

Perceived quality of life and meanings attributed to the experience of extreme maternal morbidity: a qualitative study

Natalia Chávez Narváez (<https://orcid.org/0000-0002-7783-5001>)¹

Naydú Acosta-Ramírez (<http://orcid.org/0000-0002-6246-560X>)²

Abstract *Experiencing extreme maternal morbidity (EMM) implies multiple changes, where the perception of quality of life is modified, generating a gap between what is perceived and what is desired. The aim is to understand the meanings attributed to EMM by survivors of the experience and the effect of these meanings on the processes of reconstruction of daily life. A qualitative study from the perspective of symbolic interactionism that included an analysis based on elements of grounded theory by conducting semi-structured interviews with women from a Colombian city. The experience of EMM is understood by the participants as “a suffering that is worthwhile” and is constructed from the meanings given to each stage that is experienced: (1) pregnancy: an unexpected event that is better when accompanied by a partner/family; (2) the complication: separation distress; (3) life after near-death. Women’s perception of quality of life depends on both the experience of the event and social support, as well as on the baby’s survival. The role of health services is critical because loneliness, worry, and stress intensify when health personnel have a dehumanized relationship with women.*

Key words *Qualitative research, Maternal health, Quality of life, Pregnancy complications*

¹ Escuela de Salud Pública, Universidad del Valle. Calle 13 # 100-00. Cali Colombia. natalia.chavez@correounivalle.edu.co

² Facultad de Salud, Universidad Santiago de Cali. Cali Colombia.

Introduction

Advances in improving care during pregnancy, childbirth, and the postpartum period have enabled many women to survive complications that were previously fatal. However, this increase in survival rates can have short, medium, or long-term consequences, which in many cases alter several dimensions of women and their families, affecting their quality of life. Women who survive severe obstetric events may recover, experience temporary or permanent disability, or even pass away later¹. Repercussions include dysfunction of one or more organs, such as impaired sexual function, hysterectomy-associated infertility, and an increased risk of complications in subsequent pregnancies². Other relevant alterations are found at the emotional and psychological level, such as post-traumatic stress disorders, postpartum depression, “maternal near-miss syndrome” (acute stress disorder directly related to the occurrence of extreme maternal morbidity)³, social isolation, altered family dynamics, divorce, increased family expenses, and even suicide⁴. All of the above constitutes a critical public health problem due to the high social and economic costs and also due to the exacerbation of mothers’ vulnerability.

Research on extreme maternal morbidity (EMM) and quality of life is usually approached through an objectivist epistemological focus using numerical health profile measurements and quantitative analyses based on numerical scales. However, in the last 20 years, progress has been made in the understanding of these phenomena by performing qualitative research with a more holistic vision, in which the voices of those women who have lived through this experience, and even the perspectives of their families and caregivers, are recognized.

In 2010, a review article evidenced that the perception of wellbeing and quality of life are affected in EMM events, which are recognized as traumatic situations that alter women’s daily-life functionality. Although the quality of life of women receiving clinical care improves over time, it remains below that predicted before the intervention and below the figures observed for women in general¹.

A phenomenological study conducted in 2012 in a hospital with women who had presented with severe preeclampsia in their last pregnancy and were in the third postpartum month portrayed their experiences as a “journey” marked by fear, anguish, and uncertainty, especially in relation to the newborn, in addition to experienc-

ing physical symptoms and undergoing painful medical procedures. Two determining situations were identified in women’s conception of the experience: (1) the hospitalization process, and (2) the birth of a premature child. Participants’ lack of preparation to face the disease and its impacts were also mentioned⁵.

An autobiographical narrative research conducted in 2016 by Valencia and Gaviria states that understanding the history of survivors of EMM allows to give new meaning to human care and the recognition of human capabilities. Furthermore, family, social, cultural, and historical conditions of a particular territory limit women’s possibilities to be, act and decide after surviving EMM⁶.

Applying a qualitative approach is important to identify the quality of life as a reality because its study as a subjective phenomenon allows the understanding of specific meaningful and interpretative mechanisms, as well as their consequences in subjects’ acts in the order of interaction⁷, incorporating and highlighting that meaning and intentionality are inherent in acts, relationships and social structures as significant human constructs⁸.

