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### Original Research - Qualitative

## Women's experiences of having had, and recovered from, eclampsia at a tertiary hospital in Tanzania

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#### ABSTRACT

*Background:* Eclampsia is a major cause of maternal and perinatal mortality that requires advanced care and long hospital stays with uncertain outcomes for mother and baby. Care of eclamptic women is particularly challenging in low-income settings. Standards for medical care for eclampsia are established but the psychosocial needs of women are under-researched.

*Aim:* To explore and describe women's experiences of having had, and recovered from, eclampsia at a tertiary hospital in Tanzania.

*Methods:* Qualitative semi-structured interviews were held with a purposive sample of 10 women recovering from eclampsia. Thematic analysis informed the interpretation of the data.

*Findings:* The women had experienced eclamptic seizure as painful and unreal as they were unable to control their body or actions despite sensing what happened. At hospital they felt being cared for and recovered but concerned because they had not been provided with enough information about the disorder. Being separated from the baby during hospitalisation was troublesome and they worried about infant feeding and health. The women experienced being connected to God and they were grateful for being alive and having recovered. However, they expressed fears over the possible recurrence of eclampsia in future pregnancies and wanted information about prevention strategies.

*Conclusion:* Experiencing eclampsia is painful and gives a sense of bodily disconnectedness. It involves worrisome separation from the newborn, not being adequately informed and concerns over future health. More holistic care would benefit eclamptic women and their newborns.

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#### 1. Background

Eclampsia is a severe complication of pre-eclampsia occurring commonly during the second half of pregnancy or the postpartum period. In Asia and Africa, nearly 10% of all maternal deaths are associated with hypertensive disorders of pregnancy, eclampsia being one of them.<sup>1</sup> Despite a worldwide decrease in total numbers of maternal deaths from 1990 to 2013, there has been no significant reduction in total number of deaths attributed to hypertensive disorders, most of which are due to eclampsia. In the years 1990 and 2013, it is estimated that 38,000 and 30,000 maternal deaths occurred globally due to hypertensive disorders respectively.<sup>2</sup> However, eclampsia is a particularly serious issue in low

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resourced countries. For instance, in Nigeria, eclampsia accounts for almost half of all maternal deaths in tertiary hospitals.<sup>3</sup> In Tanzania, a population-based incidence of eclampsia is reported to be 69/10,000 births.<sup>4</sup> Eclampsia contributes up to 12% of all direct causes of maternal deaths<sup>5</sup> and the case fatality rate ranges from 5 to 8%.<sup>4,6</sup>

Eclampsia is associated with severe maternal and neonatal morbidity.<sup>3,6,7</sup> Women with eclampsia are at risk of developing cardiovascular, renal, haematological, neurological, and hepatic complications.<sup>8,9</sup> Eclampsia is also associated with preterm birth, fetal growth restriction and placental abruption, hence contributing to fetal and neonatal morbidity and mortality.<sup>4,7</sup> Pre-eclampsia and eclampsia are associated with 25% of stillbirths and neonatal deaths in low-income countries.<sup>7</sup>

Although all pregnant women have concerns about the health of their unborn baby and the process of childbirth, mothers who have had eclampsia have reported increased fear, despair and anxiety in subsequent pregnancies.<sup>10</sup> Mothers experiencing preterm births due to severe pre-eclampsia or eclampsia report

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concerns on the care and survival of their premature babies.<sup>11,12</sup> Shock, sadness, insecurity and despair are amongst the feelings that these mothers report after knowing their babies are affected and may need extra care.<sup>13</sup>

Studies on eclampsia in Tanzania mainly cover the incidence, prevalence, risk factors, clinical management and guidelines on medical treatment.<sup>4,6,14</sup> To our knowledge, no studies have previously explored women's emotional and social needs or opinions to improve care during and after eclampsia. To optimise care and costs, health care providers need knowledge on medical, emotional and social aspects of care for women with eclampsia. The aim of this study was to explore and describe women's experiences of having had, and recovered from, eclampsia. Learning from women who survive eclampsia, may help improve policy, programmes and midwifery care for women with eclampsia, not only in Tanzania, but also globally.

### 2. Methods

A qualitative design employing semi-structured qualitative interviews was chosen<sup>15</sup> as this design allows the participants to describe their experience and reflect on how they felt and acted. Qualitative research assumes that realities are socially constructed and multiple and that knowledge is historical and culturally specific.<sup>16</sup> Thus, different social experiences and understandings of the world lead to different social actions and reactions. Therefore, a qualitative approach was chosen to allow for an in-depth exploration of women's understanding and experiences of having had, and recovered from, eclampsia. Thematic analysis guided the analysis process and interpretation of findings.

