AIMS For a better birth...

Stories behind the numbers

AIMS Journal, 2015, Vol 27 No 2

Christine Morton looks at the social invisibility of maternal morbidities in the United States

Maternal mortality and morbidity are on the rise in the United States.[1] Reasons for the rise are being investigated at the national and state levels, with a number of states conducting in-depth, medical record reviews of maternal deaths.

In the wake of the Amnesty International report,[2] and determined advocacy by organisations, there is growing public awareness in the US about the rise and to a lesser extent, about the much greater numbers of women who experience life-threatening or severe physical complications as a result of pregnancy or childbirth. Numbers don't provide explanations as to why more women are experiencing severe complications in the US.

I am often asked whether women who died had access to prenatal care or whether outcomes are worse because women are older, weigh more, or enter pregnancy with chronic health conditions. While some of those factors contribute, the reality is more complex. Findings from the California maternal mortality review provide associations between women's demographic characteristics and causes of death, but are not able to compare women who die with women who have the same condition, but do not die.[3] In addition, data sources for maternal death reviews come from official institutions: vital records (death certificates); medical examiners (autopsy and coroner reports) and health care (medical records and discharge data). This data can provide some insight into the process of care during the acute event, but very little on the nature of the health care interaction or the meanings women give to their experience.

My research colleagues (Adina Nack and Jamie Banker) and I have been conducting interviews with women, sometimes their partners, and a sample of health care practitioners who see women throughout pregnancy, birth and postpartum, and sometimes years after. We are interested to learn how women understood their experiences of severe morbidity as they occurred but also how they recovered and healed. We want to assess the impact of these severe events on their social relationships and long-term health. There have been few studies looking at these issues in the United States. We have learned much from the research done in other countries.[4,5,6,7,8,9] We are in the early stages of our research; about to begin analysis of the first 25 interviews with women who experienced a range of maternal morbidities – including haemorrhage (severe bleeding), preeclampsia/eclampsia, cardiomyopathy (heart muscle problems), amniotic fluid embolism (life threatening condition where fluid surrounding the baby or other fetal material enters the mothers blood stream) and severe perineal tears. To find women to interview, we seek referrals from friends and colleagues; from healthcare practitioners and from many

organisations that advocate for and support those with particular conditions.

Organisational advocacy and resources around maternal mortality and morbidity

Organisations don't exist for every complication nor do all organisations offer the same type of support or resources for women and their families. After a significant morbidity, women seek information to understand what happened to them and why. Sometimes women turn to organisations in lieu of therapy to connect with others and normalise their own experience:

'I never actually did get therapy or any kind of one on one, which I probably should have done. But overall, I think that's one of the reasons why I sought out the March of Dimes and the Preeclampsia Foundation, because I think that was my form of therapy, to find other women who had been through circumstances with the prematurity and the preeclampsia. It normalised it in a lot of ways so I could talk about it and I could figure out, Oh hey! I wasn't alone in this.' (Jane)

Many individuals and groups are working to put a face to the growing numbers of women who die, or nearly die, as a result of pregnancy or childbirth. These efforts are nearly always either single-issue or uncoordinated and focused on a particular condition. Some grow out of personal loss and take the form of a foundation named after a loved one. Other efforts are broader in scope such as the Unexpected Project. Designed at first as a documentary film project, the project has evolved into a national movement to raise awareness and foster discussion, with a blog, a Facebook page and a regular column on the Huffington Post. Even broader is the Every Mother Counts organisation, based in New York City and focused on the global context of maternal mortality, including the United States.

Organisations such as the Preeclampsia Foundation and the Amniotic Fluid Embolism Foundation are also single issue, but have a mission to support women and families affected by the condition as well as develop patient-data registries, raise funds to support research, and engage clinical research experts as Advisory Boards. Single-issue groups attract women who got a specific diagnosis, especially when the condition is often fatal:

'I started doing research online. I started looking. I was, like, how did I not know about this before I had him? Why did I not know anything? Why was this never even mentioned to me? I found where there were links to Pitocin, you know. And I said, God. If I had known that, I would have never had Pitocin... Why did I not know these things? I realise it would scare the crap out of me, yeah, if I had been pregnant and then found out about it. But at the same time, maybe I might have made different decisions. I don't know.'(Julie)

[Editor's note. Pitocin is called Syntocinon in the UK. It is a drug used to induce labour. For more information see the AIMS book Inducing Labour.]

Finally, it is important to note that women who experience one of the most common complications of pregnancy – severe postpartum haemorrhage – have no particular organisation or advocacy group to turn to for support and information. In addition, we are not aware of US-based organisations for women who experience significant perineal damage requiring surgical repair. Indeed, those women often

describe feeling erased from public awareness of, and support for, their complication, as injuries like fistulas are not assumed to occur in high income countries. Even their physicians downplay the possibility, as Athena experienced when she returned to her obstetrician at nine months postpartum:

I told her, *"I'm still having multiple cases of fecal incontinence..." ...because she had warned me a bit that I could have..., I think it was even the next day after the birth, she said I'm at 50% risk of incontinence. Now to me, incontinence, I always thought meant urine. I never thought that fecal incontinence really was [possible].'* (Athena)

Our research on women's experiences with severe maternal morbidity will include analysis of organisational missions and their strategies and engagements with clinical and research experts.

