of this study, the period of time since experiencing the severe obstetric haemorrhage was not deemed crucial as most women who experienced this event would have had strong memories of the event even though a significant amount of time may have elapsed.

4.4 EXCLUSION CRITERIA

Participants were excluded if they declined to be audio-recorded, were unable to converse in English or declined to be interviewed.

4.5 INSTRUMENTS

Research data was collected through in depth face-to-face interviews to gain insights into the experiences and perceptions of the participants. Interviews were open-ended thus providing participants with the opportunity to describe their experiences fully.

Interviews were conducted by the principal investigator (PI) at Tygerberg Hospital in a safe, comfortable and private environment at a time convenient to the participants. All transport costs were covered and they received a monetary incentive. The face-to-face nature of the interview allowed for immediate clarification or expansion of the participant's thoughts and access to nonverbal cues such as gestures and facial expressions (26).

Intricate nuanced narrative descriptions are the essence of interpretive analysis, which dictates that data should be collected through situation-based in-depth interviews (27). In-depth interviewing is a well-established technique and aims to discover the participant's own framework of meanings, by exploring what is said in as much detail as possible and going below the surface of the topic being discussed (28). For the purposes of this study, a semi-structured in-depth interviewing technique was used.

4.6 DISCUSSION SCHEDULE

A discussion schedule was utilised. This contained open-ended data generating questions. Probes were used, as needed, to clarify the meaning of responses and encourage in-depth descriptions. The discussion schedule included questions regarding experiencing the event of severe obstetric haemorrhage, the immediate reaction including the physical experience,

perceptions, coming near to death and feelings about care. Probes were used for fear, concern, anger, guilt, loss, faith and spirituality, bonding with baby, post-traumatic stress disorder, and inadequate information from health care providers as well as any positive responses.

These guides were used to indicate the general area of interest and to provide cues when the participant had difficulties expressing herself. The interviewer's role, however, in a semi-structured interview, is to facilitate and guide, rather than dictate exactly what will happen during the interview. Therefore, this approach allowed the PI to follow the agenda of the participant and to diverge from these guides in order to pursue an idea or response in more detail (29).

Table 4.6.1 – Discussion schedule

Question	Prompts
Tell me about your experience of the birth?	unexpected/expected sudden information blood transfusions ICU admission
Tell me about your immediate reaction to what happened?	pain discomfort loss of blood loss of consciousness
Tell me about your perceptions or interpretation of what happened to you?	near death feelings about health care loss of control loss over medical decisions loss over a life event
Describe the emotions you experienced?	fear concern anger guilt faith and spirituality
Tell me about how you feel now looking back at the event?	information (too much or too little) seeing causes blame post-traumatic stress symptoms bonding with baby/childcare gratitude regret

4.7 DATA ANALYSIS

The goal of analysis using an interpretive analysis approach is to reveal the meaning of the lived experiences of the participants. It aims to capture and communicate to the reader the meanings that are lived, but not necessarily clearly communicated or in full awareness of the participants. Ultimately, the analysis will produce a detailed description of the event in order to create understanding. Interview transcripts were examined simultaneously with the emerging interpretation, thereby not losing sight of each participant's story (30). The PI used a combination of steps of interpretive analysis to derive meaning from the data. This was facilitated electronically by the data management program Atlas.ti 7.

All interviews were audio recorded and transcribed verbatim including the descriptive context (i.e. facial and hand gestures). Data analysis began immediately after the first interview. Initial analysis of the data also influenced further subsequent data collection. The PI's interview schedule was adapted slightly in light of emerging findings where additional clarification was required. Field notes and a research diary was kept and utilised in analysis. The transcribed interviews formed the raw data.

A stepwise data analysis approach was undertaken as outlined by Hycner et al (31):

Phase 1 – Organizing and preparing the data for analysis

All audio-recordings were rigorously transcribed. This included a verbatim account of all verbal and sometimes non-verbal utterances. In this way, the transcriptions remained true to

their original nature (i.e. punctuation added appropriately so as to truly capture the meaning of the data from the participant), thus making sure that the transcription was practically suited for the purpose of analysis. The first 4 transcriptions were exclusively transcribed by the PI. The remaining transcriptions were performed by a professional transcription service specialised in qualitative research. The transcriptions performed by the transcription service were re-read with audio and field notes. Appropriate additions were made to assure the accuracy of the transcriptions.

Phase 2 – Immersion in the data

The PI became familiar with all the data in order to obtain a general sense of the information (32). All interviews were conducted exclusively by the PI, therefore prior knowledge of the data was possible before the analysis phase began. Some initial analytic interests and thoughts were noted using memos. These were also used in the analysis.

All transcriptions were read in conjunction with audio to adequately appreciate the context of the text. The transcriptions were re-read, searching for patterns and meanings. This process of familiarisation ensured that the PI remained faithful to the event and did not impose his own ideas on the data (These initial findings were documented for review in future phases of analysis).

Phase 3 – Generating initial codes

Coding is defined as the process of organising narrative data into segments of text before bringing meaning to the information (33). The process included segmenting sentences in the transcripts into categories and labelling each of these categories with descriptive terms. These labels are called codes.

Predetermined and emerging codes were used to analyse the data. A list of initial codes was created from the objectives of the study and the literature review. These were applied to the transcripts, adding new codes as they arose. Two-hundred and thirty six codes were generated. An example of a coded interview is provided in Appendix A

Phase 4 – Searching for themes

The codes were evaluated and sorted into candidate themes. This refocused the analysis from codes to the broader level of themes. Visual representations were used in the form of a thematic map and colour coding in order to examine the relationship between codes, themes and different sub-levels of themes (main theme and sub-themes) to be examined. Codes that did not fall strictly in a theme were kept separate in a miscellaneous category.

Phase 4 – Reviewing themes

The candidate themes were reviewed and refined. This occurred at two levels:

Level 1 incorporated reviewing the themes at the level of the coded data extracts. All collated extracts for each theme were re-read. If a coherent pattern was identified, reviewing at level 2 began. If themes did not cohere adequately, they were reworked by either creating a new theme or moving codes and extracts to already cohered themes or discarding them from analysis.

Level 2 refinement reviews the themes in relation to the entire data set. The data set was re-read to make sure that themes represented the data set. As coding is an ongoing process, additional coding was undertaken for anything missed prior.

Phase 5 – Generating a general description and interpretation of the data

A stable set of themes was derived. The importance of each theme was reflected by the number of times it was stated by the participants. Four major themes were identified and are presented in the results section.

Phase 6 – presenting the themes

The themes are presented in a narrative passage in the results section. The descriptions are illustrated using quotations from the interviews.

4.8 VALIDITY

Validity of research corresponds to the degree to which the findings are regarded as trustworthy, useful and legitimate. Added to this, validity in the content of this study must refer to the degree to which the explanations of the phenomenon match the realities of the world (34).