Therefore, through an orientation based on the theoretical approach of symbolic interactionism, it is possible to conceive the condition of EMM survivors from the subjectivity of the experience, including the voices of those who experience it and recovering the idealistic essence of quality of life, which is understood not as a static reality independent of the subject, but as a construction of meanings and symbols resulting from social interaction. These meanings are grouped into four categories: EMM meanings, survival meanings, coping mechanisms, and reconstruction of daily life, and an emerging category related to the perception of care services⁹.

This approach allows for the incorporation of women’s perception into the evaluation of health outcomes, providing analytical elements that can guide the construction of policies for the comprehensive protection of maternal health from a biopsychosocial level, in order to overcome the traditional individualistic approach focused on isolated and depersonalized disease and promote the welfare of women, their families, and their community through a gender approach, thereby mitigating the conditions of vulnerability that the event can generate in the population that experiences it^{10,11}. Within this framework, the purpose of this research was to understand the meanings attributed by EMM survivors to their

experience and the effect of these meanings on the processes of reconstruction of their daily lives and the perception of their health-related quality of life.

Methods

In order to meet the objectives of the study, a qualitative approach based on symbolic interactionism and the use of grounded theory analysis techniques was selected so as to gain better understanding of the construct of health-related quality of life in the context of women who survive EEM, focusing on what the experience of suffering and surviving an obstetric event meant from the constructions of their relationships with the social environment⁹. The qualitative approach is holistic because it allows the understanding of phenomena within their context and as they occur in reality. It also allows the analysis of interactions within a system or culture based on the understanding of their meanings and dynamics. In this way, it is possible to understand reality as it is felt and lived by the subjects¹².

For the definition of health-related quality of life (HRQoL), a theoretical model is proposed based on the suggestion made by Schwartzman (2003)¹¹, which integrates components of Engel's Biopsychosocial model, Ware's HRQoL model, and Sprangers/Schwartz's proposal (Chart 1). A distinction is made between quality of life emphasizing the psychosocial aspects of social well-being and general subjective well-being and HRQoL, which is based on the assessment of an individual according to the limitations caused by a given disease or its treatment in biological, psychological, and social development areas.

Sampling strategy

Participants were selected by purposive sampling, according to the objectives of the study, and subsequently by theoretical sampling, taking the reports of the event made by second- and third-level health care institutions of the city of Popayán (located in the southwestern region of Colombia) as a starting point between January and December 2014. A total of 203 records were found in the database, of which 127 were selected based on the inclusion and exclusion criteria established for this study (Chart 2). With these 127 records, participants were contacted or enrolled by telephone, excluding women who did not have a working contact number. Finally, the

Chart 1. Origins of the theoretical model of HRQoL in EEM.

Origin	Author	Year	Contribution
HRQoL definition	Laura Schwartzman	2003	Definition of each of the dimensions
Biopsychosocial model	George L. Engel	1977	Biological, emotional/psychological and social dimensions of the individual
HRQoL models	Ware	1984	Model of the progressive relationship between disease and QoL fields
	Sprangers/Schwartz	1999	Concept of "response change"

Source: Authors.

study included five women who agreed to participate in the research voluntarily and responded to the saturation criterion in the information analysis.

Data collection methods

Information was obtained through semi-structured interviews with each of the study participants. Each interview lasted between 60 and 90 min and was recorded with prior authorization. To guarantee the confidentiality of participants' identities, a pseudonym was assigned in the order of the letters of the alphabet according to the order of participation.

For the interviews, a guide was developed based on the following lines of inquiry according to the specific objectives of the study: (1) meanings of the EEM experience, (2) meanings of the survivor condition, and (3) coping mechanisms and reconstruction of their daily life. Initially, these lines of inquiry were approached in a broad manner and were progressively adjusted as categories and substantive theory emerged. All the in-

Chart 2. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> . Women reported in the records of second and third-level health care institutions of the municipality of Popayán as cases of EMM . Over 18 years of age . Residents of the municipality of Popayán during the study period . Having experienced an MME event between January and December 2014 	<ul style="list-style-type: none"> . Being hospitalized because of the event or other situation at the time of the study . Cognitive or language disabilities that hinder the collection of information

Source: Authors.

interviews were developed following an open-conversation model, with a listening attitude on the part of the researcher, stimulating narrative and guaranteeing an atmosphere of trust, confidentiality, and favorable dialogue, which is why the meetings were held in places and times defined by the participants.

