Survival and negotiation: narratives of severe (near-miss) neonatal complications of Syrian women in Lebanon

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Abstract: The World Health Organization has elaborated a maternal and neonatal near-miss reporting, audit and feedback system designed to improve the quality of care during and after childbirth. As part of a four-hospital comparative study in the Middle East, this article discusses the experiences of mothers whose newborns suffered from severe complications at birth in the Rafik Hariri University Hospital, the only public hospital in Beirut. Based on in-depth home interviews several weeks after childbirth, it aims to explore the experience of neonatal near-miss events through the mothers’ birth narratives. The central concerns of these vulnerable and marginalised women regarded access to neonatal care, and how to negotiate hospital bureaucracy and debt. It argues that financial and bureaucratic aspects of the near-miss event should be part of the audit system and policy-making, alongside medical issues, in the quest for equitable access to and management of quality perinatal care. DOI: 10.1080/09688080.2017.1374802

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Introduction

In the context of a region beset by political instability, hosting the highest number of refugees in the world, as well as a significant foreign labour force, it is important to have a multi-layered perspective on the relationship between health, access to care, and health care systems in the Middle East. Recent scholarship has been particularly attentive to the social production of illness,1 the relationship between war, refugees, and healthcare,2,3 and governance.4,5 Building on this literature, we explore the narratives of women and families whose infant has experienced severe (near-miss) complications in Rafik Hariri University Hospital, the only public hospital in Beirut. This paper asks: how can the women’s understanding of severe complications in childbirth inform our awareness of the causes and management of the risky events? And how can a broader understanding of vulnerable women’s trajectories assist providers and policymakers in overcoming barriers to quality childbirth care?6 Poor refugee and foreign women in Lebanon have precarious access to healthcare. Postnatal care for high-risk neonates is particularly problematic given the cost and scarcity of high-technology neonatal care; and evidence shows that universal coverage of cost-effective interventions would reduce neonatal morbidity and mortality,7 whereas unexpected high costs of maternal or neonatal intensive care may push families further into destitution.8

The concept of “near-miss”: a short history

In health care, it was not until the mid-1990s that a critical mass of safety research was put forward in various specialties of medicine to institute near-miss reporting systems.9 Development programmes and World Health Organization (WHO) policies emphasise “the geographies of public health,”10 focusing on the interconnections between institutions, providers, other stakeholders, and the socio-political context. One result has been the establishment by the WHO of a maternal and neonatal near-miss reporting, audit and feedback system designed to improve the quality and performance of care by investigating the series of events leading up to serious complications.11 Researching neonatal near-miss cases rather than only neonatal deaths (a rarer phenomenon) can provide more information on what goes wrong as the sample is larger, the parents are more...
available to give feedback, and the obstetric and neonatal staff can improve their practice, avoiding an environment of blame.\textsuperscript{12,13}

Building on the literature regarding the social production of disease\textsuperscript{14,15} and drawing on Sherine Hamdy’s concept of “political etiologies” of disease,\textsuperscript{1} I argue for a more expansive understanding of near-miss events that encompasses social, economic, and bureaucratic factors. One of the main concerns of family members is their feared inability to secure funds for treatment of the infant and the various tactics used to negotiate neonatal intensive care. But the concept of “near-miss” currently considers mainly proximal medical factors to the detriment of questions of access and cost. Thus, the concept of near-miss needs to broaden its focus to address social, bureaucratic, and managerial issues affecting women’s and newborns’ lives.

The data presented here has methodological implications for research on maternal and child health. While this project, like most previous work on neonatal near-miss, focuses on mothers’ experiences, the women’s narratives suggest that for hospitalised babies, the fathers as well as hospital staff are primary caretakers and thus need to be integrated in future research.

This article will proceed in four parts. First, it presents the case study and methods. Second, it describes the context of the health system. Third, it recounts three narratives of the near-miss experience. It concludes by arguing for an integration of micro-level managerial and financial issues at play in the hospital as part of the “near-miss” event.