The PI debriefed with the research supervisors once a month to review the research process. Furthermore, the PI presented progress and provisional findings to the Obstetrics and Gynaecology department 6 monthly. The PI also had informal conversations with colleagues who were not directly involved in the study. These discussions allowed the interviewer to debrief and share what was discussed in the interviews. This assisted with preventing interview bias and allowed the PI to obtain alternative explanations for findings in the interviews.

The emerging codes and themes were discussed with the supervisors. This allowed the analysis to have multiple perspectives and make sense to other people. These discussions also aided in identifying other codes and themes that the PI had not already noted. This, therefore, improved the consistency and coherence of the analysis (34).

4.9 ETHICAL CONSIDERATIONS

Ethical approval to conduct the study was obtained from the Health Research Ethics Committee, Faculty of Medicine and Health Sciences of Stellenbosch University.

All participants gave written informed consent to be interviewed and participate in the study (Appendix A). They were informed that their participation was entirely voluntary and they had the option to withdraw from the study at any point. All participants received a participant information booklet with a description of the study with frequently asked questions and the PI's contact details. By signing the consent, the participants indicated that they were voluntarily participating in the research study and granted the researcher permission to audio-record the interviews.

The participants were assigned a number linked to their hospital folder number. This document was kept on the supervisor's computer on the hospital premises and was password protected. The recordings and transcripts were also kept on the PI computer and were password protected.

Data from interviews was kept confidential and not discussed openly. No forms or notifications were placed in the patient's files indicating that they were part of the study. Transcriptions were only identified by a number. The participants were not identified by either name or hospital number on the interview transcriptions.

Participants were informed prior to the interview that they may terminate the interview at any point or may decline to answer questions.

The audio recordings will be destroyed 1 year after submission of dissertation.

The population is a vulnerable one. Reflecting on these experiences induced emotional distress during the interviews. In these cases, emotional support, counselling, psycho-education and containment was provided. Interviews were only terminated once the participant was stable and were not terminated abruptly.

All participants were screened for PTSD using the "PTSD Checklist for DSM V" (PCL-5). The PCL-5 is a self-report measure that can be completed by participants prior to the interview. It takes approximately 5-10 minutes to complete. For a person to have a probable diagnosis of PTSD sufficient criteria must be at least moderately met in each of the four symptom groups This means you need to have one or more symptoms from questions 1 to 5, either question 6 or 7, two or more from questions 8 to 14, and two or more from questions 15 to 20, each of which must be met moderately, quite a bit or extremely. In addition, a score of 38 or higher indicates probable PTSD. None of the participants screened positive for PTSD.

Furthermore, the PI familiarised himself with DSM V criteria for PTSD, depression and anxiety. Should any patient have screened positive for PTSD or the PI felt that they had DSM V features of depression, anxiety, or PTSD, the candidate would have been referred to the Tygerberg outpatient psychology services. This service potential referral pathway was arranged prior to the study with the Tygerberg Department of Psychology. The participant would then be given an appointment with a qualified clinical psychologist.

5. RESULTS

Major themes and sub-themes are provided in Table 5.1.

Table 5.1 - Major Themes and Sub-themes

Major Themes	Sub-themes
Physical Experience	Site of own blood Pain and discomfort Loss of consciousness and confusion Severe weakness
Perceptions	Near death Loss of control Urgency Information Health care workers
Support	Religion and spirituality Family
Emotions	Blame Anger Fear Guilt Hope Isolation Gratitude

5.1 Theme 1: Physical experience

The women described the physical aspects of their experience with disbelief and disappointment. Many were overcome with emotion as they recounted how they felt at the sight of their own blood, immense pain, sudden lack of consciousness, altered time perception and accompanying severe weakness during and after the experience.

Sub-theme 1.1 - Site of own blood

For most women, the sight of their own blood was the first indication of the severity of their situation. Lwazi (P10) described how she had been patiently awaiting medical attention, but suddenly her world was cast into turmoil as she noticed blood pouring from her:

'Then, I was sitting with the other lady outside and waiting for the doctor, and then I was busy chatting with this lady about the cramps, like what I'm feeling, and that lady, how she is doing. Then I was so traumatised when I saw the blood come.' Lwazi (P10)

Busi (P2), who survived an abruptio placentae with an intra-uterine death was sitting at home when she first saw blood and felt her uterus become hard as it distended with blood:

'Because the moment the blood came was the moment the baby move up into my stomach. Busi (P2)

Jolene (P9) was oblivious to her situation and only grasped the severity when she woke up in the hospital and noticed blood on her bed:

'Then they took me to the bed, and they put me injection, and then I fell asleep, and then when I wake up, I saw the blood…' Jolene (P9)

For some, the realisation of what had occurred to them only happened when they saw the number of blood transfusions they received. This was the case for Felicity (P11) who realised the severity of her situation when she saw the substantial volume of blood being transfused:

'I actually realised but this is quite serious because I think they gave me quite a few pints of blood.' Felicity (P11)

Some participants expressed shock and disbelief at the amount of blood and relentless flow they saw on their clothes, the bed and on the floor.

'It's like when the blood comes out, it was like when you open the tap, like and the water comes so fast, it's sudden like that, and then I fall down, and then the nurses come and pick me. Then they took me to the bed. It was when I lost the mind.' Lindiwe (P4)

'Oh, the blood. I can see the blood was streaming out that time. That, I was seeing that, and that made me think I'm not going to make it, because it was worse.' Lindiwe (P4)

Women expressed their fear and uncertainty that they would be able to continue living for much longer due to the large volume of blood lost. This was a source of emotional turmoil for the women as they worried that their bodies would no longer be able to sustain life. Felicity (P11) expressed concern that she had enough blood left in her body during her PPH:

'I was just thinking do I still have blood left in my body? How much blood do you actually have?' Felicity (P11)

Busi (P2) was alarmed at the amount of blood that was forcibly expelled after her delivery of an intra-uterine death following an abruptio placenta:

'It was light blood. Then there was a lot of it in the room, in the curtains and everything. I could hear the nurses saying "Dr please be careful" because the baby got far and there was a whole lot of water that came out. It was all over the bed and curtain.' Busi (P2)

In contrast to the shocking site of their own blood, many women welcomed bags of blood for transfusion that the majority referred to as "the red bags". They associated these with 'new strength' and energy. Lindiwe (P4) recounted how the blood "gave her new life":

'The only thing I remember is that I just begged the doctor. I said forgive me [cries]. Just help me to... [sniffs] just help me with more blood. That's the only thing I said to him, "just help me with more blood". I remember, I said it to him, "just forgive me, just give me more blood", that's what I remember, and I was praying the whole time.' Lindiwe (P4)

'It was... for me, like I said, at the time I didn't... I didn't realise, but like the next morning when I woke up, I was still full of blood. I was soaked, my feet and everything was soaked with blood. It was kind of, it was very scary for me because I didn't... I didn't expect there to be so much blood.' Felicity (P11)