The information from the interviews was complemented with a field diary where the interviewer's comments about interpretations, intuitions and emerging conjectures, notable gestures, and non-verbal expressions essential to understand the meaning of what was said by the participants were recorded.

Data analysis

Data analysis and collection were conducted simultaneously in accordance with the principles of grounded theory. To this end, the information collected from the interviews and the field diary was transcribed, reviewed, edited, and coded as quickly as possible to avoid loss of information. The interviews were fully and verbatim transcribed in 2010 Word processor. Each file was saved under the name of the pseudonym assigned to the participant (fictitious name to ensure confidentiality). The analysis of the qualitative data was conducted using Ethnograph v6 software.

For the analysis of the data obtained, Glaser and Strauss' constant comparison method was used, which includes open coding, axial coding, and selective coding¹³. In the open coding

process, 112 descriptive codes corresponding to traits or patterns identified in the interviews were initially generated. These codes were reviewed, grouped, and conceptualized in a more abstract manner until emerging categories were constructed, which were reviewed again, thereby allowing new categories to be transformed or to emerge. Subsequently, the categories obtained were related through axial coding and confronted with the bibliographic review for their theoretical development and generation of core categories and substantive theory.

As with all qualitative research and the application of grounded theory, there are accuracy-related challenges in terms of validity and reliability, and these were resolved through an exhaustive or detailed and in-depth analysis of data and intersubjective consensus that accounts for the interpretation and construction of shared meanings¹³. Exhaustiveness was sought through the textual transcription of the interviews to generate the codification of the information collected later. Intersubjective consensus was achieved through the identification of similarities, differences, and contradictions in the interpretation of the dialogues and interrelation with the evidence available through bibliographic review.

Ethical considerations

This research was approved by the ethics committee of the university where the principal investigator was assigned to during her master's degree in Public Health, under record number 06-015, renewed on September 3, 2020. The provisions of resolution 8430 of 1993 were considered, under which this study is classified as a higher than minimal risk since sensitive aspects of the participants related to the experience of a serious obstetric event considered traumatic were addressed.

The international ethical principles of the Declaration of Helsinki were followed, and in order to guarantee the autonomy and voluntariness of participation, the objectives, methodology, benefits, and possible negative effects of the research, as well as its free entry or withdrawal without any type of consequence, were divulged. Once the total understanding of the information provided was assured, and participation in the study was accepted, a written informed consent document was signed, a copy of which was provided to participants.

Results

The study was conducted with five women over 18 years of age who survived a severe obstetric complication classified as EMM and who resided in the city of Popayán. Chart 3 describes the characteristics of the study participants (a fictitious name was used to guarantee anonymity).

The meanings constructed by EMM survivors about their experience and its effect on the processes of recovery and reconstruction of their daily lives are presented below. As substantive theory, the experience is presented as “a worthwhile suffering” with the following core categories:

Pregnancy: an unexpected event that is better when accompanied by a partner/family, accounts for the moment when the pregnancy is known and how it is assumed.

The complication: separation distress focuses on the meanings of the complication and its experience at the hospital.

Life after near-death describes the return to daily life and the mechanisms of its reconstruction after overcoming the hospitalization stage.

Pregnancy: an unexpected event that is better when accompanied

The discovery of pregnancy was described by the participants as surprising, shocking, and distressing. It is a moment of crisis where motherhood materializes as a reality seen in some cases as a remote possibility, specific to adulthood. Motherhood as a social construct is a role attributed to women and in many cases is expected in the context of a stable relationship and as a consequence of an active sexual life: *We had been together for a long time (with her partner) [...] when you are young you don't expect these things (pregnancy). But as soon as you know that you are having sex*

with someone, you have to get used to the fact that it is obviously going to happen (Estella).

Family support favors the acceptance of the new condition, reaffirms the decision to continue with the pregnancy, and is even experienced as the beginning of pregnancy: *It was hard for me because I didn't know what my mother was going to say... but when I told my mum, she supported me and then I decided to continue with the pregnancy* (Ana).

