European Journal of Obstetrics & Gynecology and Reproductive Biology 211 (2017) 33–36

Contents lists available at ScienceDirect

European Journal of Obstetrics & Gynecology and Reproductive Biology

journal homepage: www.elsevier.com/locate/ejogrb

Full length article

Reproductive decisions after the diagnosis of amniotic fluid embolism

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ARTICLE INFO

Article history:
Received 6 December 2016
Accepted 20 January 2017
Available online xxx

Keywords:
Amniotic fluid embolism
Diagnosis
Maternal mortality
Contraception
Sterilization

ABSTRACT

Objective: This study aims to describe the subsequent reproductive outcomes in women who either correctly or incorrectly were diagnosed with amniotic fluid embolism (AFE).
Study design: Medical records were obtained, abstracted and reviewed by authors with extensive experience in critical care obstetrics. Telephone interviews of all survivors were conducted to determine obstetrical and contraceptive history. A subgroup underwent further telephone interview to address subsequent reproductive decisions.
Results: By November 2015, 116 medical records of patients diagnosed with AFE were reviewed. Patients who had undergone hysterectomy (n = 26), died (n = 9), or developed Sheehan's syndrome (n = 1) at the time of the original event were excluded from the present analysis. Of the remaining 80 women, 30% (24/80) had subsequently conceived and 32.5% (26/80) patients or their partners had undergone permanent sterilization. At the time of this report, 66% (21/32) of registry participants were categorized to have had AFE and 34% (11/32) as not likely AFE or indeterminate.
Conclusions: The syndrome of AFE is over-diagnosed. Women diagnosed with AFE who survive conceive another pregnancy less frequently than US women over similar time intervals and often choose a permanent sterilization method, whether or not they actually had AFE, largely out of fear of AFE recurrence.

Introduction

Amniotic fluid embolism (AFE) remains one of the most enigmatic and devastating conditions in obstetrics [1]. In its classic form, AFE presents with the acute onset of hypoxia, cardiovascular collapse and coagulopathy, during labor or in the immediate postpartum period. In such cases, maternal mortality is high, with reported death rates exceeding 60% [2]. However, it is clear that some patients with AFE present with a modified form of the condition in which one or more of the classic triad of clinical signs may be absent. In such cases, mortality rates are lower.

Our understanding of this condition has been hindered by the absence of definitive, objective diagnostic criteria. AFE remains a clinical diagnosis, often subject to error, especially with less-than-classic presentations [3]. Further, the rate of AFE recurrence in subsequent pregnancies is unknown; the number of reported cases of pregnancy following AFE is small and limited to a dozen individual case reports. Hence there exists no reliable data to cite recurrence risks in counseling these women; this uncertainty may impact future reproductive decisions [4].

Because the treatment of AFE is non-specific and directed at the correction of presenting pathologic physiologic alterations, the over-diagnosis of AFE is uncommonly detrimental to the patient's ultimate recovery. However, less is known about the long-term psychological impact of over-diagnosis on future reproductive decisions. Of particular concern is the impact on future reproduction in women in whom AFE is over-diagnosed, a group comprising 30–60% of women with an AFE diagnosis in some series [2]. We sought to investigate this question.

Materials and methods

The Amniotic Fluid Embolism Registry is an international database established at Baylor College of Medicine (Houston, TX, United States) in partnership with the Amniotic Fluid Embolism Foundation (Vista, CA, United States), a non-profit organization dedicated to advancing research, promoting education and awareness, and supporting those affected by AFE. The AFE Registry was IRB-approved in May 2012 and the database opened for enrollment in August 2013. Cases were obtained via advertisement

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http://dx.doi.org/10.1016/j.ejogrb.2017.01.050
0301-2115/

using social media through the AFE Foundation and Baylor College of Medicine websites. All cases submitted to the registry were accepted for review, regardless of year of occurrence, as long as medical records were recorded in the English language. Cases from the previously published US Registry [5] were not included here because all of the US Registry cases occurred prior to 1995 and the original medical records were no longer available.

Surviving patients and non-survivors' families were self-identified with AFE and contacted the investigators by email directly or through the AFE Foundation. Written informed consent was obtained from survivors of AFE or from relatives of non-survivors, who voluntarily released pertinent medical records to the Foundation and Registry. We requested pertinent medical records were then examined and abstracted by the investigators (AM & GAD).