Sub-theme 1.2 - Pain and discomfort

Busi (P2) described the severe discomfort she felt while she was experiencing abruptio placentae:

'I was panicking. I was feeling like when you were running and when you get hot and then then you get tired at the same time and you don't have the power to breathe or do anything.' Busi (P2)

For Busi, the dyspnoea and discomfort from an abruptio placentae was extremely distressing. She described vividly how she could not breathe and pleaded with health care workers for air:

'Then I was pleading with this woman, "Please give me some air, I need some air". And she was busy giving me air and my body was falling down. I couldn't even stand…And it was the baby that makes me hard to breathe. I can't breathe because the baby is pressing here (points to upper abdomen while crying).' Busi (P2)

After being told that she had suffered an intra-uterine death, she went on to explain the severity of the pain as unbearable. This was to such an extent that she no longer wanted to live:

'It was my turn to be NO MORE because of the pain. This severe pain, I couldn't breathe, I couldn't move. I was just lying there.' Busi (P2)

Lwazi (P10), who also had an abruptio placenta with an intra-uterine death similarly described how she welcomed the idea of death as a means to escape her unbearable pain:

'Even the pains that I felt, it's like even if God took me, it's fine right now because the pains that I feel…' Lwazi (P10)

Sub-theme 1.3 - Loss of consciousness and confusion

Most of the women experienced periods of loss of consciousness during their event. This was mainly attributed to hypovolaemic shock. Phumla, who survived a massive PPH that caused a cardiac arrest described how she "stopped feeling" and woke up a few hours later in a different hospital:

'…I started not seeing the people, I feeling dizzy, then nothing after that until I discovered myself at Tygerberg Hospital.' Phumla (P1)

This was associated with disorientation and confusion:

'They asked me if I knew where am I and said "No I don't know where". Then they tell me that I am in TBH hospital.' Phumla (P1)

Many women reported difficulty remembering the event and details that surrounded it. On reflections of the event, the inability to remember details of what had happened was a source

of sadness and frustration for some. This was particularly so for Anathi. Anathi survived abruptio placentae and required a blood transfusion of 5 units. In the aftermath, her family described their multiple visits and affectionate gestures while she was in the critical care unit, however, she does not recall any of these:

'My mother said she came and she called me, but I don't remember seeing her when she was here. Even my brother told me he came and held my hand. I don't even remember those things…' Anathi (P3).

Some described significant time lapses or altered time perception. This was mainly the case when participants were rushed to the operating theatre and only regained consciousness hours or days later in an ICU or high care.

Sub-theme 1.4 - Severe weakness

All of the women expressed the feeling of severe weakness during and after the event.

Phumla, a mother of three, spent more than a week in the ICU after an emergency hysterectomy for a PPH. She described the severe weakness she felt and considered the implications it would have for her as a mother:

'Because now I am struggling, I can't walk, I can't even turn myself from the bed. I'm lying like straight. Then I was thinking who will be take care of my kids if I can't do nothing. And then I

couldn't even hold a child. I can't hold my new child. It was very bad situation for me. I was thinking that I'm not going to be the same.' Phumla (P1)

She also explained how her prolonged exhaustion and fatigue impacted negatively on the bonding experience with her new born child:

'Yes, I was lost some connection with my child, because there by Khayelitsha hospital, they were looking for someone to take care or bond with my child, but there was no one who came there, until my friend who came and looked after my child. Then he came here. She saw my child lying there in the bed.' Phumla (P1)

Phumla only held her child for the first time after 3 weeks of being in a critical care facility.

The inability to care for their new born child was a significant concern for most mothers who were left feeling weak and exhausted after their events. Unable to perform motherly duties festered anxiety and frustration and even evoked feelings of failure. Lee-Ann described how she wanted to care for her new born child after her hysterectomy for PPH and MAP, but was unable to:

'I tried to come and reach her but it was too... I was too tired, I was too sore. I was not so strong to get up.' Lee-Ann (P8)

5.2 Theme 2: Perceptions

Sub-theme 2.1 - Near death

Women experienced fear, uncertainty and concern about their life and whether they would survive their event. Many of the women were overcome with the perception of the imminence of death. Busi, who experienced abruptio placentae with intra-uterine death at term, described that she felt that she was about to die, and the health care workers were avoiding telling her the truth. This sensation was augmented by her severe dyspnoea and weakness.

'I didn't have energy. I couldn't even lift my arm. I was struggling to breathe. I was having a short breath. All the time I would just lay on my side and just sleep, just sleep? Listen to the pain, and I couldn't even breathe. I would just take small breathes, small breathes, bit by bit…And when I pressed that thing, I said, "No doctor, you can just tell me, because I know is the time I'm going to die now".' Busi (P2)

Overcome by the fear of impending death, some turned to their religious backgrounds. For example, Lindiwe, who was bleeding from a major placentae praevia, called for her pastor:

'I was so scared, but the only thing I was doing because they had asked me who are you shouting? Then I said it's one of my pastors. I think he needs to pray for me, because I am dying now [crying].' Lindiwe (P4)

Ntando had a massive PPH following a retained placenta. Her condition made her feel so close to death that she wished a family member was with her to hear her last words too. For her, it was the site of blood filling her hospital bed that made her feel closest to death:

'I... I think of uh, I wish one of my family was here… And see me, maybe if I die, maybe I'm going to say the last words.' Ntando (P7)

When prompted as to what she thinks her last words would have been she replied:

'I was going to tell them that please guys, take care of my children.' Ntando (P7)

During the event, women not only feared for their own lives, but feared for the lives of and futures of their babies, partners and other family members. The majority of the women interviewed were single parents and the thought of life without them was overwhelming. A few, despite realising their situation, tried their hardest to suppress thoughts of the consequences of their possible death. Lee-~Ann, a single parent with adverse social circumstances thought about who would care for her children and imagined the worse:

'My children, I don't want (to leave) my children, they won't treat my children okay. My children are going to need me. They are still small. What is going to happen? All the time I think about it. Still now I'm thinking, I'm praying God, don't take me away, because of my children, what will happen with them.' Lee-Ann (P8)

Although only 3 of the participants were in stable relationships, they all thought of how their partners would react to their death and how many life experiences they would now not experience.

'Yes, "Please don't take me God". I know you are going to take me God because of the pain I'm feeling now. I don't want to leave my newly husband here. There's still much things we have to do together. There's a whole life ahead of us.' Busi (P2)

Furthermore, some women's perceptions were influenced by preconceived ideas about hospital admissions and certain medical conditions. For example, Ntando was asked what she felt when she saw all the blood on the floor:

'I thought that now, I am going to die now, because I heard that if the placenta wouldn't come out, that person dies.' Ntando (P7)

Sub-theme 2.2 - Loss of control

Women experienced a real sense of loss of control. This included loss of control of their bodies, their choices and even propelled them into a somewhat surreal or trance like state. Many women used words such a "helpless" and "weak' in their descriptions.

