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Maternal Death Reporting

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Ina May Gaskin looks at financial pressures versus accurate maternal death reporting within the US private healthcare 'system'

I certainly can't predict what is going to happen in the UK, where since the early 1950s, those in the know take accurate maternal death reporting for granted. I can, however, explain to some extent (it would require a book to list all of the weaknesses in the US system) how large a role financial considerations have played in my country in the prevention of designing a system of even accurately identifying and reporting maternal deaths, let alone extending that system to reviewing, analysing and then making public their findings.

I was shocked when I first became aware that in my beloved country, it was possible in some hospitals for a mother to die as a result of a mistake and then to have the actual cause of her death falsified on her death certificate in order to lessen the chance that the real cause of her death might be discovered.

I had already read a brief report in a bulletin published in 1998 by the Centers for Disease Control (CDC) to the effect that maternal deaths in the US were seriously underreported - to such a degree that possibly more than half of the actual pregnancy-related deaths were not identified. That impressed me as a pretty serious flaw in the system, one that prompted me to start asking questions. I listened to countless stories from doctors, bereaved family members, nurse-midwives and nurses about how lies and cover-ups happen when death certificates are filled out.

Realise that it was only in 2003 that a standard US Death Certificate intended for use in all fifty states came into being. It took at least two decades of strenuous effort by state epidemiologists to reach consensus on the questions that should be included on a death certificate to catch those deaths that could possibly have been pregnancy-related. The brilliant new idea was that the standard certificate would replace the fifty individual state death certificates that were in use prior to 2003.

Our epidemiologists are not idiots. They have to be aware of the statistical garbage that results from data gathered in such an inconsistent, haphazard way. How embarrassing it must be for them to attend international conferences and have to admit to international colleagues how primitive our maternal death reporting 'system' has always been.

However, having created a standard death certificate form in a country in which private medicine and private hospitals are the norm and states' rights are held sacred, particularly as related to matters of health care, does not mean that the product will come into use in every state. That next step may take as

long or longer than it took to create the standard form.

It might be different if the CDC had the clout to make it mandatory for the states to replace the form they are currently using with the standard. It doesn't. The states have the right of refusal. Who will pay for the change? Only Congress could settle that question once and for all, but it is not a US habit to think about national solutions in such matters. Old habits die hard, to say the least. The states were left to bear the financial burden, and quite a few decided not to switch to the new standard form. The CDC can coax, but it cannot compel.

Now more than a decade has passed since the Standard Death Certificate became available and the CDC began encouraging its use. I tried calling every state several years ago to find out how many states had refused and found more than fifteen 'hold-outs' then. Living in one of them let me know they still exist. The CDC hasn't told us how many still refuse to open the state purse strings to make this onetime change to help the CDC be able to make an announcement that the Standard Death Certificate actually deserves its name.

It boggles the mind to understand how hard it is in a country where private health care and hospital ownership have long been the norm, for the concept of the necessity for accurate maternal death reporting to be introduced, let alone accepted. How would one 'sell' such a revolutionary concept to national or state legislators? Who has the attention span to follow the argument? There is so much inertia, indifference, deception, denial and disbelief to overcome that people can't find the words to make something different happen. I tried but in the end, I've had to leave that work to others.

I nearly wept the first time I was handed a copy of the book that was published triennially in the UK by the Confidential Enquiries into Maternal Deaths before its privatisation and saw the care, the detail, the thorough planning and the level of social agreement that had produced such a continuing effort. To be told that this book (Why Mothers Die and later Saving Mothers' Lives) could actually be purchased by any member of the public at a bookseller was a revelation to me. I realised that people in my country are far from imagining that such an effort could be possible, let alone why it might be necessary.

The more questions I asked, the more I found out that maternal mortality review committees in several states which had previously been organised by certain obstetricians with active consciences had been undone and disbanded during the 1980s and 1990s. This backward step taken by several states was prompted by pressure from lobbying groups representing the interests of private hospitals. These groups claimed that the continued existence of the statewide mortality and morbidity review committees would increase the chance of reports resulting from such investigations being obtained as evidence in malpractice lawsuits. Never mind that laws could be passed to provide confidentiality for such reviews. Fears of bad publicity or financial loss to private hospitals trumped any positive action to reduce maternal death rates by first reaching a high degree of ascertainment.

