A Hierarchy of Sadness?

A Study of Late Miscarriage, Stillbirth and Early Neonatal Death

Alice Lovell

Sorgens hierarki ifrågasatt

Alice Lovell är sociolog och universitetslektor vid South Bank University i London. Den artikel hon här bidrar med publicerades ursprungligen i "Social Science and Medicine" och återges i en bearbetad version med vederbörligt tillstånd.

Under en period kom Alice Lovell att hjälpa sin man David som är patolog med en del sekreteraruppgifter. Hon blev då medveten om hanteringen av dödfödda och tidigt döda barn och började intresera sig för vad som hände med föräldrarna. Detta är bakgrunden till denna studie som ursprungligen pub-licerades 1983.

I studien tar Lovell med inte bara barn som dött i anslutning till förlossningen, det vill säga barn som fötts döda efter utgången av tjugoåttonde havandeskapsveckan eller som dött inom en vecka efter födseln (perinatal death or early neonatal death), utan också sena missfall. Hon har genmfört intervjuer med 22 mödrar samt med personal av varierande kategorier, obstetriker, barnläkare, sjuksköterskor, barnmorskor, kuratorer och sekreterarpersonal, vid fyra sjukhus i London. Praxis beträffande omhändertagandet av föräldrarna varierade vid de olika sjukhusen. Somliga var beredda att konfrontrera dem med verkligheten; medan andra praktiserade en beskyddande attityd, som innebar att man ville skona dem från att se det döda barnet och ta hand om begravningen av det. I fyra fall rörde det sig om missfall, tio barn var dödfödda och åtta hade dött inom en vecka efter födelsen.

Bland personalen var det vanligt att man såg ett missfall som en liten förlust jämfört med de övriga och förlusten av ett dödfött barn som mindre än om barnet levt vid födelsen. Kvinnornas erfarenhet var annorlunda men starkt påverkad av inflytandet från personalens attityder. Detta gick särskilt tydligt i dagen när det gällde frågan om modern skulle se det döda barnet eller inte. Personalens ordval antyder att man ansåg sig veta vad som var bäst. Det talades om att 'låta' en kvinna se sitt barn. Olika uttryckssätt kontrasteras effektfullt mot varandra. En närvarande barnafader som avstår från att se sitt barn får veta att han gör alldeles rätt för "det är en ful liten en" eller mera ordagrant "en ful liten sak". En av mödrarna ser sitt barn sedan hon fått veta av barnmorskan att det är ett vackert barn, "för vackert för den här världen". Ingen av dem som sett barnet ångrar det.

Det finns enligt Lovell ett uppenbart samband mellan att se barnet och att vilja ta hand om begravningen. Tio mödrar hade sett barnet och arrangerade begravningen och visste var graven fanns, medan de andra som inte visste vart barnet tagit vägen och heller inte sett det talade om en känsla av overklighet. De flesta beklagade att de inte sett barnet. Lovell skiljer mellan informellt och formellt ritual. Det senare syftar på begravningen. Med informellt ritual menar hon alla olika tillfällen som ges att tala om barnet, information, småprat, genetisk rådgivning, förklaringar om vad som hänt och meddelande av obduktionsresultat. De mödrar som tillhörde en social lågstatusgrupp var ofta otillfredsställda med den information som erbjudits.

Endast i ett fåtal fall hade Lovell möjlighet att träffa fadern, varför hon måste koncentrera sig på de uppgifter modern lämnat. De kunde ha varit av intresse att veta kvinnornas religiösa tillhörighet. I den ursprungliga studien framgår deras etniska bakgrund. De flesta, det vill säga fjorton, är födda i Storbritannien, fyra är av asiatiskt ursprung, en från Nya Zeeland, en från Västindien, en från Mauritius och en från icke angiven bakgrund. Två av kvinnorna är yngre än tjugo år och fyra är mellan tjogoett och tjugofem. De flesta är mellan tjugosex och trettiofem år och bara två äldre än trettiosex. Bara någon enstaka har eftergymnasial utbildning.

