

# Women's Experiences following Emergency Peripartum Hysterectomy at St. Francis Hospital Nsambya. A Qualitative study.

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## Research article

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# Abstract

**Background** Women who undergo emergency peripartum hysterectomy (EPH) are at greater risk of experiencing severe negative psychosocial sequelae. However at St. Francis Hospital Nsambya and much of Sub-Saharan Africa, these women are not routinely followed up to explore these experiences. This study sought to explore women's experiences and coping strategies following EPH St. Francis Hospital Nsambya, Kampala, Uganda.

**Methods** This qualitative study was based on in-depth interviews of women who had undergone EPH at St. Francis Hospital Nsambya EPH between January 2015 to August 2018. Out of 66 women who had undergone EPH during this period, 18 were purposively selected and interviewed between August to December 2018. All the information obtained was audio-recorded, transcribed and then analyzed in three phases of pre-analysis of intense reading, exploration and comparison and then interpretation.

**Results** These women disclosed feelings of loss of womanhood, Uncertainty about the future, Joy for being Alive, and professional abandonment. Their coping strategies were living in denial, believing in God and acceptance.

**Conclusion** Women experience severe negative psychosocial sequelae following EPH therefore routine ongoing psychotherapy should be offered to these women until full acceptance is achieved.

## Background

Globally severe postpartum haemorrhage (PPH) still remains the leading cause of maternal morbidity and mortality accounting for about 25-28% of all maternal deaths (1-3). Emergency peripartum hysterectomy (EPH) is the surgical removal of the uterus within 24 hours of delivery in order to control haemorrhage after failure of conservative means the sole purpose of saving the woman's life (4) (5, 6). However EPH can induce pronounced emotional responses, such as anxiety, depression, denial, anger, marital disruption, and a sense of loss and inadequacy (7-9). These feelings are contrary to the ones of joy and gratitude which the women had hoped to experience following the birth of their children (10). In sub-Saharan Africa 1 in 200 women will lose their uterus through EPH due to severe PPH compared to the developed world of 1 in 1000 women (11-13). This is mainly due to lack of skilled attendance at birth, multiparity, prolonged and obstructed labour (14, 15). At St. Francis Hospital Nsambya, much as EPH is done, these women are not routinely followed up to explore their psychosocial wellbeing once they have been discharged home. The purpose of this study was to explore women's experiences and coping strategies following emergency peripartum hysterectomy at St. Francis Hospital Nsambya, Kampala, Uganda.

## Methods

### Design

This was a qualitative phenomenological study (16-19) done in the obstetrics and gynecology department of St. Francis hospital Nsambya, a Catholic founded, 114 year old, 361 bed capacity private not for profit (PNFP) hospital located in Makindye Division, 3.6 km from Kampala city centre in Uganda.

### Participants

All women who had undergone EPH between January 2015 to August 2018, stay within 100km radius of the hospital, were willing to be tape recorded and able to facilitate their transport to the hospital for the interview were eligible to participate in the study.

### Sampling

Purposively sampling was employed. Each participant was selected based on the specific experience intended to be obtained and they included prime para, multipara, catholic, moslem, married, single, those who were recently operated (6weeks-

6months) intermediate (1 year-2 years) and those who had spent more than three years following the hysterectomy. All women who had undergone EPH during the four year period of the study were identified from the theater records book and given participant numbers to mask their identity. Those selected were using the available telephone contacts provided. During this call each was explained to the purpose of the study and its significance to the management of their issues. A verbal consent and a tentative time and date for the interview were agreed upon with those who were willingness to participate one week prior to the presumed interview date. This was done in order to give the would be participants time reflect and make the necessary consultations. 24 hours before the agreed interview date a follow-up call was made to confirm their participation. On the day of the interview the participants were received by a member of the study team and led to a private room within the hospital away from the labour wards in order to minimize flash backs and bad memories. Before starting the interview a formal written consent was obtained both for the interview and to be audio-recorded. Each interview lasted between 45 minutes to one hour and was conducted by two trained research assistants. Out of 66 women who had undergone EPH during this period, those who were contacted after fulfilling the eligibility criteria were 30. 22 women verbally consented to be interviewed and saturation was reached after 18 interviews. The four remaining participants were called and informed about the saturation and were assured that the findings would still be shared with them. The interviews were all audio-recorded and notes were also taken to capture the non verbal communication.