Based upon medical records review, patients were categorized into 2 major groups: (1) Probable AFE and (2) Probably not AFE or diagnosis indeterminate, per criteria we have previously published [5]. The "Probably not AFE" group consisted of cases of maternal hemodynamic collapse deemed likely due to other causes, such as protracted uterine atony or anesthetic complications. The "Diagnosis indeterminate" category consisted of cases in which the records were complete but etiology was unclear following review, or in some cases available medical records were suspected to be incomplete. Completed case report forms were reviewed by two authors with extensive experience in AFE research and critical care obstetrics (GAD, SLC & MAB) and any differences in opinion arbitrated by a third author.

Telephone interviews using standardized questionnaires of all reported AFE survivors were conducted by two investigators (EHM & MK) to determine obstetric and contraceptive history subsequent to the diagnosis of AFE. Three contact attempts were made, after which we assumed the individual declined participation in follow-up interviews. A follow-up standardized questionnaire to address to what extent fear of repeat AFE impacted these decisions was conducted by one investigator (MK) for available participants. We examined subsequent reproductive decision making, specifically contraceptive use and permanent sterilization of the patient or her partner. We also determined whether fear of repeat AFE played a major role in these decisions, based upon the telephone interviews described above.

It should be noted that post-AFE medical consultations were performed by local health care providers and not by AFE Registry or Foundation personnel. All information regarding reproductive recommendations to these patients was obtained by patient telephone interview and not from chart review, so we were left with the patients' impressions and not documented conversations. Neither the AFE Registry nor the AFE Foundation provided recommendations about medical care or future family planning.

This project was approved by the Baylor College of Medicine Institutional Review Board (H-29335 and H-36129). Statistical analysis was performed on statistical software package SPSS 21.0 (SPSS Inc., Armonk, NY). Normally distributed data are reported as mean (standard deviation) and nonparametric data as median (range).

Results

By November 2015, medical records of 116 women diagnosed with AFE have been submitted to the Registry (Table 1). There were 103 cases from the US (representing 32 states), 7 from the UK, 3 from Australia, 3 from Canada and 1 from Switzerland. One of the patients had two pregnancies complicated with the diagnosis of AFE. At the time of the AFE diagnosis, the median (range) age of these patients was 32 (19–49) years, pre-delivery parity was 1 (0–11) and gestational age was 39 (24–42) weeks. There were 113 singleton pregnancies, 3 twin pregnancies and 1 triplet pregnancy.

Of these 116 women, 36 were excluded from analysis: 9 women who died after the AFE event, 26 who underwent hysterectomy, and 1 who developed Sheehan's syndrome in conjunction with the index diagnosis (Table 2). Of women with the diagnosis of AFE who had preserved fertility after delivery, 70% (56/80) had not had further children at a median (range) interval of 4 (1–18) years from the index delivery.

Contraceptive practices are summarized in Table 3. Of women diagnosed with AFE who did not suffer involuntary loss of fertility, 32.5% (26/80) of these women or their partners had chosen permanent sterilization.

We performed additional extended interviews with 65 women enrolled in the registry, according to availability. In this specific group of patients, the median (range) interval between the AFE event and interview was 6 (2.5–13) years. The reported desired number of children prior to and after the AFE event was 3 (2–3) and 2 (0–3), respectively which reflects a deficit of 1 (0–2) in the desired number. The diagnosis of AFE affected child bearing desire in 57% (37/65) of individuals while 43% (28/65) did not confirm such an impact.

These women reported that the primary delivering physician advised against future pregnancy in 52% (34/65) cases. The reported reasons that physicians recommended against future pregnancies were: chance for recurrence (n = 19), potential emotional distress (n = 7), non-gynecologic complications

Table 1
Characteristics of women with prior diagnosis of AFE. Data are reported as median (range) and as proportions.

Number of enrolled women	n = 116[a]
Maternal age (years)	32 (19–49)
Pre-delivery parity (term + preterm)	1 (0–11)
Gestational age at delivery (weeks)	39 (24–42)
Mode of delivery	Spontaneous vaginal delivery 12.7% (15/117) Operative vaginal delivery 10.2% (12/117) Cesarean delivery 75.1% (88/117) Dilatation and evacuation 1% (1/117) Unknown 1% (1/117)
Fetal gender	Male 40% (48/122) Female 60% (74/122)
Neonatal outcome	Liveborn 93% (113/122) Neonatal Death 4% (5/122) Stillborn 3% (3/122)

[a] One woman had two suspected pregnancies.