Two of the women experienced a type of out of body experience with feelings of disconnections from their own bodies. Lindiwe commented:

“That moment of losing the blood, when they were like, we’re going to give you blood, I could feel I was gone… I was no longer in my body, because I couldn't see or do anything.’ Lindiwe (P4)

Felicity, who had a massive PPH explained her sense of disconnection from the world and detachment from her body:

‘I... for me, it was like I was here, but I wasn’t really here… I felt like zoned out…It’s like everybody, I was there, I was awake, but everybody was talking, and I didn't really, anything didn't really register with me. I just heard like people talking and stuff like that… I was aware that everybody was there, but I didn't feel really like I was there.’ Felicity (P11)

Sub-theme 2.3 - Urgency

Obstetric emergencies strike with urgency, compelling medical staff to respond quickly. This often resulted in the women taking a passive role and becoming observers to their own events. Lee-Ann awakened after her caesarean section for morbidly adherent placentae with a flurry of health care workers around her. They were preparing her to go back to theatre for an emergency hysterectomy because of a PPH.

‘They were busy, busy with me, trying to stop the bleeding…So they told, the one doctor said we must open you again to take out your womb… I must go in for operation again, it’s going to be a long one… I didn't know what to think. I was so… I don't know what’s happening around me. I'm alone there.’ Lee-Ann (P8)

Sub-theme 2.4 - Information

Some of the participants expressed the impact of the lack of information passed onto them from health care workers in the antenatal period, during the acute event and in the period after. The lack of information led to a great sense of frustration for the women as they were led into a state of confusion and started believing what they had been told by friends and family members. Some only learnt about their diagnosis from the PI during the interview. Surprisingly, some of the women who had a hysterectomy did not know this and furthermore were shocked at the fact that they would no longer be able to carry a pregnancy.

Ntando, who had a subtotal hysterectomy after a retained placenta and PPH associated the inability to remove a placenta with demise:

'I have heard that if the placenta didn't come out, the placenta, I don't know which pipes closes, and then you stop breathing and then you die.' Ntando (P7)

Ntando further went on to mention that she had been informed that a 'piece' of her uterus has been removed, and she was interested to find out if she could still conceive:

'So I am still asking myself that can I have a chance again to have children because of that piece they cut, or I'm not going to have other kids, because that doctor said there is a womb inside you. Even now, you can go and do a pap smear, like everybody else, because your womb is there. They just take a piece, I don't know which piece. Maybe that placenta was

stuck in that piece they cut, or that piece was damaged, because they were trying to catch it with hands. I don't know…. I still say to myself, maybe I can have the children, maybe I don't have the children. I don't know where must I go and ask? I don't know who has got that information.' Ntando (P7)

Jolene, who has a hysterectomy following a placentae praevia with MAP still did not understand why her uterus was removed or what a praevia was:

'Why remove my womb? I said to myself, where is that placenta stuck? Yoh, I'm still asking myself, where, how? How it happened.' Jolene (P9)

This theme impacted largely on other themes including guilt and self-blame, loss of consciousness and confusion and health care providers.

Not being provided with adequate information regarding the location or status of their newborn babies was a source of anxiety and frustration. This also tied into the sub-themes of health care workers and the emotion of anger.

Lee-Ann described how no one knew where her baby was which made her angry and anxious:

'So I said sister, where is my baby?...She tried to find my baby, she doesn't know where's my baby…. I think she was dead. I cried, everything…. I was stressed out. I was angry, because I want my baby.' Lee-Ann (P8)

Lwazi, who had an abruptio placentae with an IUD only learnt of the demise of her baby 2 days after delivery. She assumed that the baby was in NICU and when she was stronger, she would go to visit:

'I was like telling myself no, my baby is still alive, and then I'm going to, maybe after a few days, I'm going to see my baby maybe in the machines, because I think the baby is premature.' Lwazi (P10)

Sub-theme 2.5 - Health care workers

Women's perceptions of health care workers were varied. Some participants expressed anger towards health care workers covered in the sub-theme anger. A minority of women interviewed relayed that some of the staff did not express appropriate empathetic care towards them. This mainly included nursing staff and cleaners. However, most of the women felt that they were treated sympathetically and with care.

Felicity, who had an abruptio placentae and PPH felt that she was not treated with care by health care workers:

'Well, it was, for me it was very traumatic. I personally feel that the way the staff handled it, they could have handled it better, I mean for me, from a psychological point of view. I think I was out for most of the time. I think only on the third day I actually realised what was happening. They were very blunt.' Felicity (P11)

Her condition prompted her to research her condition during her subsequent pregnancy in an attempt to gain further insight:

'I'm also thinking now for this pregnancy also, I'm not sure if something will happen now again with all the bleeding and stuff, because um, I did read a couple of articles. I didn't realise it, but women do actually die from losing a lot of blood during pregnancy and during labour. I wasn't aware of it before. So it is quite serious, I think.' Jolene (P11)

Theme 3: Support

During their event, the women received support from various sources including partners, immediate and extended family, friends, doctors, nurses, social workers and counsellors.

Sub-theme 3.1 - Religion and Spirituality

All but one of the women used religion and spirituality to transcend beyond the difficult situation they found themselves in. The women felt that prayer was beneficial in helping them cope with the acute event and most ascribe their survival to religious beliefs and prayer.

After the nurses at the MOU were unable to locate the fetal heart while she was experiencing abruptio placentae with IUD, Anathi started to pray that her baby was still alive:

'I seriously don't know what I was thinking at that moment, but at that moment, I was praying please God, don't let this be true, don't let what the nurse was saying be true. Just let the

baby live, just let my baby live. That was all that was going through my mind at that moment.' Anathi (P3)

Lindiwe turned to prayer during her acute event of an APH due to a placentae praevia:

'Like in my situation, I've never been angry to God, and I told him, I know I'm in a very big problem, but you are the only one that can make me out of here… He is the only one that can rescue me [sniffs].' Lindiwe (P4)

Ntando was probed as to the content of her prayer while she was experiencing a haemorrhage from a PPH with a retained placentae:

'I felt that, I prayed inside, yes, a lot. Please, help me, help the doctors to take out this placenta, so that I can go out of the hospital and see my child.' Ntando (P7)

Sub-theme 3.2 - Family

Only Phumla had absolutely no support from family or a partner. Busi, in a state of complete self-blame, was overwhelmed by the support of her partner, her family and extended family who were at her bedside when she experienced an abruptio placentae with IUD:

‘My mind was still… I was not thinking anything. Yes, I was just shocked. Why are they here? Why are they so caring about me? Why? Because it’s like I am the reason, yet they are so supportive.’ Busi (P2)

Felicity was overcome with emotion when she described the overwhelming support from her family:

‘My whole family was here. That was quite a big support for me.’ Felicity (P11)

Theme 4: Emotions

The most dominant emotions experienced were blame, anger, guilt, fear and gratitude.

