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Major obstetric hemorrhage: Patients' perspective on the quality of care

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ABSTRACT

Objectives: Major obstetric hemorrhage (MOH) is the leading cause of severe maternal morbidity and mortality, and can have a significant impact on a woman's life. This study aims to gain insight into the patients reported experiences (PREs) and outcomes (PROs) after a major obstetric hemorrhage, and to investigate which patients are most at risk for negative experiences.
Material and methods: A Consumer Assessment of Healthcare Providers and Systems (CAHPS) based questionnaire was developed covering items on the PREs and PROs, and send to all patients with blood loss exceeding 2500 ml in six hospitals over the period of 2008–2012. A regression analysis was performed to find determinants for negative experiences.
Results: In total 372 of the 570 questionnaires were returned. Women scored the overall care before, during and after the MOH with a mean of 7.67, 7.62 and 7.28, respectively. However, most PRE items individually were scored suboptimal, with items regarding information supply scoring the lowest. Our results on the PROs showed 81% of the women (362) sustaining extreme fatigue, whereas problems with concentration (53% of 373 women), memory (49% of 353), or reliving (49% of 356) and irritability (51% of 355) were also frequently endured. Negative long term effects were observed in 28% of the women (106 of 372). We found 'year of the MOH longer ago', 'a lower total blood loss' and 'a large location of birth' to be determinants for negative experiences.
Conclusions: Women frequently reported negative experiences and outcomes following a MOH. Information supply after an MOH concerning both physical and psychological complaints is essential for the improvement of care.

Introduction

Major obstetric hemorrhage (MOH) is the leading cause of severe maternal morbidity and mortality [1,2]. MOH and other severe maternal morbidity can be dramatic life-threatening events with negative physical and emotional consequences for the woman and her family [3–5]. Although comparison of reported incidences of MOH, post partum hemorrhage (PPH) or severe morbidity is problematic due to the lack of universally accepted definitions, MOH incidences of 0.5% have been reported, and an increasing trend in MOH and PPH has been seen [6–10]. Quality of care can be measured from various perspectives, with different

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types of quality indicators (process, structure and outcome indicators) [11]. Quality indicators are defined as "measurable elements of practice performance for which there is evidence or consensus that they can be used to assess the quality, and hence change in the quality, of care provided" [12]. The measurable outcomes 'morbidity' and 'mortality' have long been used as main quality indicators. Over the last decades, patient reported experiences (PREs) and patient reported outcomes (PROs) have gained support as outcome indicators [13]. Nowadays patients have nearly unlimited access to information online, they become more involved in their healthcare and wish to be more informed about conditions, treatments and risks. It is important to pay attention to their perspective on quality by assessing their experiences and health outcomes. Even though sometimes addressed as controversial, when set up accurately, valuable information can be gained to improve quality of care from PRE and PRO results [14].

Knowledge of PREs and PROs will allow for better counseling and guidance by clinicians, contributing to the improvement of the quality of care. However, little information has been published on the experiences and physical and emotional complaints following a MOH and possible long-term consequences. Studies performed on either experience or outcome after a major or severe hemorrhage were of short sample size [15–17], focused solely on postpartum depression or post traumatic stress disorder [16] or had a very short follow up period [16,18,19]. Thus giving an incomplete picture of patients' experiences and outcomes.

In this study we aim to gain insight into the patient reported experiences and outcomes of MOH care. Moreover, after identifying areas for improvement, it is valuable to find determinants at the patient level to recognize those women most at risk of negative experiences.

Materials and methods

Study design and setting

We conducted a cross-sectional questionnaire survey. Six hospitals geographically spread over the Netherlands participated, including two university hospitals (UH), two large teaching (non-university) hospitals (TH) and two smaller non-teaching (non-university) hospitals (NTH).

Population

Retrospectively, we included all women who received treatment for a MOH between January 1st 2008 and December 31st 2012. For this study we defined a MOH as a total blood loss (TBL) of $\geq$2500 ml, corresponding to the definition of major hemorrhage classification by the Advanced Trauma Life Support (ATLS) classification for hypovolemic shock (a loss of more than 40% of the total blood volume) [20]. Exclusion criteria were: women with stillbirth or neonatal death (as the questionnaire could trigger an emotional response and this was considered too much of a burden by the ethical committee), and maternal death. The incidence rate was calculated using the total parturition rates of each hospital, as provided by the participating hospital.

Development of the questionnaire for measuring PREs and PROs

A questionnaire was developed to report women's experiences and outcomes following the MOH. Topics were identified from international literature [18,19], Consumer Assessment of Healthcare Providers and Systems (CAHPS®) [21] and the Consumer Quality Index (CQI, a Dutch translation of the CAHPS) [22] questionnaires and previously held interviews with 11 women who experienced a postpartum hemorrhage [23]. These interviews were held to evaluate the care given in case of a PPH and to identify barriers for adequate care. Topics included in the questionnaire concerning the PREs were: information supply from caregivers, attention from caregivers, capabilities of caregivers, continuity of care, coordination of care, satisfaction with the overall care, and type and number of consultations in the period after discharge. Topics concerning the PROs were: physical and emotional complaints after MOH, long-term consequences, and effect on a possible next pregnancy. Questions about a possible next pregnancy were not asked to those women who had a hysterectomy due to the hemorrhage.

The topics, excluding the patient characteristics, were investigated with 44 questions. The questions evaluating the PRE's used four-point Likert-type scales (comparable to the CQI questionnaire), ten-point rating scales for evaluation of the satisfaction level with the MOH care and the likelihood of recommending the participating hospitals to other pregnant women and multiple choice questions for type and number of consultations. All items of the four-point likert scale were positive and desired experiences in the antenatal period, during the delivery and postpartum, for which the women could indicate to which extent the experience was applicable to their situation with the options always, mostly, sometimes, or never. Multiple choice questions were used for the PRO questions with room for additional remarks. A covering letter providing information on the aim of the study, the manner in which the data collected would be reported and stored, and contact details, was enclosed with the questionnaire. Informed consent forms were sent and returned with the questionnaires. An open comment section at the end of the questionnaire was added for women to make any remarks in case a topic they deemed valuable was not included in the questions, The questionnaire was piloted among women in the maternity ward for comprehensibility and was refined where necessary All questionnaires were send at the same time for each hospital, independently of the day of the delivery (varying between approximately 0.5 to 6 years after the MOH). A reminder was sent after four weeks.

Determinants

To recognize those women most at risk for negative experiences, we performed a determinants analysis. Characteristics that were collected and used as independent variables are listed in Table 1 and include year of hemorrhage, total blood loss (TBL), location of birth, location of antenatal care, parity, maternal age, mode of delivery, and location of referral. The participating hospitals supplied the following characteristics of all eligible women: location of birth, year of MOH, and TBL. The other characteristics of the included women were extracted from the medical record as part of a clinical audit (one UH) or through 11 questions preceding the questionnaire.

Statistical analysis

Quantitative data analysis was conducted using IBM SPSS Statistics 20 (IBM Corporation, Armonk, United States). In order to control for significant difference between responders and non-responders the four variables location of birth, year of MOH, TBL, and location of antenatal care were compared using the Pearson Chi-Square test.