## **Interviews**

Prior to the interviews, an interview guide was developed and approved by a social scientist specialized in phenomenology. The interview guide was piloted with women who had undergone traumatic deliveries and their comments enabled the guide to be improved. The guide included a section on demographic characteristics and a section regarding women's experiences and coping strategies. Open ended questions like tell us about your experiences following the EPH were included. This interview guide can be viewed on the section of additional file 1, titled "Interview guide for women who had undergone EPH".

## **Data analysis**

Latent content analysis was used. All the interviews were transcribed verbatim and the transcripts were analyzed in three phases: pre-analysis, exploration and interpretation (20). In the pre-analysis phase the first five transcripts and audio-records were independently read and listened to by the three authors. Subsequently as a group they discussed their findings and agreed on meaning units and codes that would be used for the subsequent interviews. The exploration phase involved generating categories based on the information already obtained and relevant literature. In the interpretative phase all these information was used to generate themes in line with the objectives of the study.

## **Ethical considerations**

Full ethical approval was granted by the Research and Ethics Committee of St. Francis Hospital Nsambya (REC No: UG-REC-020). Each participant signed an informed consent and the transcripts were allocated pseudonyms to keep the identities of each participant confidential.

## **Results**

### **Table 1. Socio-demographic Characteristics**

Participant No.	Age group (Yrs)	Parity	Delivery Mode	Indication for EPH	Education level	Occupation	Religion	Marital status	Living children
1	25-30	2	SVD	Uterine atony	Degree	Sales manager	Moslem	Married	2
2	30-35	3	C/S	Uterine atony	Degree	Business lady	Catholic	Married	3
3	30-35	3	C/S	Placenta accrete	Diploma	House wife	Catholic	Married	3
4	30-35	4	C/S	Abruption placenta	Degree	Police officer	Protestant	Married	4
5	25-30	3	SVD	Cervical tear	Degree	House wife	Protestant	Married	2
6	45-50	10	C/S	Ruptured uterus	Primary	Business lady	Protestant	Widowed	8
7	30-35	1	C/S	Uterine atony	Diploma	Teacher	Catholic	Widowed	1
8	35-40	6	C/S	Placenta previa	Secondary	Business lady	Born again	Married	5
9	20-25	2	C/S	Uterine Atony	Secondary	Business lady	Catholic	Married	2
10	35-40	5	C/S	Placenta Previa	Secondary	House wife	Catholic	Married	4
11	25-30	3	C/S	Ruptured uterus	Secondary	Business lady	Moslem	Separated	2
12	30-35	3	C/S	Uterine atony	Degree	Banker	Catholic	separated	3
13	35-40	4	SVD	Ruptured uterus	Degree	Business lady	Catholic	Married	3
14	35-40	4	C/S	Ruptured uterus	Diploma	House wife	Catholic	Married	3
15	35-40	3	C/S	Placenta accrete	Secondary	Housewife	Protestant	Married	3
16	35-40	3	C/S	Uterine Atony	Degree	Teacher	Catholic	Married	3
17	35-40	6	C/S	Uterine Atony	Secondary	Business lady	Born again	Separated	6
18	40-45	3	C/S	Uterine Atony	Degree	Business lady	Catholic	Married	3

18 women were interviewed. The average age at the time of the hysterectomy was 34 years, nearly all the women except one were multiparous and all had a minimum of secondary education. Caesarian section was the commonest mode of delivery with uterine atony being the number one indication for EPH. All the women except two were married and gainfully employed. 15 out of the 18 women ethnic Baganda and Christians. The average time after the hysterectomy was two years.

## WOMEN'S EXPERIENCES FOLLOWING EPH

Four major themes emerged on women's experiences following EPH. They were **loss of womanhood, Joy for being alive, Uncertainty about the future and An over-whelming need for emotional support.**

### LOSS OF WOMANHOOD

To most women being a woman means having a uterus, getting monthly periods and being able to bear children, if she could not achieve these three basic things, it meant loss your womanliness. Most expressed sadness, emptiness, incompleteness and a sense of loss.

*"I felt sad, lost and empty...I wanted five children of my own but I only have two, Its like being a woman has now lost meaning..." Participant No.2.*

*"I am an only child, I wanted to have a big family of my own that's why I decided to start producing at an early age, now look at what has happened hmmm, i can no longer achieve my goal so being a woman is now meaningless"Participant No.1*

These women also experienced loss feminine attributes such as stamina in bed and attractiveness.