\textbf{Methods}

This study was part of a larger four-country study of maternal and neonatal near-miss cases in four public hospitals in the Middle East. The study protocol was approved by the WHO Research Ethics Review Committee and that of the American University of Beirut. In Lebanon, data were collected in the Rafik Hariri University Hospital for a period of 41 weeks between 1 August 2011 and 31 May 2012.\textsuperscript{16} Out of a total of 1,178 births, 4 maternal, 17 neonatal, and 1 maternal-neonatal near-miss cases were identified by a hospital resident paid to collect the data according to WHO criteria and fill out the WHO-specific form (further elaborated in the previous reference). A neonatal miss was defined as any neonate who had severe morbidity (criteria of less than 1.5 kg, less than 31 weeks gestation, or Apgar less than five at 5 minutes) who survived the complication within the first seven days of life. The subsequent stage involved criterion-based audit and feedback through team meetings designed, in a non-blame environment, to identify factors requiring modification.\textsuperscript{17} Mothers were contacted first by a staff nurse, after which I arranged meetings in their homes throughout Lebanon, in the weeks following. My goal in collaborating with this project was to develop a set of anthropologically oriented (in contrast to predominantly clinical) case studies drawn from the mothers and/or newborns who had experienced near-miss events. I invited these women to tell me stories about their near-miss event and to describe their illness experience, to tell me about their births, hospitalisation, their effort to manage and treat the events, the responses to their condition by people at the hospital and in their communities, and the effects of those events on their lives.

I conducted, recorded, and transcribed in-depth home interviews in Arabic one to three months after childbirth with eight mothers of neonatal near-miss cases and their families, after an explanation of the study and a detailed process of written informed consent. In addition, I recorded my field notes and observations after each visit. Most of the interviewees lived quite a distance from the hospital (1–2 hour drive). While travel to the homes was time-consuming, the interviewees felt at ease talking outside of the hospital, and the time-lapse following delivery enriched the understanding of how parents deal with neonatal complications. The interviews lasted two to three hours. While I requested to meet with the mother, other family members joined in the conversation. Thus, in some of the interviews, the husband gives his version of the story too. The narrative presented here is mainly based on the interviews with women. The eight interviewees are from marginalised populations in Lebanon. Five were Syrians, one Ethiopian, and two Lebanese nationals from an underserved region (Akkar). Their homes were small, ranging from two-room apartments to a prefabricated cabin on a construction site. I limited this paper to three of the narratives due to limited space but also because they best communicate themes from all eight, namely the struggle to survive and negotiate payments of near-miss events while at the same time keeping specificities of the case at hand. I chose three cases of Syrian nationals because their difficulties in accessing
health care are even more acute than other migrant and marginalised populations in Lebanon and therefore they show the survival tactics and negotiations more clearly. One of the three cases has an infant who dies after his release from the hospital. While in this study, it is an exceptional event, the story illustrates the ways in which cost and access are essential to reducing the risks of neonatal deaths and morbidity.

The interviewees were asked to tell the story of the birth from the onset of labour until the baby’s discharge from the hospital. This elicited “stories” of birth and their babies’ hospitalisation.

Setting
Most of the women had planned to give birth in other hospitals but because of complications, they went to Rafik Hariri University Hospital in Beirut. The protracted Civil War in Lebanon (1975–1990) resulted in a health system with minimal state regulation, unhindered development of the private sector, a fragmented group of providers in addition to non-governmental organisations, and high out-of-pocket expenditures (about 39% of health spending). Slightly less than one-half of Lebanese nationals receive coverage through national health programmes, the rest being dependent on subsidies provided by the Ministry of Public Health and NGO sector. Lebanese citizens are entitled to care in a public hospital at low cost (85% of hospital fees are covered). Marginalised groups in Lebanon without national status, such as Palestinians, Bedouins and Syrians, suffer from greater limitations on access to health care. Some, before the Syrian war, could cross the Syrian border and get cheaper services. The 1.5 million Syrians, constituting 25% of the Lebanese population, are scattered throughout the country, complicating the administration of humanitarian aid. This poses a burden on the already strained health services. Hospital referrals are limited to emergency obstetric and medical cases, the cost of which 75% are covered by the UN High Commission for Refugees. Thirty-four per cent of the referred deliveries in 2015 resulted in caesarean operations. Otherwise, the average cost of childbirth in a Lebanese hospital is about $350, prohibitive for many families. Non-nationals are required to pay a deposit on arrival. Women reported barriers to accessing reproductive health care related to costs, distance, and the scarcity of female health providers.

