AIMS For a better birth...

Why Mothers Die

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Jean Robinson concludes her review of the latest Confidential Enquiry into Maternal Deaths for 2000-2002[1].

We sent in so many questions and comments about the last report on maternal deaths that the Director, Dr Gwyneth Lewis, suggested a meeting, so Beverley Beech and I went off to the Department of Health. We took the opportunity to express our gratitude, on behalf of all parents, to her and the whole team involved, for the work that goes into the Confidential Enquiries, and particularly for her work in extending their scope. Our lengthy meeting was helpful and constructive, and we were reassured to meet someone who genuinely listens to consumer views.

Because records of cases analysed are destroyed, to preserve confidentiality and protect staff, unfortunately many of our questions could not be answered (e.g. how labour and birth had been managed in cases of women who had had a fatal haemorrhage after vaginal birth). However, we flagged up our concerns and hope they will be remembered in the preparation of the next report. And we are sure that phrases like "the obstetrician allowed the woman to labour" will not be used again.

Suicide - the biggest killer

Once again, the largest single cause of maternal deaths was suicide - as it was in the previous report for 1997-99[2]. This has been revealed because the UK looks at maternal deaths up to one year, whereas most countries collect deaths only up to 6 weeks after a birth.

About 50 women in England and Wales committed suicide in that first year, or there was an open verdict at the inquest. Another 14 women died from accidents or overdoses that were likely to have been self inflicted. This total greatly outnumbers the 30 deaths from thrombosis - the largest direct cause of maternal death.

AIMS can claim credit for its long campaign for collection and analysis of suicide figures. For many years we had little response from the Department of Health. However, when Dr Gwyneth Lewis took charge of the Enquiry at last someone listened, and we are immensely grateful for the thorough way psychiatric deaths have been covered in the last two Reports. Because most suicides happen after 6 weeks, when women are no longer having maternity care, they are not reported as "maternal" deaths. However with data collected from the Office of National Statistics, most of these later deaths are now picked up by the latest Confidential Enquiry.

This report, like the previous one, shows that the women who killed themselves were different. In most

other causes of maternal death the women were more likely to be poor, live in deprived areas, come from minority ethnic groups, or be socially excluded. But the suicide cases were mostly white, older women who were married and reasonably well off, and some were health care, or other, professionals.

Women who have previously suffered from severe mental illness, whether postnatal or otherwise, are more at risk. If they had postpartum psychosis there is a 50/50 chance of recurrence after another baby, so they should be carefully monitored.

AIMS comment

The previous report for 1979-992 report showed that half the women who killed themselves had a previous serious mental illness. One of the problems found was that sometimes previous serious episodes like post-partum psychosis had been wrongly recorded in the notes as "postnatal depression", so that the Report recommended that all pregnant women should be questioned about their psychiatric history "in a sensitive manner". Overnight, without discussion or consultation, screening pregnant women for any past mental illness became national policy. Those of us on the consumer sharp end know that recommendations for sensitivity in official reports cut no ice with staff having to get through the agenda dictated by Risk Management for the booking visit. And routine probing and recording of mental illness history clearly began long before the necessary staff training was put in place. (And what, exactly, does this training consist of?) We also knew from our clients that mental illness on the case notes can adversely affect care in many ways.

We immediately sent in a warning to the Confidential Enquiry as to what we knew would happen - and it did. Complaints quickly appeared in our postbag, from women who felt harried, labelled and permanently stigmatised - and no longer trusted maternity care as a result. The latest report1 now says "local training must be put into place before routine screening for serious mental illness is implemented". Too late.

To identify women who have a past history of postnatal psychosis, or any mental illness serious enough to put them in hospital is important, because they are likely to be those most at risk. But will the attempt to record ALL past episodes of mental illness improve care and decrease risk to the extent that it outweighs possible disadvantages? Will it do more good than harm? That has yet to be proved. All our past data suggested it might put the woman at further risk - of stigmatory care, of being disbelieved and most certainly - of being summarily dismissed if she made any complaints about her care. What is likely to happen is what has happened with health visitors screening for postnatal depression- women have learned to lie3. Already women are telling us they wish they had never told the truth, and they are telling their friends to be careful. Identifying women who could be at risk sounds fine, if supportive care follows. But the report itself shows that psychiatric care that diagnosed women receive may be inadequate. All this has happened at a time when the witch hunt for potential child abusers has reached alarming proportions. Identification of potential risk merely triggers referral to social services (to cover everyone's back), and from personal observation we have seen how some social workers treat mothers with postnatal depression. Mental illness is considered a risk factor for child abuse - and safeguarding the child has taken priority over helping the mother - even if it further damages the mother. We also have to

be aware that in the current climate some local social services are receiving instructions from their Inspectorate to increase their figures for adoptions3, and babies are the most desired adoptees. Mothers with postnatal depression are in just such a position.