*"Ever since the operation I feel less attractive to my husband and I have lost all my confidence in bed" Participant No.7*

*"After my first operation I was determined to push the next baby. The doctors said my bones would not allow but I insisted. I wanted to be like other real women...unfortunately I got complications which has led to me losing my uterus, now I feel less of a woman". Participant No.9.*

### JOY FOR BEING ALIVE

Not all the women experienced sadness, hopeless or worthless, quite a number said they felt a sense of pleasure, gratefulness and delight for being alive. They believed life was more important than the uterus.

*"Me I knew I was dead because by the time they took me to theatre i was no longer understanding anything... being alive is a miracle to me, am so happy to God and the doctors for saving my life" Participant No.13*

*"I was giving birth to my tenth child, so loosing the uterus was not an issue to me, in any case am happy because it has saved me from having more children" Participant No.6*

Some felt God had given them a second chance to live again and for that they were grateful. They said they now have the time to focus on their children and other important things in their lives instead of looking for more children.

*"Initially I was very depressed, stopped working and kept away from people. One day my good friend came to visit me and told me to count myself lucky for being alive because two of her other friends didn't make it even after their uterus were*

*removed...from that day forward my life changed, I now appreciate life more than before and thank God for saving it... Participant No.3.*

## UNCERTAINTY ABOUT THE FUTURE

Questions like so what will happen to me as time goes on? Is my life span reduced? Am I at risk of cancer? These and other questions kept being repeated through out the interview processes. Most of the women looked worried and less sure about their future.

*"I have heard people say when your uterus is removed, you will die early...now am so worried for my life, what exactly happens after such an operation? Participant No.2.*

Fear, anxiety and worry were very common among these women, they reported getting nightmares about the future.

*"Whenever I remember how I nearly died that day, my heart starts beating very fast and I start sweating. These things make me worry so much about the future" Participant No.1.*

## PROFESIONAL ABANDONMENT

After living the hospital, a number of women felt abandoned, not valued and not adequately supported by the hospital. They said after going through such a dreadful event, they expected close follow-up, counseling, empathy and even home visits.

*"Do you people really have hearts? After four years of being abandoned now you want us to talk (she looked angry), I nearly died in that hospital and on top of that I was neglected after the operation, you people had better improve..." Participant No.10.*

*"Frankly speaking, I felt emotionally unsupported, there was so much going on, at least I needed some one to talk to from the hospital since I lost my uterus from here" Participant No.14.*

## WOMEN'S COPING STRATEGIES FOLLOWING EPH

### LIVING IN DENIAL

Losing a uterus is considered untenable and unimaginable so to be able to cope with this catastrophe most of the women said they had to suppress their emotions, live in denial, isolate themselves and pretend that everything was fine.

*"I thought the doctors were joking when they told me they have failed to stop the bleeding so the only solution was to remove the uterus, I never imagined myself being without a uterus so I guess am still in denial" Participant No.4.*

*"Not telling people is the only thing that has kept me going, even my husband is not aware, since I was the one who signed the papers" Participant No.14.*

*"Deep inside me I was hurting, I wanted to cry until all the tears were over but I kept on pretending that every thing was ok, I didn't want to appear weak and feminine" Participant No.1.*

# BELIEVING IN GOD

He knows why everything happened, he created me and gave me the uterus, I have faith in him and I know he has spared me for a reason. These were some of the common expressions from some women especially those who were strong believers. They believed nothing could happen without God's plan. So it is useless to blame people or the doctors, it is God alone who gives and takes.

*"Without God nothing is possible, he is the alpha and omega of every thing so I know it was his plan, I cannot complain, how about those who were born without a uterus or those completely infertile, me I have my three children so am fine with it"* Participant No.13.

*"Miracles happen, Virgin Mary gave birth without a husband, so am also waiting for my miracle so that I can have my three remaining children. Next year (2019) am planning to go to Rome and pray at St. Peter's Basilica together with the Pope and after that you will see"* Participant No.7.

*"Am grateful to God for sparing my life, I have heard others died following these operation, so I believe it was Gods plan to save my life for the sake of my children. Participant No.8.*

# ACCEPTANCE

Whether you cry, blame, hide or deny it, what has happened has happened and there was nothing they could do about it. The only thing left to do was to accept it and move on with life. These were mainly women who described themselves as realists, they didn't want to pretend or have hope that a miracle would happen so it was better to accept it.

*"I watched a TV program and the pastor said that the uterus can grow back and you can have as many children as you want so I kept on waiting and waiting, but nothing happened I had to accept it"* Participant No.15

*"I knew from antenatal care that the placenta was lying low so the doctors told me during the operation if bleeding does not stop my uterus will have to be removed so by the time I went to theatre I had accepted my fate"* Participant No.10.