Need I mention that if lies are legal and may protect the financial interest of a hospital, they will be told? It boggles the mind to realise how little provision for preventing maternal death exists in the current US

system, even after so many media reports have appeared about the rising maternal death rate in our country. These reports rarely mention the serious underreporting factor or the fact that failure to gather data in a way that meets international epidemiological standards is only one of the many reasons behind the underreporting.

Journalists continue to assume that the CDC's reported maternal death rates are reasonably accurate when that is still far from the case. Few people understand that women of childbearing age die for all kinds of reasons that can be easily covered up when there are no rules governing the process of data collection that provide for punishment when they are not followed. How many legislators at the state or national level even know that accurate data gathering is vital to accurate answers as to the leading causes of death? When these answers aren't available, it becomes habitual to guess, and such guesswork often leads to answers that would suggest that the woman herself might have been the author of her own demise. She was too old or too overweight for her own good.

A maternal-fetal specialist told me that 'amniotic fluid embolism' recorded as a cause of death is often suspect, because it's the 'waste-basket diagnosis' - the cause of death least likely to invite suspicion or investigation. When I first started asking questions that might shed some light on why there could be so much underreporting on such a grave matter I remember a case in which the family had first been told that the mother's uterine artery had been nicked and repaired during an emergency caesarean but that she had survived. When the repaired artery burst and she haemorrhaged a few hours later, her life couldn't be saved.

I decided to see if an ordinary citizen such as myself could have a look at the death certificate. Since I had lived in the university town where she died, I knew the name of the county and was told that I could get a copy if I sent $10. (This would no longer be possible, by the way). Cause of death: amniotic fluid embolism.

The fact that autopsies after a pregnancy-related death in the US are not required by law or custom creates another reason to doubt the answers to the 'cause of death' questions on death certificates. A nurse-midwife from California told me about a death from the haemorrhage that followed a sliced uterine artery in which the cause of death was filled out with 'anaemia'. Tears came to her eyes when she told me the story.

The fact that most of our fifty states allow hospitals to have internal, closed-door, highly confidential reviews following a maternal death because there is no morbiditymor tality review committee at the state level with the authority to demand access to the records of the deceased woman's care adds another incentive to record a lie on a death certificate. There is no audit. I can't count how many times I have listened to stories of frustration from obstetric nurses and nurse-midwives who were not allowed to be part of the 'review' that was carried out after a maternal death in their maternity unit and were left suspecting that a cover-up was being made.

Another important issue within a private system is that an autopsy following maternal death is not covered by public insurance or by most private maternity care insurance. This puts the burden of

payment on the family in grief and is a big factor in why autopsies are more rarely done than they were decades ago. Autopsies tend to be reserved for cases of criminal death, not for death in the maternity ward. I have talked to several bereaved family members who wished, months or years after a mother's death, that they had insisted on an autopsy to identify the real cause of her death, who were influenced not to by a person in the hospital who was represented as a 'grief counsellor'. One woman told me that such a hospital employee had made comments to her daughter's husband about how an autopsy wouldn't bring her back to life and linked this to his decision to forgo one in her case, a decision he later regretted. What I have written here is far from complete, I have only touched on some of the fundamental reasons for the gross inaccuracy of US maternal death reporting and the failure to organise a system of enquiry worthy of the name.

Another time when I felt like crying was when I read about the removal of the Confidential Enquiries process in the UK from directly under the Department of Health to a commissioned consortium that reports to a number of different bodies and realised that the four copies of that comprehensive triennial report that I made sure to get while they were still being published stand now as evidence of a bygone era in the UK. Fortunately the enquiries are currently being carried out by the National Perinatal Epidemiology Unit (NPEU), but there is the possibility of these being placed elsewhere and of them not being in such good hands, as the state increasingly gives up responsibilities for services.

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