Sub-theme 4.1 - Blame

Following the acute event, when the women had an opportunity to ruminate over what had happened, many questioned why this had happened to them. Some women viewed the event as a form of punishment and blamed themselves for wrongdoing in the pregnancy or before. Others blamed doctors or other health care workers as they felt that their situations were avoidable and as a result of sub-standard care.

Phumla was overcome with emotion when she expressed how she felt about the staff at the referring hospital. She felt that she was forced into a caesarean delivery, after which she had

a PPH requiring relook laparotomies with multiple surgical complications. She blamed them for being the cause of her event and the turmoil for which she suffered during recovery.

Busi, who lost her baby due to abruptio placentae, expressed blame towards the medical staff involved in her antenatal care. She blamed them for not picking up the complication earlier:

'I asked myself… I did go to day hospital… in my 6th months of pregnancy. They said everything was fine. It was the starting of the time where I could smell blood, where I could feel blood in my throat. They checked baby with the scan and said everything was fine and I can go and we cannot see the baby's gender. Why didn't they pick up anything then? Why the nurse, I was at the clinic on Thursday and then I lost the baby on Saturday. Why?' Busi (P2)

Sub-theme 4.2 - Anger

Anger was not expressed by all participants. For those that did, the anger was varied and directed at health care workers, partners, towards their spiritual beliefs and their own bodies. Anger towards their own bodies' ties in with the sub-theme of guilt, expressed as self-blame, and is discussed later.

Anathi, who had an IUD from and abruptio placentae, explained how she felt anger towards God for allowing her to lose her baby and suffer severe morbidity. However, despite the emotions of anger, she later described how her spirituality helped her survive the event and heal in the aftermath.

‘I lashed out at God at first. I said a lot of things to him… I sweared at him. I asked Him where are you? You always say you are with us. Why did you let this happen?... I sweared at him. I really said some hectic shit. My mother said I must never say those things again. I seriously felt that God had abandoned. Like I was one of his sheeps that he had not taken care of. My mother said that sometimes God takes something, but he might give you something better. So there might be something better.’ Anathi (P3)

Phumla, had feelings of anger towards her partner. She spent 2 weeks in ICU and high care after a massive PPH following a caesarean. She felt abandoned and angry at his lack of support and un-empathetic actions. He only visited her once in ICU, then ended all contact. He also refused to care for the baby while she was too weak to care for her newborn at TBH. Furthermore, he left her with thousands of Rands of store card debt that she is still paying off 2 years later:

‘He did come once, just for my baby, and after that, he never came…Yes, so I was struggling, I was on my bed, calling him up until I went to hospital for my child. And then even then, he never go there for me.’ Phumla (P1)

Women expressed anger towards health care practitioners for various reasons. Mostly this was a perceived failure to perform successful procedures such as the cases of Nandipha (P6) and Akhona (P7) who had retained placentas. Phumla (P1) attributed all of her complications to the medical practitioner who decided that she needed a CS. She expressed anger as she felt that that was the root of her later suffering. As described earlier, Busi expressed anger

towards the health care professionals at the MOU for not picking up that something was wrong before she had and abruptio placentae with an IUD.

Sub-theme 4.3 - Fear

Women reported feeling a sense of fear for the lives of their babies and fear for their own lives. The fear of losing their babies seemed to supersede that of the fear of their own death. The sub-theme of fear was a common one, that was linked to the other subthemes of “sight of own blood”, “loss of control”, “near death” and “information”.

Sub-theme 4.4 - Guilt

Guilt was most commonly linked to self-blame. Women felt guilty for falling pregnant, not terminating their pregnancies when advised to, over working, neglecting their health and ignoring advice of medical practitioners.

Nandipha, a poorly controlled diabetic blamed herself for having a baby with anencephaly. The birth was complicated by a retained placenta and PPH:

‘…because I looked at that baby, and then I saw yoh, why is God did that to me? I asked myself that, why God did you do that to me? But I... and then I know, and before they gave me counselling and then they told me, because you are diabetic... I know, because I didn't take care of myself when I was pregnant. I didn't take my medication. I was eating a lot of sugar.’ Nandipha (P5)

Felicity blamed her poor choices in her pregnancy for her abruption placentae, PPH and IUD:

'I felt guilty because um, I remember, I think two weeks before the incident happened, um, I was at the clinic, at the MOU, and then my blood pressure was high and there was protein in my urine. I wasn't um, I wasn't educated about those types of things, so I didn't really think it was serious, and also at the time I was also smoking in that pregnancy. So I thought okay, maybe that is the reason I didn't take note of it, and I was smoking maybe too much. Ja, that was, I just really felt that it was my fault and that is what I deserved.' Felicity (P11)

Busi felt overwhelming self-blame for her abruptio placentae with an IUD:

I was disappointed in myself. Disappointed with my whole body. WHY is this happening? Why is my body doing this to me? Busi P2

Sub-theme 4.5 - Hope

Many women derived hope and motivation from the thought of being with their newborn baby. Lee-Ann (P8) described how the knowledge that her baby was a few stories above her was the driving force to get up and out of bed despite severe weakness after a massive PPH:

'So the doctor came, they told me no, your baby is upstairs there, so I said I want to go to her. They said no, you can't go now, you're too tired, you're too weak. We are taking care of her on third floor, you're on second floor. So I tried to stand up, I forced myself up, and go to her.

I went on my own way to her, and I did find her…At first I crawled to the lift, and after I lift, lift, lift, lift, a little bit, a little bit, till I'm straight again, so that I can walk, but slowly, slowly. But I went to her every two, three hours, to go and feed her.' Lee-Ann (P8)

In a similar vein, some mothers felt more motivated when they were given frequent updates on their babies and ultimately were allowed to care for their babies in their high care bed.

Sub-theme 4.6 - Isolation

Some of the women described feelings of isolation and loneliness mostly in ICU and high care. Furthermore, many were separated from their newborn babies as they were too critical to care for them. One participant with particularly poor social circumstances felt isolated from the world and described being "helpless" as she was abandoned by her partner and had no visitors. What was particularly frustrating for her was being unable to move or speak while she was being ventilated and worrying about her children surviving on their own at home.

Sub-theme 4.7 - Gratitude

The women expressed gratitude for their own survival, their baby's survival or both. Others expressed gratitude for the medical staff and management, their families and God.

Ntando described the gratitude for being alive and having her baby:

‘It made me stronger when I see my baby running around the streets, calling me mommy, because now she is...I am grateful that I survived.’ Ntando (P7)

Some of the women used expressions like “second chance” and a “favour from God” when describing the gratitude, they felt for surviving their event.