Lovell påpekar att intervjuerna genomfördes under åren 1980-82 och att mycket förändrats i Storbritannien under de följande tio åren. Det gäller främst frivilligorganisationer som "The Stillbirth and Neonatal Death Society" (SANDS) och "The Miscarriage As-

sociation". Båda har haft och har stor betydelse för att påverka attityder både på sjukhus och i samhället i övrigt. Fortfarande tycks dock missfall innebära en situation som är sämre tillgodosedd i fråga om psykologiskt omhändertagande än de övriga. Den organisation som arbetar för kvinnor som fått missfall fanns dock inte när Lovells studie genomfördes.

Här i Sverige har vi en lång tradition, där enligt lag dödfödda barn som fötts döda efter utgången av tjugoåttonde havandeskapsveckan skall gravsättas. Sedan 1982 är det också möjligt att gravsätta foster som framfötts döda före tjugoåttonde veckan. Socialstyrelsen har 1990 utgett råd rörande omhändertagande av foster efter spontan eller legal abort under graviditetsvecka 13-28, varvid man rekommenderar att sådana foster kremeras och att askan gravsätts anonymt. Socialstyreslens råd har varit föremål för ganska skarp kritik. Man har befarat att kvinnor som gjort abort skulle uppfatta detta som skuldbeläggande, medan andra har tyckt att ett sådant förfaringssätt bättre svarar mot en etisk hållning.

Utvecklingen i Sverige, Storbritannien och USA mot en ökad medvetenhet om kriser och krisreaktioner och vikten av konfrontation med verkligheten i samband med att föräldrar förlorar barn vid förlossningen finns beskriven i Andersson Wretmark, Perinatal Death as a Pastoral Problem.

Alice Lovell, Senior Lecturer, är verksam vid Legal, Political and Social Sciences, South Bank University, London.

In the Middle Ages, various categories of people considered 'undesirable' were denied Christian burials; these included pagans and excommunicates. It was believed that if we may not associate with them in life, then we must remain apart in death. Unbaptised infants fell into this 'undesirable' category. They were not buried in Christian cemeteries, just as their souls, tainted by 'original sin', were banned from entry to heaven. Such babies were imagined to be in limbo (1). The dictionary defines limbo as:

> "Region on border of hell, abode of pre-Christian just men (sic) and unbaptised infants; place in which *unwanted or forgotten things collect*." (my emphasis)

The present study tried to see to what extent these views prevail.

Aims and Method

The research looked at various aspects of the loss of a baby through 'late' miscarriage, stillbirth and early neonatal death (2). It seemed to me that these losses are on a continuum and I was interested in the similarities and differences in the way they are perceived and managed. How definitional labels are applied gives clues to a better understanding of the social construction of personhood and non-personhood.

In this study, I looked at some of the recommendations of the Stillbirth and Perinatal Death Association* which suggests that a mother be encouraged to see her dead baby, hold a funeral and have counselling. I widened the concept of counselling to 'informal' ritual (3). This includes receiving information and talking in general.

The hospital management of death associated with birth was explored and fairly concrete factors, such as a woman's length of stay and where she was located, were noted as well as actions and attitudes of staff.

In order to gain the perspectives of the health professionals, I talked to staff at four London hospitals. Semi-structured interviews were conducted with hospital workers, including obstetricians, paediatricians, nurses and midwives, social workers, technical and clerical staff.

To find out how the mothers (4) perceived their experiences, I carried out interviews with 22 bereaved women (5). I visited the mothers in their homes and tape-recorded the interview which lasted between 1,5-3 hours. The interview covered a range of topic areas about their pregnancy and post-pregnancy experiences in hospital and in the community. Each mother was asked the extent to which she felt she had 'accepted' her loss and factors which had been a help or hindrance.

The 22 losses focused on in the study were as follows: Four late miscarriages, 10 stillbirths and 8 early neonatal deaths.