Hasty, inadequately prepared, recommendations for screening or different care can go awry when policy makers do not understand the culture within the service. The consumer view can sometimes help in avoiding mistakes.

Quality of psychiatric care

One of the most valuable findings of the last two reports is that only one of the many women who committed suicide in the past six years had ever been treated in a mother-and-baby psychiatric unit, and it seems they reduce suicide risk. Unfortunately these units where a mother can be treated by specialist doctors and nurses, without being separated from her baby, are few and far between. Ten women had been in psychiatric hospitals during this pregnancy or after the birth, 13 had been treated by a psychiatrist or community nurses, and 5 were being treated by their GP. As with the previous report, more than half the women who killed themselves were receiving, or had received, treatment for their problem.

AIMS comment

We are grateful that this report, once again, calls for use of specialist mother-and-baby psychiatric units. The shortage of such units is a scandal. The Department of Health does not even know how many there are, and where they are located! We had to fight vigorously to get one of our Mums admitted to such a unit - bitterly opposed by the social worker, who had booked her baby for adoption, although she had a treatable, curable, severe postnatal depression and was suicidal. Another mother temporarily lost her baby too, because what turned out to be postnatal depression was diagnosed as Munchausen Syndrome by Proxy in an area we know clinicians to be that way inclined. The new Mental Health Act in Scotland requires that mothers requiring to be admitted post natally must be treated in units where they can have their baby with them. They are a long way ahead of us.

An additional scandal is that some of our major maternity units do not even have a specialist perinatal psychiatrist, and there are restrictions on referring mothers outside their own area. One of our mothers was told she could not be referred to a perinatal psychiatrist elsewhere by the GP, so he referred her to a local general psychiatrist who could make such a referral. However, the psychiatrist kept her as his own patient, and did not provide the treatment she wanted and which we felt she needed.

In the last two Reports, educated, middle class mothers who died had concealed their previous history of post-partum psychosis, and killed themselves when it recurred. Is it possible that their experience of previous care in general psychiatric hospitals had not given them confidence in a repeat dose? It was these knowledgeable families (including health professionals) who were sometimes helping the mother to conceal their past medical history, well aware of the implications of psychiatric records and diagnosis.

They knew that a psychiatric medical record can be a handicap, both medically and professionally.

Yet this was not taken on board when it was decided that all expectant mothers should have previous psychiatric history recorded. There are insufficient provisions to deal effectively and humanely with the potential problems identified, and they may simply be increasing the size of the haystack, making it more difficult to pick out the needles.

Postnatal post traumatic stress disorder - the missing diagnosis

The Reports says

"The term postnatal depression should not be used as a generic term for all types of psychiatric disorder. Details of previous illness should be sought and recorded".

AIMS comment

Nowhere in this report, or any previous one, is there any reference to postnatal post traumatic stress disorder (PTSD). Yet after the last report, we published a summary of our clients' experiences, showing that they were more likely to be suicidal, or to have attempted suicide, than our "depressed" clients[3]. And many of the women with prolonged depression had either experienced some birth trauma, or had undiagnosed PTSD. We believe that diagnosis and early treatment may reduce the risk of suicide; it would certainly reduce suffering considerably. Unless health professionals are warned to look for it, potential suicide cases may be missed.

Infanticide

There were three cases where a woman killed both herself and the baby, and two of these killed an older child as well. One had a history of bipolar disease. In a fourth case, a woman who had had an unassisted birth, killed herself when she and her partner were about to be charged with wilful neglect leading to the baby's death. The Report points out:

"Implementing child protection procedures alone is not only unlikely to protect the mother and infant, but also may increase the risk by increasing guilt and the fear that the child may be removed. The most effective way of protecting both the mother and infant's life is early risk identification and rapid and effective treatment."

AIMS comment

We do not know that the fourth case listed was, in fact, infanticide committed by the mother, or should be labelled as such. What is clear is that the risks to the mother of suicide are far greater than the risk of her killing the baby. Yet health visiting and social services, and to some extent maternity services, are now concentrating on potential risks to the child, whilst psychiatric care for affected mothers is both inappropriate and inadequate, and interventions to protect the child can increase her risk of suicide. In the last two reports mothers who feared their children would be taken, or who had previous children

taken, killed themselves.

