# The changing identities of miscarriage and stillbirth

## Influences on practice and ritual



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Losing a baby through miscarriage or stillbirth is not always viewed as a 'proper' bereavement. Because there appears to be no person to grieve for, the loss may be devalued or ignored by social and religious

institutions. In order to understand how and why this happens, and to promote more sensitive treatment of parents bereaved in this way, it is useful to trace the changing identities of miscarriage and stillbirth.

he influence of support organisations, such as SANDS (Stillbirth and Neonatal Death Society) and the Miscarriage Association in the UK, as well as the bereavement literature and awareness in the media, means that some attention is now paid to pregnancy losses. Ways of supporting parents, including creating memorials for the baby, have been devised. However, most of the traditional religions do not have formal rituals or mourning periods for parents following miscarriages and stillbirth, and these omissions mean that the needs of bereaved parents, from a range of religious backgrounds and cultures, are often overlooked. These issues were explored in my qualitative study<sup>2</sup> based on in-depth interviews with religious professionals of various faiths, and a collaborative study<sup>3</sup>. Extracts will be used in this paper in addition to material from an earlier study4.

#### **CATEGORISING THE LOSS**

How life is defined in a society reflects social and religious moral values and expectations. The steadily declining perinatal mortality rate in more affluent countries means that today parents expect to have a live baby. In countries where infant mortality rates are high, and mothers have large families because they expect many of their children to die, the death of a baby is not treated as such a

#### EDITOR'S NOTE

In the Western world the birth rate is declining and the death in the womb of a planned and wanted child is therefore thought to have more impact on parents than in other countries and at times when couples had less control over their fertility. Certainly there seems more desire to name stillborn babies and to accord them a proper burial. Lovell charts this secular change, and the role of belief systems and religious institutions, in shaping attitudes to fetal death. She makes suggestions for more sensitive disposal of the body and ceremonials for these losses, drawn

from good practice and her research. Consideration must also be given to the other children in the family after a miscarriage or stillbirth. They need an explanation of what has happened to the eagerly expected baby. If the mother returns home from hospital alone and the parents do not refer to the dead baby, siblings can learn a maladaptive lesson: do not ask questions, it is dangerous to talk. In some cases this can result in a child not speaking in certain settings - elective mutism. It is important to help parents find a way of talking to their other children of the reason for the baby's nonappearance. If possible they should be taken to see the stillborn baby. Children as young as three and four can be helped to understand that the baby's body was not strong enough to keep him or her alive, and that the parents feel sad about losing their baby.

major cause for grief. In north-eastern Brazil, the dead baby is taken in a cardboard coffin to the cemetery for burial and the death dismissed as 'only a baby'<sup>5</sup>.

The frequency of infant deaths, let alone miscarriages and stillbirths, in the past explains why governments and the major religions have neglected these losses. In the UK there were no infant mortality statistics until 1877 because before this children under the age of one year were not socially recognised as separate entities; perinatal mortality statistics - deaths within the first week of life plus stillbirths - only emerged in 1950. Recently the figures for stillbirth have been separated out and in 1993 the UK Department of Health began to publish annual statistics on late fetal loss, defined as 20-23 weeks or weighing at least 500g6. No official statistics exist for earlier miscarriages and many go unreported.

#### Gestational age and viability

The rationale for defining miscarriage or stillbirth and for making assumptions about grief is based on gestational age, viability and presumption of survival. Criteria are based on the length of the pregnancy and the size and weight of the newborn. The definitions carry legal, social, ethical and religious consequences, affecting the documentation as well as judgements about which are 'lesser' losses.

However, for parents, it is not necessarily viability that transforms a fetus into a baby and makes real the baby's identity. The ultrasound scan provides the first image of the unborn baby and even the first picture for the family album. Johnson and Puddifoot<sup>7</sup> quote a father '...so taken aback by the experience, that I handed cigars out'.

Official definitions bear little relation to grief when things go wrong. Nevertheless, these definitions have an impact on how the parents' experiences are managed by the caring professionals. They play their part in creating a hierarchy of sadness which assumes that the earlier the pregnancy fails, the 'lesser' the loss. During pregnancy, a woman is referred to as a mother but loss during or soon afterwards renders this identity precarious. Depending on hospital protocol and

avialability, she may be placed in a maternity, antenatal or gynaecology ward. Some hospitals provide a special room and include a bed for the bereaved father.

#### How many weeks?

Defining when a fetus becomes a baby varies:

Although the law places the onus of deciding whether a child was liveborn or stillborn on the parent (or other qualified informant) in practice, the medical attendant usually decides<sup>8</sup>.

In 1992 stillbirth was re-defined in the UK as occurring at, or after, 24 weeks but before that was held to occur at 28 weeks. The law requires that the bodies of stillborns are buried or cremated and a stillbirth certificate is issued; for babies born dead prior to 24 weeks, there is no legal requirement to bury or cremate, although this can be done. No certificate is required although a Non-Viable Certificate is issued if a funeral is arranged.

Anomalies occur, as I found in my early study<sup>4</sup> based on interviews with 22 bereaved mothers and 30 health professionals. Diana's baby was born at 22 weeks with a congenital heart defect, lived for nine hours and then died. A birth certificate and death certificate were issued and a funeral held. However, Dolores' baby, delivered lifeless at 23 weeks, was classified as a late miscarriage and disposed of as clinical waste, compounding her distress.