Of the issues which emerged, some are looked at both from the 'official' position using the viewpoints of the professionals and from the perspective of the bereaved mothers.

The issues concerning identity construction and deconstruction of the baby and mother have been posed as questions. Attempts to answer 'What is a baby?' and 'What is a mother?' lead into deep philosophical waters, but the aim is to point to their problematic nature and

---

* Now known as Stillbirth and Neonatal Death Society (SANDS).

Attempts to answer 'What is a baby?' and 'What is a mother?' lead into deep philosophical waters

question the dominant influences which shape and define our thinking and our care.

What is a Baby?

It seems ironic in a social climate where technically-induced cessation of fetal life is carefully addressed from all angles, 'natural' deaths should be so neglected as an area of professional concern, and also so poorly managed. Perhaps death in birth is a very threatening anomaly.

The way death is defined is currently one of the most controversial issues in medical, legal and social terms. At the other end of the spectrum, an equally emotive controversy rages: the way in which life is to be defined. Before 1803, abortion prior to 'quickening' was not a crime (6). 'Quickening', when the baby's movement is first felt, usually occurs around the twelfth week of pregnancy and was when the soul was presumed to enter the fetus. In considering the status of a baby, then, we are led to question when a baby becomes a person; what *is* a baby and how does it differ from a fetus?

Stillbirth (7) can disappear as a category when it is encompassed by the Perinatal Mortality statistics, though a stillborn is not treated identically to a baby who has 'shown signs of life' but dies perinatally (within seven days). Determination of weeks of gestation is not an exact biological fact and can be manipulated to suit perceived needs (8). Hospital professionals are unclear about how and when these categories appear, disappear and change.

All live births require a birth certificate. Thus, at present early neonatal deaths have a birth and a death certificate although the concept of a single perinatal death certificate has been suggested (9). Stillbirths require a Certificate of Stillbirth (10) which is not given automatically to the parents. Miscarriages require no such documentation and can be treated as gynaecological scrapings.

By conflating the birth and death on a single form, stillbirth registration may contribute materially to the lack of due significance of two events: life and death seeming to cancel out. Whilst the lack of paperwork surrounding miscarriage may be seen to deny that the baby ever existed.

In his discussion of everyday and medical knowledge, Hughes (11) looked at the way specialised knowledge in medical practice was sometimes substituted for everyday theorising in identifying patients' conditions. Kovit (12) noted that medical professionals often referred to a stillborn as a 'bad baby'. In my own study, this linguistic slippage between medical and everyday terms indicated deep-rooted feelings as to what constituted a baby and what babies 'ought' to be like. Such ideology was barely disguised.

I found that health workers considered that the earlier the pregnancy failed, the 'lesser' the loss, making miscarriages less sad than stillbirth; and stillbirth less sad than losing a baby who had lived (13). It followed that miscarriage and stillbirth were not viewed as proper bereavements. Similarly, when the lost baby had a physical deformity, he or she was not considered to have been a proper baby. In such cases, there was a strong likelihood that the perceptions of the people around the mother helped to confer a spoiled identity upon the baby and this process may have led to the de-construction of the baby's identity altogether. Thus, the woman who, as well as having a dead baby, had an imperfect baby, seemed to feel that she had been doubly deviant. This theme was illustrated by the professionals' influence on the mother regarding contact with her dead baby.

Seeing the Baby

Of the 22 mothers interviewed, ten of them never saw their dead babies (14). One of the ten glimpsed the top of her stillborn baby's head before he was whisked out.