Rafik Hariri University Hospital has 64 beds for obstetrics and gynaecology and 20 incubators. Public sector institutions remain underfinanced and under-staffed. Providers suffer from low morale. In a national survey of maternity hospitals, nearly one-half lacked a neonatal intensive care unit. Referral of neonates to intensive care appeared to be based on negotiations with clinicians.

Stories about complicated births
A significant common theme in near-miss stories regards financial access to care and how burdensome it is to manoeuvre the systems of payment at the hospital, involving the ministry of health, non-governmental, or charitable organisations and loans from family members or friends. The following three ethnographic vignettes point out these financial concerns in addition to medical and social issues. The three stories are of Syrian migrant families in Lebanon who had previously relied on a robust health care coverage in Syria but since access to Syria has been difficult or impossible since the war, they have found themselves in precarious conditions. The stories of the near-miss events illustrate the struggles for survival.

Azza and Ahmad’s story
I called Azza. Her husband, Ahmad, answered. I said I was part of a research group studying near-miss cases and would like to meet with his wife to discuss their experience with the baby’s complications. I met with him the next day at his place of work. Ahmad, of Syrian origin, had been working in Lebanon since he was a child, sewing clothes in a factory. After long years, he had finally collected money from relatives and now worked on his own account out of a store. He took me to his house in a poor part of the Burj el-Barajneh neighbourhood in southern Beirut, located on a dirt road. Here I met Azza. Azza told the story of her first birth in the presence of her husband, her baby, and her nephews and nieces.

At six and a half months, her waters broke. She and her husband had planned to go back to her village near Aleppo, where the daya [traditional birth attendant] would have assisted her birth. But when her waters broke, a doctor told her to go to Rafik Hariri University Hospital. She went there by motorcycle with her husband. They told her she was in labour. She requested something to stop the labour but they told her that one cannot stop
labour. She requested pain relief; they said “it is too late, no use at this point, you will give birth before the pain relief comes into effect.” Within a half hour, she had given birth to a baby boy. She overheard the doctor telling the nurses that this baby would not live. But the doctor came back and announced the baby would live. And he lived. The next day, the staff told her that she could see the baby. She walked into a room with incubators and babies in them, including hers. That same day she went home.

Azza and Ahmad speculated on why the delivery was early. Ahmad said, “well maybe it has to do with the fact that we had just moved to this house and Azza had a lot of work moving things here and taking care of my brother’s children.” He also thought there had been “psychological fatigue” (in Arabic ta’ab nafsi), due to displacement and living with his brother’s family and mother. In another case, the husband had said,

“The night of her early delivery she and I had an argument. You know she has quite a bit of work because we are six living in this room and that night she was upset [za’lana]. Do you think this could be why she gave birth early?”

Ahmad and Azza’s baby spent one month in the incubator. She would pump breast milk and send it with her husband to the hospital every day. By the fourth week, she no longer had milk. She saw the baby only twice during this period, the first day and two days later. They let her touch him once, passing her hand through the incubator window.