6. DISCUSSION

The aim of this study was to describe the experiences and perceptions of women who survived major obstetric haemorrhage. Emphasis was placed on experiencing the event including the reaction to the event, the physical experience, interpretation of the situation and emotions, and the aftermath. This deeper understanding of how the women experience a major obstetric haemorrhage is valuable as it can enlighten health care workers and possibly act as a platform to improve patient care during and after SAMM. It is clear that traumatic reactions to childbirth are an important but poorly addressed public health issue. This was also emphasised by Olde et al in a literature review of PTSD following traumatic delivery (35).

6.1 Physical experience

The findings of this study reveal that women feared for their lives while experiencing a major obstetric haemorrhage. The fear was largely prompted by the physical experiences resulting from severe morbidity. These included the visual image of their own blood, severe physical pain and discomfort and severe weakness. This was augmented by the associated loss of consciousness and confusion. Souza narrated the experiences of 30 women who survived SAMM (6). His study produced similar findings in relation to the physical experiences of SAMM in that he found that the experience of SAMM is intense, leads to a sensation that death is imminent and is one of the most significant aspects of the entire experience. Souza also found that the imminence of death was reinforced by physical pain and dyspnoea. Elmir et al, who conducted a qualitative study to describe women's experiences of having an emergency hysterectomy following a severe post-partum hysterectomy similarly found that

bleeding and the sight of blood further enforced the imminence of death for the women experiencing SAMM (36).

The women in the study described how they were overcome with severe weakness. Findings from De La Cruz (in a doctoral dissertation) (37) and Elmir et al (36) demonstrated that prolonged exhaustion and fatigue often forced the women to hand over care of their new born babies to family members or health care workers. This often hindered the women's opportunity to establish breast feeding, bond with or develop a close relationship with their babies and often created a sense of failure as a mother. This is in contrast to the findings from the Tygerberg study as most of the women who survived with live babies expressed the "special bond" that had been formed, often more so than with their other children.

6.2 Perceptions

As described by Elmir et al, the depth of a woman's despair was related to their perception that they were close to death (8). Souza et al studied the experiences of women who survived a "near miss" during their pregnancy and childbirth (6). The findings included that women experienced the imminence of death, fear, frustration and grief during the event. In the study by Souza et al, extreme pain and dyspnoea led the women to believe that death was imminent (6). Near death experiences have been described by Greyson (38) and Simpson (39) as a subjective event that may involve individuals dissociating from their body and demonstrating an increased awareness of their spiritual or religious beliefs.

In keeping with the findings of this study, the theme of loss of control was also strongly expressed in the study by Kidner et al (40). They identified three sources of feelings of loss of control: over one's own body, over medical decisions, and over a life event. The sense of 'not being able to influence what happened' or having 'no choice' with regards to medical decisions often evoked feelings of powerlessness as documented by Elmir et al (8) and Snowdon et al (41). These findings were echoed in the current study. Souza et al further described this element of powerlessness by an impression of a 'Superior Being who has control over the process… in which the health care service operates' (6).

6.3 Support

The participants in this study all commented on the valuable support they received, and those that did not noted how it would have benefitted them during their experience. Sources of support included husbands, partners, immediate family, extended family, doctors, nurses, social workers and counsellors. Wereszczak et al found that support acted as a valuable resource and a lack thereof resulted in personal distress (42). Disruptions in support were experienced as stressors which were similar findings to the current study. In contrast, however, Leichtentritt et al found that sources of support were an asset for some, but a burden for others. Support was an important aspect and hence a major theme in this study (43). Dunning and co-workers in a similar study found that the birth partners required more information, especially if separated from their partner during the acute event (44).

Souza et al noted that women who found themselves in a critical health crisis turned to their religious and spiritual beliefs to help them (6). The findings in this study were similar in that

most of the women derived comfort from their faith and spirituality and used it as a mechanism to stay grounded when they realised the gravity of their situation. The concept of coming close to death and then experiencing a "spiritual awakening" was described by van Lommel et al (11) and Wilde and Murray (10). Blackmore concluded that people develop strong religious beliefs following a close encounter with death in an attempt to reduce the fear of dying and death which was a similar finding to the current study (9).

6.4 Emotions

In this study, the sub-theme of guilt was mostly linked to feelings of self-blame. This was also noted in Carvalheira et al who found that the women often associated the experience of maternal morbidity with their mistakes during their pregnancy (45). Similarly, Elmir et al commented on the ruminative thoughts that women experienced asking themselves "why? and "why me?" (36). The findings in this study were also supported by those by Souza et al who found that women had a belief that the complication was a result of their own behaviours, blaming themselves and regarding the event as a form of punishment (6). Occasionally, this aroused a sense of unfairness or injustice.

Leichtentritt et al found that anger could be attributed to hospitalisation and the loss of normal life (43). However, in this study, anger was directed towards health care workers, partners, religious beliefs and their own bodies. Kidner et al had a similar finding with regards to anger towards medical practitioners and their own bodies (40).

The findings of this study reveal that women feared for their lives and hence fear was a common emotion experienced. Ryding et al noted that fear was a dominant feeling expressed by women in relation to the possibility of impending death, or serious injury as a result of having a caesarean section (7). Nilsson et al found that feelings of fear and death can be compounded by unrealistic ideal expectations of a perfect birth (46).

Loneliness and isolation is a painful experience for patients. Leichtentritt et al found that loneliness was a common experience in hospitalised patients (43). Karhe et al looked at the different dimensions of loneliness in hospital (47). One of the concepts was loneliness in association with health care providers. This was expressed as a sense of not being seen, not being heard and not having their needs met. Lack of time for patients and task-orientated treatment also compounded feelings of loneliness and isolation.

Gratitude is an emotion not often associated with high risk pregnancies. Even in the study by Kidner et al where participants were probed as to positive aspects of their experiences, they either did not elicit it or failed to include it in their report (40). In this study and in keeping with findings by Souza et al, most women viewed their life in a different way, appreciated life more than before and were grateful for their survival (6). Furuta et al noted that most women placed less value on material things and gave more value to spiritual or religious beliefs, family and people who were truly fond of them (48). This aspect of gratitude was not seen in this study.

As highlighted by Fallowfield (14), receiving “bad news” can be distressing for the women, particularly if it involves life changing consequences.

Fear for the lives of their babies and their own lives was a theme that was expressed by most of the women. This was a similar finding in studies by Kidner et al (40), Mapp et al (13), Souza et al (6) and Elmir et al (36). Research indicates that fear during birth does occur, but the fear is usually related to dying (47). Power et al reported that the intensity of fear was influenced by a woman's interpretation of the event and the impending danger (49). Souza et al reported that fear was the driving force behind the sensation of impending death with the combination of fear and feeling near to death constituting a vicious circle (6).