### 2.1. Ethical considerations

The ethical clearance was granted by the Senate Research and Publication Committee of the Muhimbili University of Health and Allied Sciences (MUHAS) in Dar es Salaam, Tanzania. Permission to conduct the study was obtained from the Executive Director of the tertiary hospital where the study was conducted. Informed oral and written consent was obtained from all participating women. The women were informed about the procedures of the study, assured that participation was voluntary, that if they did not participate their rights to treatment would not be jeopardised, and that all of the information given would be treated confidentially. To maintain confidentiality, pseudonyms were assigned and names of the referring health care facilities were not mentioned in the reports. In addition to individual consent, the researchers ensured that the interviewed women were assessed by a doctor or nursemidwife in charge of the ward to ensure their general condition permitted their participation in the interview. Providers were requested to observe the health status of the interviewed women and refer them to the facility's psychological support/counselling services if the women showed signs of not coping well with their situation. However, none of the women required additional support.

### 2.2. Study setting

The study was conducted at a tertiary hospital in Tanzania which services a population of about 4.5 million. The hospital receives referrals from the three municipal hospitals and surrounding districts but there are also some self-referrals. The average number of births in a year is 10,000 with about 45% being caesarean sections. The hospital offers maternity services including: antenatal, labour, postnatal, and neonatal care. Women with severe pre-eclampsia or eclampsia are admitted in a semi-intensive care unit located in the first floor. The unit has seven

beds and can offer childbirth, oxygen, Ambubag resuscitator and other simple life support services. Women needing ventilation and other major care are transferred to the intensive care unit. The unit has three shifts of nurse-midwives and, in each shift, three nurse-midwives are available to provide care. The registrar and resident doctors attend the women on admission and whenever the need arises. Each day, there is a major ward round led by a specialist in obstetrics and gynaecology. The hospital protocol prescribes that convulsions should be controlled by giving intravenous magnesium sulphate. High blood pressure should be controlled with intermittent injections of hydralazine if the woman's diastolic blood pressure is  $\geq 110$  mmHg. Methyldopa tablets are also given orally to reduce and maintain blood pressure within normal range. Induction of labour is provided to women unless there is indication for caesarean section according to the hospital's protocols.

According to the hospital protocol, relatives are only allowed to stay with admitted women during visiting hours, which are scheduled from: 06:00 to 07:00; 12:00 to 14:00 h; and 16:00 to 18:00 h. All newborns in the eclampsia ward are sent to the neonatal ward for care involving feeding, warmth and hygiene. Treatments are provided to newborns according to their needs. The women start to visit the newborns when they are able to walk to the neonatal unit, which might include using stairs in the absence of elevators.

Women are discharged from the semi-intensive care unit to the postnatal ward when their blood pressure is controlled and when other complications associated with severe pre-eclampsia and eclampsia have been treated. Discharge from the postnatal ward occurs when the mother and the baby are clinically well. Follow-up in the postnatal clinic is recommended after two weeks, depending on the condition of the mother. If the woman's blood pressure remains high six weeks after birth, or if there are other complications related to eclampsia, the mother is transferred to the medical outpatient clinic for further treatment.

### 2.3. Sampling and data collection

Purposive sampling<sup>17</sup> of 10 women was undertaken seeking women who had eclampsia and who were admitted to the semiintensive care unit at the hospital during the 8 weeks of data collection. Participant selection was undertaken in collaboration with nurse-midwives caring for the women. The potential participants were approached in person by the researcher. The interviews were only conducted with women whose conditions were stable, those who were able to express themselves and who had been discharged from the semi-intensive to the postnatal ward. All women who were approached consented to be interviewed.

Individual semi-structured qualitative interviews, following the guidance of Kvale and Brinkmann<sup>15</sup> were conducted by the first author (AMM), a native Kiswahili speaker, and a Tanzanian registered nurse experienced in qualitative interviewing. The interviews were conducted in Kiswahili which was spoken by all women. The interviews were held in a side room within the postnatal unit, where there were no interruptions from health care providers, other women or relatives. The interview guide with the following topic areas was used: recognition of having eclampsia, eclamptic seizure, antenatal and hospital care, and expectations upon returning home. The interviews started by posing the question:"Could you describe in as much detail as possible your experience of having eclampsia during your pregnancy, first at home and at the health care facility?" Probing questions followed to stimulate the women's reflection and thus create rich data. The interviews took 45-60 min and were audio-recorded with the permission of the women. Afterwards, field notes were taken on the general impression of the woman's accounts and interaction

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