# Discussion

The study found that emergency peripartum hysterectomy causes severe psychological morbidity. Most of the women experienced loss of womanhood, uncertainty about the future, joy for being alive and professional abandonment. To most women being a woman means having a uterus, getting monthly periods and being able to bear children. Majority of the women demonstrated lack of knowledge about the consequences of hysterectomy and therefore could no longer predict the future however not all was lost for all women as some felt a sense of pleasure, gratefulness and delight for being alive. These ones believed life was more important than the uterus.

De la Cruz et al 2013 found numbness, loss of pleasure, hopelessness and uncertainty about the future was a very common occurrence among women who have undergone hysterectomy. This study also found uncertainty about the future as one of its themes. Uncertainty arises because most women didn't know what would happen to them after hysterectomy.

The fundamental desire of every human being is to be happy (21). In this context of hysterectomy, happiness arose as a result of surviving death. Most women reported that much as they regret the loss of their uterus, deep inside they feel joy because of being alive. Hannus, 2017 found that surviving death following emergency hysterectomy meant joy and happiness for being alive. Noel et al 2008 also found that women felt joy after surviving death because they said they had not yet said bye-bye properly to their families so being alive was such a pleasurable feeling.

The study found living in denial to be the most important coping strategy employed by the women. This strategy was for the purpose of appearing strong especially to their loved ones (children and husband) so as not to cause additional worry or suffering to them. This process according to Morse (2001) is called enduring. When people are enduring, they only want to focus on the present so that they can function properly, they block out these emotions because looking backwards is too overwhelming to them. The advantage of this coping mechanism is that there is no emotional investment, no opening up to people and being affected by the pain and suffering of losing a uterus. The disadvantage of this mechanism is that you risk becoming numb and apathetic to every situation (22). Rationalization, self-reassurance (“I’ve come this far,” “I will be fine”) denial and minimization (“this issue is very simple I have been in worst situations before”). Emotional suppression is the best coping mechanism for acute stress which unfortunately this is not the case with losing a uterus (23)

Living in denial is a short term measure, eventually one has to face reality and deal with the situation by themselves. This process is called acceptance. Elmir, 2014 found that most women reported that without acceptance it is almost impossible to move on with life. According to Hannus, 2017, Realizing that there was nothing you could do about it facilitated acceptance and the search for information to help them deal with the whole situation. Acceptance was easier for those who knew from antenatal care that they stood a risk of losing the uterus due to underlying conditions such as placenta previa and those who felt they had completed giving birth. But very difficult for young mothers who still wanted to add more children or whose husbands had expressed desire for more children.

God as a solution. This study found believing in God to be one of the commonest coping strategies. Those who described themselves to be highly religious and God fearing coped better compared to those who were not so religious. So the degree of religiosity is the most important determinant in this coping strategy. These same findings were echoed by O’Donnell et al (2013). Davis, 2001 in his study titled “Does prayer have the power to heal? Scientists have some surprising answers” found being prayerful was an important coping strategy in times of trauma and coping with loss.

## Limitations

The findings of this study were limited to women who have got EPH in an urban and a peri-urban setting. 80% of the women were ethnic Baganda so the findings might not be applicable in other cultures. Being a doctor working in the hospital could have prevented some participants from freely expressing their views. Problems with archiving and retrieval of files by the records department has also contributed to loss of information.

## Conclusions

In conclusion EPH just like other traumatic birth experiences predisposes women to negative psychological sequelae. The study found loss of womanhood, Joy for being Alive, uncertainty about the future and professional abandonment as the major themes on women’s experiences following EPH and living in denial, believing in God and Acceptance as the major themes on coping strategies.

Formulating a post operative plan of care which includes counseling will be key to reducing the psychological symptoms experienced by these women.

## Declarations

### Abbreviations

ACOG: American College of Obstetricians and Gynecologists, EPH: Emergency peripartum hysterectomy, PPH: Post partum haemorrhage, UNICEF: United Nations International Children’s Emergency Fund, WHO: World Health Organization

### Author’s contributions

PP conceptualized the study. PP collected the data. PP, SP, AK participated in coding, analysis and interpretation. All authors were involved in manuscript preparation and approval.

### **Author's details**

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### **Competing interests**

The authors declare that they have no competing interests.

### **Availability of data and materials**

The data sets generated and analyzed during these study are available from the corresponding author on reasonable request.

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### **Ethical approval and consent to participate**

Ethical approval for the study was granted by the research and ethics committee of St. Francis Hospital Nsambya. UG-REC-020

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