6.5 Recommendations

The experience of SAMM encompasses physical, emotional, social and spiritual challenges. The findings of this study indicate that a more integrated approach to the management of a woman experiencing SAMM would be beneficial. The implementation of a "care package" for women who experience SAMM could possibly reduce the burden of the complications. We propose that a designated health care practitioner be allocated. Their role would be as a liaison between the women, her family and the medical team, creating a much-needed communication bridge. This health care practitioner will be available to answer questions and co-ordinate any other social or psychological interventions. Added to this, psychological and spiritual support should be available. Detailed debriefing sessions, both pre and post-discharge, would be able to provide containment measures in the acute phase and assess coping mechanisms, recovery progress and social support in the aftermath of SAMM. This information is important to ensure that future care of women with severe morbidity includes a mental health component, with appropriate referral for psychologic counselling and long term follow up.

7. STRENGTHS AND LIMITATIONS

This study had a number of strengths and limitations.

A key strength of this study was the exploration of a relatively unchartered area of research, particularly for South Africa. A systematic review on the emotional sequelae of PPH could only identify 6 studies of sufficient quality to include in a pooled analysis (50). They reported persistent morbidities 3-6 months after PPH that included postnatal depression (13 %), PTSD (3 %), and a health status that was perceived as 'much worse than one year ago' (6 %). Another systematic review and metanalysis, on debriefing interventions for the prevention of psychological trauma in women following childbirth found little evidence for a benefit of psychological debriefing for the prevention of psychological trauma in women following childbirth (51). There are therefore more studies on the subject needed. The use of semi-structured in-depth interviews facilitated the accumulation of data that had depth and richness and can serve as the basis for further studies. The qualitative approach was another strength as it gave a voice to participants and gained insight into the experiences of women who survive SAMM, whose stories are seldom heard.

The study had a few limitations. The accounts were all retrospective and, therefore, subject to the memory of their experiences. Therefore, the possibility of errors in recollection must be considered. The Xhosa and Afrikaans patients were all interviewed in English and, therefore, they had to express themselves in their second language. The richness of the data may have been enhanced by interviews being conducted in the patient's first language;

however, this was beyond the budget and remit of this study. In an attempt to counteract this, all participants had to be comfortable and fluent in English.

Some may view the limited number of participants as a limitation as it can lessen the extent to which the findings can be generalised. This is not an issue for qualitative studies as the aim was not to provide generalisable information, but rather detail an in-depth understanding of an event or phenomenon. Data saturation was already achieved after the 6th interview.

8. AREAS FOR FUTURE RESEARCH

A qualitative study looking at the experiences of the partners and family of women who survive SAMM would provide greater insight and possibly assist in improved overall counselling to patient and partner.

A qualitative study examining how health care workers experience the care of women experiencing “near miss” events.

A qualitative study focusing on the immediate and long-term impact of hysterectomy post a SAMM event in a South African context.

A qualitative study looking at the experiences of women who have infant deaths due to SAMM.

9. CONCLUSION

The findings of this study have shed light on the experiences and perceptions of women who came close to death following a major obstetric haemorrhage. The study described how the women experienced the acute event, their immediate reaction to the event and the aftermath that followed. The value of this is to enlighten health care workers to the nonphysical aspects of experiencing SAMM and aid them in dealing with the mothers in a more empathetic manner. Furthermore, the findings of this study can assist in the development of integrated care that incorporates physical, psychological, social and spiritual aspects and could partially alleviate the devastating burden of SAMM.

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11. APPENDICES

APPENDIX A: Extract of Coded interview

PI: Could you see blood?

MN: No, there was nothing blood, just the smell or the feel of blood in my mouth. Then everything was fine, went to clinic like my normal routine, then I was supposed to give birth at February, then there were contractions. People usually say that there is a Braxton Hicks… yes, I usually felt that and then the pains would come come come and usually disappear. Then they said no, its normal. Your body is just reacting with the pregnancy. Then this day, it was on Saturday. I was with my husband at home. Then the contractions came and then they just became severe, severe. It was not even 10 minutes and then after all he go to call someone to help and then there was a lot of blood that came out… it was A LOT that came out. And then immediately, the baby move up.

2:1 I... Pain, Unexpected

2:2 It wa... Pain, Sense something was wrong

PI: So, in summary, your pregnancy was uneventful, it was going very well…

MN: Very well… cos it was on Saturday, that thing happened on Saturday, on Thursday I was at the clinic for my routine check, then they check me cos there was no scan because I was at the Durbanvill clinic. The nurse put something on my stomach and listen and then the nurse said no its fine, if you haven't given birth until next week then we can just come back. Then it was only Friday, then Saturday this thing happened.

PI: So, everything was going very well, you were happy about the pregnancy?

2:3 PI: S... Excitement about pregnancy

MN: YES! And I was very much excited, because it was our first.

PI: And you had already married?

MN: Yes, we were married at that time.

PI: Then suddenly, on Saturday, you noticed that there was blood pouring out.

2:4 PI: Then... Bleeding

MN: There was so much blood

PI: Can you describe that moment?

MN: I panicked, I really panicked. And I was crying, calling for my husband. Luckily, he was already here at the gate coming in to check on me.

PI: Here at Tygerberg?

MN: No, at home. And then I was busy crying and so nervous, I didn't know what to do or what to say. I didn't know how a pregnant woman is supposed to give birth or what's supposed to happen, what's not supposed to happen. I really didn't know because it was my first pregnancy. I didn't know anything about being pregnant. And then a lot of blood came, and I was sitting on the bed, opening my legs, crying and saying, calling his (husband's) name to come and help me.

2:6 I didn... Lack of empowerment, Lack of understanding

2:8 ... Bleeding

2:7 I didn... Lack of basic health education

2:... Anxiety, Fear

Then immediately the baby moved up and then I couldn't breathe, that was the hardest part. Because the moment the blood came was the moment the baby move up into my stomach.

2:9 ... Pain, Severe discomfort, Unable to breathe

Then there was a woman who came, my neighbor and another woman. Then they came, they took me from bed and put me down and said everything will be fine. Then they tried to call an ambulance, but the blood was not stopping. It was coming out. I don't know how, it was coming very much out, out of nowhere.

2:10 ... Support from friends

2:11 ... Bleeding

I was panicking. I was feeling like when you were running and when you get hot and then then you get tired at the same time and you don't have the power to breathe or do anything.

2:12 ... Lack of power, Unable to breathe, Weakness

Then I was pleading with this woman, "Please give me some air, I need some air". And she was busy giving me air and my body was falling down. I couldn't even stand. Then they said, "no don't push". Because when you on labour they say you are pushing the baby, so they say no don't do that because you are pushing the baby away and the ambulance is still not here. But I would feel that the baby was not going anywhere. And it was the baby that makes me hard to breathe. I can't breathe because the baby is pressing here. Then my body got tired. Then eventually the ambulance came. Then when ambulance came, they took me in ambulance. Then on the way to ambulance there was a lot of blood still coming. Then they put me in ambulance, I got in with my sister in law.