The complication: separation distress

Interventions derived from the complication almost always lead to the separation of the mother from her child, hindering practices such as early breastfeeding, which can produce feelings of sadness, guilt, regret, and a sense of failure as a mother due to the premature rupture of the bond. All this makes possible the experience of abnormality, where the idealized pregnancy is blurred in the face of a disappointing and distressing present¹⁴: *Immediately after I came out of surgery, they were going to take me to the ICU because I got very sick, but I told the doctor not to take me to the ICU because they were separating me from my child* (Ana).

Mothers' emotional turmoil becomes more evident if the hospital setting does not meet their expectations: *They never told me that I had pre-eclampsia, they never told me that I had altered blood pressure, they told me nothing. So they knew, and they didn't help me. I am not a fortune teller to know what is wrong* (Estella).

Life after near-death

Motherhood motivates a feeling of attachment to the baby as the object of her total attention and care; it is the very essence of being a mother. This is why the survival of the baby

Chart 3. Description of participants.

Participant (pseudonym)	Age (years)	Education	Occupation	Cohabiting	Background
“Ana”	19	Technical	Student	Mother, siblings	First pregnancy
“Berta”	20	Technical	Student	Mother, siblings	First pregnancy
“Carolina”	22	University	Student	Couple	Spontaneous abortion
“Diana”	31	Incomplete High School	Housewife	Couple	First pregnancy
“Estella”	20	Technical	Student	Single	Previous abortion

Source: Authors.

substantially marks the satisfaction with the experience. Therefore, for women whose babies survive, the experience of EMM can mean the acceptance of motherhood, a learning experience, or the blessing of being alive: *Yes, it hurts and all, but that was nothing. Thank God he was born well. The scare he gave me was just that. Thank God, it was worth the suffering* (Diana).

I see what happened to me in a positive way. Suddenly it was something that made me react and it was bad, as at that moment, my life and Sofi's life were in danger. But it really had a good impact on my life because it taught me something (Carolina).

In contrast, when the loss of the baby is experienced, the notion of the experience becomes negative and unexplained: *So, I was left with a very low morale towards it. But I would definitely call it a misfortune or a curse, I can't explain why that occurred to me* (Estella).

The survival of the baby becomes a coping mechanism that facilitates the reconstruction of daily life and gives meaning to life, otherwise the reason for life is lost: *My mission is to be with him and protect him [...] we both have to move forward* (Berta).

During the complication, family and partner support is highlighted. This has a positive impact on the process of accepting the situation: *That was what helped me a lot because if not... imagine me in that surgery alone, without support, without anyone, that would have been very difficult! Alone, no way, you can't imagine it...* (Berta).

In line with EMM consequences, affection is not relevant much in women's narratives; however, some of them evidenced affectation of this domain, which even interfered in their daily work: *Now that I have had a baby, I feel like my head is going to explode and I get very hot. I even feel dizzy [...] I got a little sick.... Now I can't even sweep* (Diana).

Finally, when talking about how women faced the puerperium, the construction of meanings was focused on the importance of the newborn to resume daily life. In this way, family support at this stage was not discussed in depth. However, the narratives of Estella allow us to believe that, after the death of her child, a closer professional and family support should have been provided because there was apparently an dysfunctional grieving.

Discussion

Among the multiplicity of meanings given to EMM, most revolve around the survival and maintenance of the child, which becomes an important factor on the effect the experience has on the quality of life of survivors.

The possibility of death due to maternal complications is perceived as a sudden and unexpected event, generating extreme vulnerability and helplessness, given the inability to escape or control the situation¹⁴. Therefore, EMM is reconstructed as a traumatic event, and, in the case of women whose children survived, the way of signifying it is related to its revaluation, and women even reflected upon its positive effects. Souza et al (2009) argue that the experience of EMM can be perceived as an "opportunity for internal growth," in which many women find something useful and see life differently³. In contrast, in the case of women who lose their children, it is much more difficult to rebuild their daily lives and they may feel that there is no way to overcome it, despite trying and planning to do so. Most likely, there is a traumatic response that requires attention because it delays the possibility of physical, emotional, and social recovery, making the complication experience more intense.