Childbirth is a unique health condition

Childbirth is a unique health condition, with not one but two 'patients,' and the meanings attached to the birth of a baby are qualitatively different from other medical treatments where a mishap or diagnosis error may occur. Patient advocacy groups addressing medical errors, or 'medically induced trauma' bring unique contributions from patient perspectives to hospital level process improvements. Yet while these advocacy groups are gaining recognition within healthcare quality improvement circles, they tend not to address (or include) the unique set of concerns facing women who experience severe complications in pregnancy and childbirth.

One of the common concerns raised by women after a severe maternal event is how health care providers communicate with them, especially when there has been an unexpected or unwanted outcome:

'I can remember waking up and feeling... I was just mad. I was angry that it [a hysterectomy] had happened. I don't remember how I knew that everything had happened. I was told that a nurse had told me. She didn't know that I didn't know, that I wasn't going to be able to have any more kids. I had no clue what she was talking about and no one wanted to tell me at that point because I still wasn't stable and I guess this nurse kind of messed up and told me.' (Annabel)

After a severe morbidity, some women fear being back at home and alone with their baby, post-hospital discharge. Many women may be physically weak and require additional help at home. The US has no national maternity leave policy; family members may not live nearby, and partners may have to return to work. Terri describes how she felt after her third trip to the hospital postpartum after passing out and experiencing severe bleeding at home:

'I got released the next day and I wasn't feeling too bad. I went back to my mom's house and baby and I stayed there for a couple days because my husband had used any time he had off during the birth and afterwards. So he still had to be at work all day and ...even though I really didn't think it was going to happen again, I was nervous about being alone. With the passing out.' (Terri)

Women who have experienced a life-threatening event experience an existential crisis as well as a

medical one.[6,8,9,10] They need to process the event yet often find that family members and friends wish to put the ordeal behind them.

'There are times...when people say, "Oh, you should just be thankful you're alive." Well, I totally agree with that, but ...you know, it's hard. I guess every once and awhile you need a pity party and just to feel bad.'(Julie)

Our research is ongoing; we have much still to learn about how women recover and heal from a severe morbidity; some women carry the burden for years, with the child's birthday an annual reminder of what they have but also what they have lost. Our research is informing national initiatives around supporting women and their families after a severe maternal event and we hope our findings will also help the women who share their stories with us as well as those who are yet to experience this most unexpected outcome of pregnancy.

Christine Morton Christine is a medical sociologist at the California Maternal Quality Care Collaborative (CMQCC) at Stanford University.

References

1. Creanga AA, Berg CJ, Ko JY, Farr SL, Tong VT, Bruce FC & Callaghan WM (2014) Maternal Mortality and Morbidity in the United States: Where Are We Now? Journal of Women's Health, 23(1), 3–9. doi:10.1089/jwh.2013.4617.
2. Amnesty International (2010) Deadly delivery: The maternal health care crisis in the USA. N. Strauss. London, Amnesty International Secretariat.
3. California Department of Public Health (2011) The California Pregnancy-Associated Mortality Review. Report from 2002 and 2003 Maternal Death Reviews. Sacramento.
4. Mapp T (2005) Feelings and fears post obstetric emergencies – 2. British Journal of Midwifery 13(1): 36-40.
5. East C, Conway K, Pollock W, Frawley N and Brennecke S (2011) Women's experiences of preeclampsia: Australian action on preeclampsia survey of women and their confidants. Journal of Pregnancy, vol. 2011, Article ID 375653. doi:10.1155/2011/375653.
6. Elmir R, Schmied V, Jackson D and Wilkes L (2012) Between life and death: Women's experiences of coming close to death, and surviving a severe postpartum haemorrhage and emergency hysterectomy. Midwifery 28(2): 228-235.
7. Priddis H, Dahlen H and Schmied V (2013) Women's experiences following severe perineal trauma: a meta-ethnographic synthesis. J Adv Nurs 69(4): 748-759.
8. Furuta M, Sandall J and Bick D (2014) Women's perceptions and experiences of severe maternal morbidity – A synthesis of qualitative studies using a meta-ethnographic approach. Midwifery 30(2): 158-169.
9. HealthTalk Online (2014) Conditions that threaten women's lives in childbirth & pregnancy. HealthTalk Online: People's Experiences, from healthtalkonline.org/peoples-experiences/pregnancy-children/conditionsthreaten- womens-lives-childbirth-pregnancy/topics.
10. Morton C, Nack A and Banker J (2014) The social invisibility of maternal morbidities in US

motherhood narratives: Giving voice to lived experience. Motherhood Conference. New York City, MOM Museum.