Azza’s baby needed blood transfusions so they rallied all their family and friends and provided what was required. I asked who paid for the incubator. Ahmad said the ministry of health paid $2000, and a similar amount was collected between the Islamic charity fund sanduq al-zakat and three NGOs located in the southern suburbs (the so-called dahyeh, controlled by Hizbullah), thanks to a friend with connections. The role of personal relations clearly emerges here. He spent 26 days going from office to office requesting funds to cover the incubator. In the end, he paid $750 from his pocket which his brother had loaned him. He did not have a penny of his own when Azza gave birth.

In the beginning, the hospital said it would cost them $10,000. He said, “well we don’t have money what can we do? I guess we take him out of the incubator and let him die.” A few nurses told him what to do. They said, do not ever take the baby away of your own accord. You need to make a little scene, in Lebanese, a mashkal [problem]. So he had his little scene where he shouted that he could not pay and what was he to do, he was poor, there is no work. “Let the baby die in the hospital rather than die in his family home … I don’t want him,” he told the hospital staff. “I am leaving him to die in your hands not in mine. I am leaving and I can’t pay you. If you want to throw out the baby and kill him you do it but don’t ask me to do it.” Twenty-four hours later, the amount the hospital was asking for went down to $5300.

For needy foreigners like Ahmad and Azza, the ministry of health seems to cover up to 50% or 60% of the costs. Ahmad went to the ministry and requested a letter from the minister, a promissory note for the $5300 owed. After three visits, an advisor to the minister wrote him the letter directing that $3000 be paid to Rafik Hariri University Hospital.

Mariam and Hashem’s story
The second couple I interviewed were from Ma’arra in the Idlib governorate and lived in the northern suburbs of Beirut. The husband, Hashem, had been working in construction in Lebanon for four years. His wife, Mariam, had been living with him since 2012. She had been planning on a birth at the Rafik Hariri University Hospital for about $400 which they could afford. She went into labour in the eighth month of her pregnancy. They rushed to the hospital and as she was delivering, the medical team used vacuum extraction, injuring the baby’s head. The baby was taken to intensive care and kept for 42 days. During that time period, Hashem went to the hospital daily and money was taken from his salary to compensate for absences from the workplace.

After weeks of managing payments and getting into debt, Hashem lost hope and told the doctors that he wanted to take the baby out of the hospital against medical advice.

“What could I do, we just could not pay and our debt was getting higher by the day, I wanted to go with the baby to Syria. One month and twelve days, I had 30 million Lebanese pounds ($20,000) in debts. 15 million I managed to get covered. But up until now I still owe 15 million.”

From the moment the hospital told him his son was in an incubator, they asked for the money.
“I went begging to the ministry of health and at charitable institutions. The first time, the ministry covered 5 million. Later, the ministry and two charitable institutions gave another 5 million. Every day, I would need to go looking for funds. I paid for transportation. All this costs money too. My salary, my brother’s and my father’s went into paying for transportation and a part of the hospital bill. And then, they told me I still owed 15 million pounds ($10 000). I signed an agreement that I would pay a monthly sum until my debt was repaid. But I don’t have anything. I can’t pay. My salary is not enough for us to rent a room and eat.”

After 1 month and 12 days, they took their son to Aleppo hospital, thanks to a loan from a friend and from a family member. But the operation the baby underwent was not successful. He caught an infection. His head started to swell and to secrete puss. They wanted to return to Lebanon, but at that time, it was illegal to bring families to Lebanon so they had to pay the Syrian authorities in order to come back.

When they returned, they went to see a paediatrician who helped them make a case for the ministry of health to cover 50% of the baby’s renewed hospitalisation ($4000). “This was on top of what the incubator had cost and what it had cost for us to go back to Syria.” Again, for three days, Hashem was looking for ways to pay for the operation his son needed. He finally found a donor from abroad, a German-Syrian donor, to cover the remaining $2000. “I thank him”, he said. “They would not have let us leave the hospital without paying the sum and without showing how we were going to pay $100 per month until we had covered the previous debt” of $10,000.