2:13 Then I was pl... Bleeding, Lack of power, Pain, Unable to breathe

Then the nurse there keeps asking how far are you? But I couldn't even answer because I can't breathe. I keep on saying please I need air. I need air, so I can keep breathing. Because if I don't have this air, I cannot breathe.

2:14 ... Unable to breathe

PI: OK, so let's go back to that moment when you started seeing the blood and it became severe and everyone started to come. What was going through your mind at that point? What were your fears and concerns?

MN: My huge fear was for the baby, because I knew something was wrong immediately when the baby came this side. Then I realized maybe there was something wrong. Because before, I've asked my mother before "Where does a baby stay in a woman's' tummy? Is it up or down?" Then she said no the baby is supposed to be down, not up. And now the baby was up, that means there's something wrong. That's the first thing that came into my mind.

2:15 ... Fear, Fear of own body, Sense something was wrong

2:16 Bec... Lack of basic health education, Lack of empowerment, Lack of understanding, Sense something was wrong, Support from family

PI: What did you think was wrong?

MN: I didn't know, but something was wrong. Why the baby must move up. The baby should move down, not up. Because now I'm in labour. I'm confused, why is the baby moving up? I was confused. And in the meantime, I don't have the strength to breathe and I don't have the power now. All of a sudden, those things just happened quickly. Then I got confused. I got confused about the whole thing, but I knew that there was something wrong.

2:17 MN: I did... Lack of basic health education, Lack of empowerment, Lack of understanding

2:18 ... Inability to move, Unable to breathe, Weakness

PI: Did you think that maybe the baby had died?

2:19 PI:... Clinging to last stand of hope, Disbelief, Refusal to accept inevitable

MN: No, I would never of thought that. It was not on my mind. My main problem was thinking why is the baby moving up.

PI: What was it like to see all of that blood on the bed?

APPENDIX B: Participant information sheet and consent form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

Experiences of Women Who Survive Major Obstetric Haemorrhage at Tygerberg Hospital

Participant Number

Principal Investigator: Dr Jason Bennett

Address: Department of Obstetrics and Gynaecology, Tygerberg Hospital

Contact Number: 0824529820

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please feel free to ask myself any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the

international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

This study is being conducted as part of a Masters of Medicine at Stellenbosch University. The study looks at the experiences of women who survive enormous amounts of blood loss at their birth.

Should you agree to participate in this study, I will interview you. The interview will take approximately 1 hour to complete. It will take place at Tygerberg Hospital in a safe, private and comfortable venue.

Several questions will be asked about the birth of your baby and your time in hospital. Your responses will be recorded and later typed up. The researcher will then look at what you have said.

Your name will not appear anywhere

Why have you been invited to participate?

You experienced severe bleeding during your birth and the researcher would like to learn more about your experience while you were in this situation.

What will your responsibilities be?

To provide accurate answers to the questions asked.

Will you benefit from taking part in this research?

There are no direct benefits, however the information you provide will be looked at closely. The findings of this study may help women in similar circumstances as yourself in the future.

Are there in risks involved in your taking part in this research?

There are no direct health risks involved in your participation.

Can I stop being in the study and what are my rights as a participant?

You can choose to not participate in this study. If you agree to participate, but later change your mind, you may exit the study at any time. There are no penalties or consequences if you decide not to participate.

Who will have access to your medical records?

The participants will be assigned a number linked to their hospital folder number. This document will be kept on the researcher's computer and will be password protected. Typed up information from interviews will be kept secret and not discussed openly. No one, except the researcher, will know you participated in this study.

Will you be paid to take part in this study and are there any costs involved?

The researcher will provide an incentive of R250.00. This includes transport costs.

What will happen if the interviews make me very upset when I relive all the memories?

If you feel upset during the interviews, emotional support will be provided.

You will be asked to complete an assessment form that tests you for something called Post Traumatic Stress Disorder. This is something that can occur after a very stressful event such as your experience in hospital. Also, during the interview I will make an assessment of you. If I feel that you have post-traumatic stress disorder, anxiety or depression, I will refer you, with your permission, to the Tygerberg Outpatient Psychology services where you will be assessed by a professional psychologist.

Is there anything else that you should know or do?

You can contact Dr Jason Bennett at cell: 0824529820 if you have any further queries or encounter any problems. You will receive a copy of this information and consent form for your own records.

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor" and that "The Health Research Ethics Committee may inspect the study documents at any time".

Declaration by participant

By signing below, I …….. agree to take part in a research study entitled Perceptions and Experiences of Women Surviving Major Obstetric Haemorrhage in the Metro East

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

I agree that the interviews can be recorded.

Signed at (place) ..... on (date) …….. 2017.

Signature of participant Signature of witness

Declaration by investigator

I (name) …… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (If a interpreter is used then the interpreter must sign the declaration below.

Signed at (place) ..... on (date) …….. 2017.

Signature of investigator Signature of witness

APPENDIX C: ETHICS LETTER

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Approval Notice
Response to Modifications- (New Application)

31-Mar-2017
Bennett, Jason JG

Ethics Reference #: S16/10/215
Title: Experiences of women who survive major obstetric haemorrhage at Tygerberg Hospital

Dear Dr Jason Bennett,

The **Response to Modifications** - ***(New Application)*** received on **15-Mar-2017**, was reviewed by members of **Health Research Ethics Committee 2** via Expedited review procedures on **31-Mar-2017** and was approved.
Please note the following information about your approved research protocol:

Protocol Approval Period: **31-Mar-2017 -30-Mar-2018**

Please remember to use your **protocol number** (**S16/10/215**) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:
Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.
Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics

approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.
For standard HREC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further assistance, please contact the HREC office at .

Included Documents:
20170315 Mods Req - Protocol
CVs of investigators.pdf
Informed consent.pdf
Application form.pdf
Full protocol.pdf
Checklist.pdf
Investigator declaration forms.pdf
20170315 Mods Req - Letter
Synopsis.pdf
20170315 Mods Req - Application Form

Sincerely,

Francis Masiye
HREC Coordinator
Health Research Ethics Committee 2

APPENDIX D: BUDGET

Incentive/Transport (R250 per participant)	R5,000.00
Qualitative Research Course	R3,000.00
Photocopies and paper	R250.00
Printing and binding	R250.00
Stationery	R200.00
Recording device (iPhone App-VoicerecorderHD)	R200.00
Transcription services	R3,000.00
Atlas.ti Licence (USD exchange rate dependent)	R1,400.00
Total	**R13,300.00**

All administrative cost was covered by the PI working within the department of Obstetrics and Gynaecology. The Department of Obstetrics and Gynaecology has covered the cost of the Qualitative Research Course.