A bereaved mother usually relied on the judgment of the health professionals about whether or not to see the child. She took her cues from the experts who also played a crucial part in defining the situation. The assumption of implicit authority was plain. Staff referred to "*letting* women see" and a Senior Nursing Officer who told me that she "would *never stop* a woman from seeing her miscarried baby", added:

> "She is *even allowed* to take a photo if she wants to." (Miss L)

In one of the four hospitals, the bereaved mother was usually encouraged to see her dead baby. The labour

The earlier the pregnancy failed, the 'lesser' the loss, making miscarriages less sad than stillbirth; and stillbirth less sad than losing a baby who had lived

ward sister told me that she cuddles the dead baby before handing it to the mother:

"...and I treat them like the others and wrap a pink blanket round a girl and blue for a boy." (Sister A)

She looked upset as she recalled a recent case:

"It was terrible ... a monster. It had two heads." (malformed twins)

A junior hospital doctor whom I found sympathetic and sensitive to talk to, also told me that he advocates a woman seeing her dead baby:

"...except the monsters...they're disgusting. They should be destroyed ...wiped off the face of the earth." (Dr J)

Doctors, nurses and midwives probably discouraged mothers from seeing miscarried and deformed babies believing that this would be upsetting for the mother. In the interviews, they also admitted their own anxieties. From the mother's perspective, fantasies about the appearance of the baby were possibly more frightening than the reality.

Nicky lost her baby at 20 weeks in a gynaecological ward screened from the other patients only by curtains:

"I didn't see the baby. I thought it would be improper to ask."

Beth lost her baby at 27 weeks:

"If only I'd kept a lock of hair to prove I'd had *someone*. I wanted to see the baby but didn't dare ask in case they thought I was morbid."

Dolores lost her baby at 22 weeks. She did not know the baby's sex until she asked months later:

"No one showed me the baby and I didn't ask. I wish we could have seen her together. Of course, she was very small and I understand that she was *damaged*."

In their accounts, health professionals and mothers alike described dead babies mainly in terms of their perfect-ness.

Two mothers whose babies were hydrocephalic expressed their sense of shame and guilt. Doubts about their own self-worth were exacerbated by their babies being defind primarily in terms of abnormality and physical appearance. (15)

Jenny was afraid at the thought of seeing her stillborn baby but agreed to let the midwife decide whether her baby was 'fit to be seen'. She saw her baby because the midwife told her:

"Your baby is perfect. You should see him. He's beautiful ... too beautiful for this world."

This particular baby was defined as beautiful and, by implication, a tragic loss. The midwife spoke of the baby as someone whom *she* might have loved. This is very different from the way that Gloria's baby was defined.

Gloria was not asked whether she wanted to see her hydrocephalic, stillborn baby. Her husband, Jim, waiting outside was asked but the *way* he was asked may have influenced his response. The nurse was holding, at arm's length, what looked like a bed-pan covered with a cloth. When Jim shook his head in reply, the nurse commented:

"Quite right. You wouldn't like it. It's an ugly little thing."

The mother felt guilty for having such a baby and wondered what she had done wrong

This remark, recounted to me by Gloria added to the anguish by devaluing their child and dismissing their experience. The implication there seemed to be that such an object was unfit to be seen, unfit to be loved, unfit to live and not worthy of mourning. The death was perceived as 'a blessing' which added to the weight of guilts on the mother. She felt guilty for having such a baby and wondered what she had done wrong (16). Finally, she was made to feel guilty for grieving for such a '*thing*'.

Where babies had congenital abnormalities which did not affect their external appearance, judgments were not made in quite the same way. The 'what-is-beautiful-is-good' stereotype was most marked when the baby's face did not jeopardise normal appearances.

Fiona's baby had a congenital kidney malformation. On her sister's advice, she asked to see her baby. The hospital staff seemed surprised but acquiesced:

"They wrapped Bill (the stillborn baby) in a blanket. We didn't look at his body ... just his little face. I held him and Michael (baby's father) sort of hung on. The nurse left us. Then she came back and took Bill away. Afterwards, she brought us a cup of tea. It was an amazingly good thing to have done."

Hospital Stay: Is there a mother?

Maternity units are geared to the production of live babies. When this goes wrong, there is the practical problem about what to do with the maternity patient - *is* she a patient? who has no baby to be weighed, bathed and fed. Such a mother - or *is* she a mother? - disturbs the equilibrium and is a reminder of failure. Failures need to be hidden. Hospitals seem to have no physical or psychological space for such a person, and the problem of a woman who seemed to have no legitimate role was often 'solved' by sending her home with what felt (to the woman) like indecent haste.