“We initially expected to pay $400 for a delivery. Which went up to $600 and then $700. We managed it. But then we could not anymore … I work in a factory that makes women’s shoes. I make $330 a month. I can’t pay an incubator. A single day costs $330. They told us God will help. Charitable institutions will help. Yes, they did help but we remain in debt.”

Amal’s story
The last story is that of Amal who lived in a prefabricated room on a construction site in Beirut. Five other male relatives and her one year-old son lived with her. She had planned on going back to her home town in Syria for the last month of pregnancy and giving birth with the local daya. But in the seventh month of her pregnancy, she started feeling strong contractions. She called the doctor and he told them to come to the hospital where he was working. She entered the hospital. It was deserted. She and her husband waited and searched the building and found no one. Finally they found a lady who said the doctor was in the operating room. Amal said she could not wait, she felt like something was falling out of her. The lady responded that the doctor said to go to Rafik Hariri University Hospital and he would follow her. They went to Rafik Hariri University Hospital. The nurse told her she was in labour and that her baby would be small and would need an incubator.

Amal started feeling strong contractions and asked the nurse to please deliver her. The nurse responded that she needed to wait and not push. The paediatrician who administered the incubators had not come yet. She said “I can’t wait” and the nurse said “you have to wait, please wait.” Then her waters broke. The nurse called for help. “Come, come, come!” she called. Two more contractions and the baby came out, little and blue. Tiny as he was, he cried. They told her “you gave birth to a boy and his situation is not good, he needs an incubator for two months.” They put an oxygen mask on him and then five minutes later they took him to the incubator.

The baby stayed in the incubator for 18 days. They paid $300 for the birth and another $330 for the first day in the incubator. Her husband went back and forth to the ministry until he was finally able to get some support. Back at the hospital, they were told the sum would cover the first 15 days, and that they needed to come up with more, which was impossible.

“We were so scared that one day they would oblige us to pay and we would not be able to. So we decided to take the baby out of the hospital and drive to Aleppo where care is cheap.”

“On the boy’s 18th day, we told the doctor we would take him to Syria. The doctor said it was not advisable, “but if you must, you need to go directly to Aleppo hospital so that they can put him in an incubator.”

They reached Aleppo and put him in an incubator for four nights. Then, he was discharged and they went back to her town. Fifteen days later, the baby started losing consciousness for about five minutes or so. Then his arm started swelling.
“We went back to the doctor in the hospital who said the baby was healthy. Maybe you dressed him too tightly or something. We said ok and took him back home. Then a few days later, he started gasping for breath during the night. We took him to the hospital, they put him on a respirator. We paid about $400 for that. They told us maybe he had not had enough oxygen during delivery. He stayed a week and then we took him to a cheaper hospital in our town. He was there three nights, then on the fourth at 1 pm, they told us he had had a haemorrhage in his lungs and died…”

Rafik Hariri University Hospital in Beirut does not have this information. I went to the interview with a present for the baby as I did for all the other interviews and was shocked to hear the baby was not alive anymore. Five months later, Amal was pregnant with another baby. In the eighth month of her pregnancy, she went back to her home town and gave birth to a healthy baby boy with the assistance of the daya.

Discussion

The concept of “political etiologies” highlights patients’ articulations of the causes of their disease as extending beyond the pathological and implicating corrupt institutions, states, polluted water, unsafe food, and toxic waste, providing an important macro-social and cosmological dimension to disease causation. Indeed, access to care is situated in larger social and economic structures, and the role of the anthropologist has often been to connect the patients’ experience to larger societal patterns. I argue here that an attention to the micro-level financial and managerial aspects of the patients’ narratives, in addition to the larger political and social causes of disease can expand understandings of the causes of ill-health beyond that of medical management. Parkinson and Behrouzan have argued for an attention to the micro-dimension of refugees’ access to healthcare in Lebanon in addition to an understanding of discursive and political dimensions of refugee life. The present cases show that the patients’ understanding of the causes of severe ill-health are not limited to larger patterns of exclusion (such as war, refugee status, displacement, poverty, being a foreign labourer) but also concern the work involved in securing funds and care often taking place in the institution of the hospital itself. In other words, the factors contributing to severe near-miss complications lie at three interconnected levels: larger political and discursive considerations, “proximal medical factors” involving the management of cases, and the institutional level regarding admission, payments, and the organisation of care.