Lyubomirsky and Cummins, cited by Vázquez and Pérez (2003), state that happiness and optimism can moderate the impact of trauma or life stressors, allowing adverse events to be evaluated in a more benevolent manner, even deriving positive consequences from negative experiences. The baby becomes a generator of happiness and optimism, being the moderator of the impact of the experience¹⁴. In this sense, the woman feels complete because she is socially seen as someone capable of fulfilling her anatomical destiny of motherhood. Her identity as a mother is accentuated, becoming a woman who did her best so that the "natural cycle of life" could take place.

Literature reports that in the event of an emergency, women may feel that they have no other option when faced with the need for care from health care services, which facilitates their acceptance. Although, as evidenced in the testimonies, women and their families also regard health care positively when they receive explanations about their situation, the procedures to be performed, and the expectations of the treatment; women even felt safe and confident with the health care personnel through non-verbal communication¹⁶.

Conclusions

EMM understood as a life experience and as a narrative event, in addition to the clinical event, allowed a more complete understanding of the meanings of the experience for women and their families, in addition to identifying the impact on the role that is socially attributed to women and that is directly linked to motherhood.

The perception of quality of life after EMM depends on the meanings given to the experience. These meanings are constructed from the moment of the pregnancy discovery and are transformed and adjusted throughout the pregnancy. In this construction of meanings, family and partner support and the survival of the baby are essential, becoming factors that facilitate coping with the situation and the reconstruction of daily life and reduce the gap between the quality of life perceived and desired.

The loss of the baby implies a greater impact of EMM in women's lives; they are generally perceived as more fragile and with greater expression of negative emotions in the face of the experience. This leads to the need for post-obstetric event support owing to greater vulnerability, not only in the physical sphere but also in the psychological and social ones.

A positive experience of care services in terms of active communication and empathetic attitude between patients and health care providers would not only increase the quality of care perceived by these women but also improve future health care sought for them and their families. It also empowers them by providing essential information about the experience that might otherwise be lost. This can make it easier to accept the consequences, deal with the trauma and potential loss, and move on with their lives.

The approach to survivors of EMM is often based only on epidemiological surveillance of the event with the gaps that this implies, denying comprehensive and humanized care focused not only on the physical but also on the social, emotional, family, and psychological consequences of the event. A change in the training of health professionals and personnel by strengthening competencies centered on a biological, psychological, and social paradigm that transforms care in this sense is a persistent challenge, and this can be certainly managed even through virtualized con-

tinuing education processes, making use of platforms and new information and communication technologies as tools for health innovation¹⁷, which are currently intensively used and which have shown their wide applicability in complex times such as those experienced in the context of the COVID-19 pandemic¹⁸.

Extreme maternal morbidity also impacts women's "living" capacity by exposing them to the possibility of their own premature death or their child's. This also exposes women to a critical reflection on the planning of their own lives by motivating the capacity of "critical thinking".

The capacities of "physical health" and "physical integrity," despite not being the most frequently mentioned in the narratives, show affectation in the sense of the physical sequelae mentioned, especially those related to sexual and reproductive health.

The capacity of "affiliation" is strengthened by the role of motherhood; living for the new human being favors the recognition of women in their new role as caregivers and protectors of life. In contrast, in terms of the relationship with the health services, it is blurred by the references of failures in communication on the part of the health personnel, late care, care failure, and dehumanization, generating negative feelings toward health services.

In this sense, it is evident that extreme maternal morbidity affects the perception of quality of life because it limits the opportunity to develop these capacities, placing women in a situation of vulnerability, with social, economic, and moral implications, not only as individuals but also as social beings.

Limitations and strengths of the study

Although this study was limited to five women, as evidenced in the discussion, theoretical saturation was achieved with relevant qualitative findings that allowed the analysis of the phenomenon of quality of life in survivors of EMM. A strength of this study was its remarkable qualitative research and analysis method based on several authors for the definition of HRQoL, which allows theoretical triangulation. This can be applied in other fields of studies such as social psychology and collective health.

Collaborations

NC Narváez: work's design, planning, analysis, interpretation, and writing. N Acosta-Ramírez: participated as director of the research and directed all methodological process, result interpretation, critical review and major contributor in writing the manuscript. All authors read and approved the final manuscript.

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