Losing a baby and losing her status as mother, did not automatically put a de-mothered woman into the 'patient' role. Often both roles were lost simultaneously. Nursing staff often stopped carrying out routine procedures such as taking her pulse and temperature.

A medical social worker remembered one case where a bereaved woman had been put into a room alone:

"No one had looked in on her for over twelve hours. She hadn't even been given a cup of tea after her baby was born dead." (Mrs J)

At one of the London hospitals, mothers usually stayed for five days after giving birth. If there was no baby, this swiftly changed and a Senior Nursing Officer explained:

"When it goes wrong, we prefer her to be on her own. Everyone finds it difficult to talk to her. Nobody knows what to say. What can one say? The staff feel that she is blaming them. We try to get them home as quickly as possible... into the community." (Miss L)

The bereaved mothers said that losing the baby set them apart:

"Three of my friends were pregnant at the same time. I'm no longer one of the girls." (Mary)

Kara said that she felt an outcast, looked down on by her husband in particular and the 'community' in general:

"They say I'm no good ... only producing dead babies."

The data suggest that hospital discharge was strongly associated with acceptance of loss. Although the mothers who left hospital within 48 hours all reported a 'Sense of Dismissal', these feelings did not always correspond to the number of days spent in hospital. Ten women spent 2-3 days in hospital afterwards but only half reported feelings of dismissal.

After her miscarriage, Beth was put into an antenatal ward with two other women who had lost babies:

"The staff were lovely. I helped them to make Christmas decorations. I didn't leave before I felt ready." (Two days later)

When Lena's baby died nine hours after birth, she was asked if she wanted to move into a side ward. Lena, herself a midwife, rejected the suggestion:

"I know what happens. They put them there and forget them. I told them straight: 'Why should I be sent away? I've done nothing wrong.'"

She went home next day to the noticeable relief of the staff:

"Everyone was glad when 10 o'clock next morning, I was out. I'd been crying in the night and there was tension. They sent me home with a temperature. I'd lost a lot of blood and felt very weak."

Gloria, placed in a side ward next to the nursery, sensed that she was an embarrassment:

"I felt as if I ought to apologise to everyone. They wanted to chuck me out as soon as I woke up on the Sunday. My mother created a terrible scene about that. In the end, I went home first thing Monday morning."

Lack of coordinated and clear policies can cause additional distress. Sandy had been put into a room by herself after having a hydrocephalic stillbirth. A well-meaning doctor, inspired by the bereavement literature told her that she should look at the live babies before going home:

"So, I screwed up all my courage and went in. The night nurses were horrified. They took me back to my room ...'You shouldn't be here' they said."

The nurses who hurried Sandy out of the nursery were understandably concerned with their responsibility towards the babies in their care. They had not been told about the registrar's suggestion to Sandy. But for Sandy, her banishment confirmed that she did not belong - only *mothers* were allowed in the nursery.

After she miscarried at 26 weeks, Pam was put in a room by herself opposite the feeding room. She felt avoided:

"The nurses couldn't cope with me. You know, they had done what they could and there were others who really needed attention. The doctors felt they had discharged their responsibility. I left my door open so people could come in, but they didn't. I could have had my meals with the others, but didn't. It was for their feelings as much as for mine. After all that waffle of antenatal care, they just drop you."

Formal Ritual

Twelve mothers never saw their dead babies. Often, it was hard to discover what happened both in those specific cases and what happens in general. Vagueness pervaded this area of my interviews. Medical and nursing staff thought that usually 'the hospital' made the necessary arrangements, without being clear *who* in the hospital or knowing any details. My information was pieced together from medical and technical staff in Pathology, clerical staff in Patients' Office, funeral directors, cemetery staff and local authorities.