Our Chair, Beverley Beech, has sent a strong formal protest about the description of late pregnancy deaths in the Report which stated:

"In addition, four suicides occurred in the last few weeks of pregnancy and a viable infant died. This could be seen, psychologically, as indistinguishable from infanticide."

We have pointed out that neither legally, ethically nor psychologically are these deaths equivalent to infanticide, and they should not be labelled as such, so that the dead and the families are further damaged by these tragic events. From the work which AIMS has done on consent by pregnant women and new mothers to research, we know that the protective attitude to the infant which has been born, seen and held, may be very different from attitudes to the one which is unborn.

A pregnant woman who failed in her attempted suicide but killed her baby could not be charged with infanticide. An unborn child has no separate legal status. We are only too aware of what is happening in some parts of the USA, where pregnant women are imprisoned, allegedly, to protect their unborn children, and we are anxious that no slippery slope begins here.

Murder

Twelve women were murdered, nine of them during pregnancy, and all of them had a known history of domestic violence. Many of them had "overbearing" partners who were present at clinics, and most had inadequate antenatal care. They were likely to be late bookers or non-attenders. A number of women had gonorrhoea from their partner during the pregnancy, and some had a history of multiple miscarriages or unexplained vaginal bleeding. Most of these women were known to social services.

Another 43 of the women who died in this Enquiry were known to suffer violence. That is 14% of total maternal deaths. These cases happened before women were routinely asked about domestic violence, and not all who were asked will tell, so the real percentage of abused women among maternal deaths is probably much higher. Seven of the nine maternal deaths in those younger than 18 happened to women who were in violent relationships, and four had a past history of sexual abuse.

AIMS comment

When the dead women had had solely midwifery care, midwives are criticised for not liaising with psychiatric services and the child protection team. But as we have seen, health and social services increasingly concentrate on potential risk to children when there is a violent partner, although statistically the greater risk is to the woman herself. If health and social services recognised this and looked after the needs of the women, they might more effectively protect children also.

Midwifery care, or coercion?

The chapter which summarises issues in the report for midwives, talks of the need to "actively follow up"

women likely to be most at risk who do not obtain regular antenatal care, and says imaginative solutions may be needed (such as different locations and times for antenatal clinics, and outreach services). Moreover, midwives should be advocates for the socially excluded and "provide navigation through health and social care systems." It admits that non-attenders may find the current service unapproachable, or that it does not "reflect their perceived wishes."

AIMS comment

Where this section falls down is when it comes to dealing with women who choose to opt out, rather than those who lose touch or can't get in:

"Where medical intervention is required but is against the woman's wishes, the midwife should seek alternative routes to ensure provision of appropriate care for instance arranging home visits by obstetricians or using family, friends or religious leaders to influence compliance with care plans."

We were deeply shocked to see this, and have sent a strong, formal protest to CEMACH. Such an action would be a breach of confidentiality, a breach of the woman's autonomy, and against the Code of Conduct of the Nursing and Midwifery Council. Any client whose midwife had behaved in such a way would be advised by us to make a complaint of professional misconduct to the NMC, and we would back her up. What is more, it sounds discriminatory. Somehow we don't think the author envisaged Church of England vicars urging members of their flock to have an induction or caesarean. We await a reply.

Clearly the author of this chapter sees midwifery advocacy in narrow terms of getting women into the system and making sure they stay there - a rather different approach to that of many of our midwife members. Another recommendation also caused us concern. Although interdisciplinary working is recommended to plan the best care, this chapter alone goes further and says:

"Midwives should access, and have direct access, to the woman's GP records and details of any previous medical, psychiatric or social history that may have a bearing. It is not fair on the woman to expect her to relay all such information."

Again, we think this outrageous. The friendly midwife has now become Big Brother, and the woman is to have no control over her poking into aspects of her past history that she may not wish to discuss. It infantilises women. The woman is not trusted. We suspect this recommendation has slipped in because some GPs have not passed on clinically relevant information, but that should be taken up with the doctors, rather than getting the midwives to bypass them. Over and over again we see people opting out of orthodox medical care, or NHS care, because they cannot control what information about them goes where - and it goes to people whom they do not like, and often have cause to distrust. There is no limit to its spread.

Such a recommendation is going to decrease trust in midwives. Once again, we have protested, and await a response. Watch this space.

References

1. Lewis, G. (ed) Why Mothers Die 2000-20002. RCOG Press 2004
2. Lewis, G. (ed) Why Mothers Die 1979-1999. RCOG Press 2001
3. Robinson J. Post-traumatic stress disorder - a consumer view. In MacLean A B, Neilson J (eds) Maternal Morbidity and Mortality. RCOG Press, London 2002 pp 313-322.