Marginalised people in Lebanon face many difficulties in accessing maternal and newborn care and dealing with the health system’s bureaucracy. Health care requires endless negotiations and survival strategies when medical complications arise. Research from other countries has shown that grief from neonatal loss as well as financial burdens, which cause severe distress for the mother and family at the time of the event, may also have long-term psychological and social consequences. Payments for health care in these particular narratives were always complicated. Everyone needs to rely on connections of some kind. In Lebanon, political relationships facilitate access to health care. Ahmad had a friend from his neighbourhood, who managed to get him funds from NGOs. Indeed, all of the interviewees knew someone who knew someone who could help them get a payment from an NGO or charitable fund. This appears as an integral part of the way poor people’s health care is financed, despite partial support by the Ministry. And there are recurrent difficulties navigating the ministries requesting money, coupled with insecurity and insufficient coverage. Ahmad and Azza, for example, did not know whether they would be able to pay for the incubator until they got the “letter from the minister.” Mariam and Hashem remained burdened with a huge debt. And Amal and her husband were so scared of having such a debt that they took the baby out of the incubator and returned to a war-torn country, with fatal results. Indeed, among the eight interviewees, the Syrian migrants had the most precarious life and health conditions because they were often new migrants and because they had previously relied on the Syrian health care system which was now inaccessible.

We have also illustrated two methodological issues with near-miss research. The first concerns the choice of interviewees. With some exceptions, qualitative research on maternal and neonatal near-miss focuses on interviewing mothers. According to my interviews with women, fathers had the most contact with the hospital and baby, because their wives were resting after delivery, or because coming from rural areas, they worked in Beirut, with easier access to the hospital. The
fathers were the ones going back and forth to the hospital, running from office to office for money. Furthermore, in two of the maternal near-miss cases, the women had been unconscious and did not remember.

Secondly, there was a high non-respondent rate, partially attributable to the migrant aspect of most of the study population. Some women lived between Syria and Lebanon and were difficult to find. But others who gave wrong telephone numbers may have feared that the hospital would contact them asking for money. The stories themselves as well as the number of non-respondents are linked to anxiety over payments.

**Conclusion**

Recounting these stories to health professionals helped to frame cases differently from the usual case history and clinical audit approach and to contextualise and humanise near-miss cases. These voices and experiences might also contribute to pushing the boundaries of what informs health policy and the allocation of hospital resources. Complications and suffering might have been alleviated with accessible basic maternal and newborn care at the community level and also with advice and guaranteed financial support when costly hospital care was required. Policy-making designed to ensure access to health care should be a dynamic and on-going process aimed at inclusion and continuity in situations of shifting populations, instability and rising numbers of marginalised people.

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Résumé

L’Organisation mondiale de la santé a élaboré un système de déclaration, d’audit et de feedback maternel et néonatal d’événements évités de justesse, conçu pour améliorer la qualité des soins pendant et après l’accouchement. Dans le cadre d’une étude comparative de quatre hôpitaux au Moyen-Orient, cet article traite des expériences de mères dont les nouveau-nés ont souffert de complications graves à la naissance à travers les récits de naissance des mères. Les préoccupations des mères sont liées à l’accès aux soins néonataux et à la négociation de la bureaucratie des hôpitaux et de leurs dettes. Il cherche à démontrer que les aspects financiers et bureaucratiques de l’événement évité de justesse devraient faire partie du système d’audit et de l’élaboration des politiques, aux côtés des problèmes médicaux, dans la quête d’un accès et d’une gestion équitables des soins périnataux de qualité.