At the time this study was carried out, local authorities tended to vary but most used mass graves, called 'public' or 'common' graves for stillborns. These were also sometimes used for early neonatal deaths. Such graves

The data suggest that hospital discharge was strongly associated with acceptance

sometimes held up to 200 bodies (17). The top would be left open until the plot was considered full. There might be restrictions on marking the place individually, the reason given was to prevent possible congestion. An individual grave could be provided if arrangements were made, and paid for, privately.

There is nothing in law to stop the interment of a miscarried baby. In practice, it rarely happened. As with stillborns, there is, of course, no death grant. Burial was not suggested to the bereaved parents as an option and although this is now gradually changing, procedures have not been established.

A pathology technician told me what usually happened:

"The bodies of the fetuses used to be disposed of in the hospital incinerator but this was messy because it is 'wet' tissue. Now we put them into our tissue macerator and the remnants are flushed down the Foul Drain." (Mr M)

Ten mothers had been involved in making arrangements and knew where the baby was placed. (All had seen the dead body too).

Fiona and Michael told me about their stillborn's funeral:

"We said what we wanted and the undertaker was very sensitive. Undertakers are 'joke' people until you need them but he understood that it was terribly important to us. We didn't want lots of people ... just us. It was very simple ... I think some poetry was said. We'll plant a little bush ... in remembrance."

After her perinatal loss, Diana's experience of undertakers wass less sympathetic:

"We went to the Coop. When I said I wanted it simple, she seemed to think we were skimping. When I told her we didn't want any Christian thing, she seemed to think we didn't have any feeling about it."

Diana wanted her baby cremated and found the arrangements painful but a positive action:

"We wanted to see it to the end. He was our responsibility. My husband said as we'd brought him into the world, we should see him off. I go to the crematorium sometimes. We walk round the garden of remembrance. I go there specially to think about him."

Gloria does not know what became of her baby after the nurse took him away in the bedpan:

"I'm not sure if they bury them with an adult. Perhaps he's in some grotty little hole. I can't bear to think of him being thrown out like rubbish."

Sandy too wonders what happened to her stillborn son:

"I have a recurring dream that I'm in that hospital searching for him. I just assumed that they burned him. I look over at the hospital chimney all the time. I can see it from my window and I can see the smoke coming out."

Most mothers regretted not having seen the baby and letting the hospital deal with the body

With two surviving children, Sandy feels that she has not 'accepted' her loss:

"If you say to me: 'Stand up and tell me what you're about.' I'd stand up and say to you: 'My name is Sandy and what I'm about is a stillbirth.' I feel it is the most important event in my life. And yet, it is a terrible nothing-ness."

The mothers who did not know what happened to their babies frequently spoke of their sense of unreality. Most regretted not having seen the baby and letting the hospital deal with the body. This was not necessaily linked to any religious beliefs.

'Informal' Ritual

In this study, formal ritual (such as a funeral) was explored as a possible factor in the process of coming to terms with loss. However, I also focused upon 'informal' ritual and the role of talking. This covered a wide spectrum from talking things over, or chatting, genetic counselling, being given explanations, to discussion of relatively concrete information such as post mortem findings.

When considering the role of 'informal' ritual, conceptions about what constitutes 'work' may be a relevant factor. One doctor pointed out irritably that he was much too busy to stop work to talk to bereaved mothers. Medical training does not prepare doctors for 'failure' (18). In that part of the hospital devoted to reproduction, instead of cure as goal, the expectation is of 'success' measured in terms of live births. Feelings of failure and the accompanying difficulty in dealing with these anxieties, may be sharper because of the relative rarity of things going wrong.

An obstetrician (Miss K) told me that part of her motivation in entering her speciality had probably been her wish to avoid death, and dying patients. The nursing and midwifery staff too find it difficult, which may explain why most of the 22 mothers were sent home with the words: 'See you next year' ringing in their ears. These words can be taken as kindly encouragement and optimism but they may also be seen to contain a hidden message telling a woman to come back to their institution ... when she is more 'acceptable'.

There is an extensive literature on information-seeking