Definitions of late miscarriage vary from country to country and in the USA from State to State. In Australia, a baby born dead at 20 weeks or weighing at least 400g is defined as stillborn. At an outer London hospital3, the late miscarriage 'cut-off' is 16 weeks although the Miscarriage Association literature puts it after about 14 weeks. 'Miscarriage' is not a medical term and Hutchon9 found that 'abortion' was more likely to be used in medical journals. Clearly miscarriage and stillbirth are not entities which can be defined, like Durkheim's social facts10, but socially constructed concepts. Similarly, the measurement 'weeks of gestation' is potentially problematic and sometimes hotly disputed<sup>2,3,4</sup>.

#### WHERE ARE WE NOW?

Many British hospitals now recognise the need to amend their policies and practice. In the UK, the Miscarriage Association offers information packs and an extensive reading list; SANDS have published a training pack, *Pregnancy Loss and the Death of a Baby*<sup>11</sup>, including a book, *Guideline for Professionals*, which is

available separately. In keeping with these and other recommendations<sup>12</sup>, parents are helped to see their dead baby and given mementoes. Hospitals help organise a funeral and perhaps an entry in a book of remembrance. If born before 24 weeks, a medical certificate may be given to acknowledge the baby's existence<sup>13</sup> although this is not a legal requirement.

'When we bury an adult, we bury the known past....a portion of which we inhabited. Memory is the overwhelming theme, the eventual comfort... Dead babies do not give us memories. They give us dreams!.'

Professionals admit<sup>2</sup> that rhetoric does not always match practice and bereaved parents are at the mercy of patchy services, dependent on individual professional styles. There is no single right answer about, for instance, what to do with fetal remains. Small embryos from abortions and fetal tissues are sometimes given to researchers, though in the UK the Polkinghorne Report<sup>14</sup> specifies that this should only be done with the parents' written consent. The medical press<sup>15</sup> has noted that the 'abortus' has no status and advocated that the law should become more sensitive and 'shed those artificial barriers of the classification of baby life'. Davies<sup>16</sup> identified anomalies, including confusion between incineration and cremation

It must also be recognised that for some women early pregnancy loss is not a tragedy and dwelling upon the disposal of the remains is inappropriate<sup>5</sup>, while for others, it is the loss of a baby needing to be mourned<sup>17</sup>.

#### Evaluating the support

Much has been written in favour of introducing support systems for parents bereaved in this way, but more research is needed to determine the value of counselling or other forms of social support. In an early study by Lake *et al*<sup>18</sup> of mothers who had suffered a stillbirth, they were assigned at random either to grief counselling consisting of two sessions in hospital and two after discharge, or to a control group. Attrition was high and the only significant results were reduced reports of diarrhoea and constipation in the counselled group, while other measures of distress were unaffected.

However, more recently Oakley and Rajan<sup>19</sup> conducted a randomised controlled study of women whose earlier pregnancy had ended in loss and who were pregnant again. The mothers were given a minimum of three home visits and two telephone calls between visits, as well as being provided with a pager to enable them to contact help. The researchers found a significant difference in the emotional well-being of the women who received social support compared with the unsupported control group. The qualitative data highlighted the need for recognition of the dead baby as a person and the mothers' right to mourn their loss.

#### THE INFLUENCE OF RELIGION

Religion and belief systems leave their mark on official institutions and public opinion, which in turn influences social policy. Religious leaders are called upon when someone dies and so they play a part in defining situations and shaping care. The major belief systems teach that there is some form of continuity after death and provide comfort to the bereaved by helping them to make sense of loss, and Humanism recognises the need for ceremonies, such as non-religious funerals, to mark important events.

There is a growing literature designed to educate health professionals addressing religious diversity and describing attitudes and rituals surrounding death and dying<sup>20</sup>. Insights into other cultures help professionals provide appropriate support but, useful as this literature is, it is understandably rarely critical. It describes existing practices, not the holes in traditions and practices applicable to pregnancy losses. Klass21 notes: 'in our first efforts at crosscultural study of grief we have fallen into the trap of confusing the official theology of a culture with the way people actually respond to deaths that are significant to them'. Gunaratnam<sup>22</sup> warns against the cultural 'factfile' or 'checklist' approach.

#### Searching for rituals and practices

In my early study I noticed that, as well as turning to health professionals, bereaved mothers - even the irreligious - looked to religious professionals for help. This observation led to an exploratory study<sup>2</sup> based on 20 in-depth interviews with functionaries of nine different religions and philosophies (Sikhism; Judaism, Islam, Methodism, Buddhism, Church of England, Roman Catholicism, Humanism and Hinduism) and bereavement counselling services. The interviews took place in an inner and outer London health authority, both with ethnic minority populations above the national average. I also searched the literature and combed religious texts for references to miscarriage and stillbirth.

My interviews highlighted practical as well as theoretical problems when there are no clearly laid down rituals and practices. I looked at what was done and why but, more importantly, what is not done and why not. To ensure I had not missed vital references. I asked the religious professionals for the official view of the after-life concerning fetuses and neonates, and beliefs about the status of the soul. I asked for references in their religious texts (chapter and verse) instructing how such deaths are to be treated, rituals including burial or cremation, funeral services, mourning rites and prayers. Having asked what should be done in the event of a miscarriage or stillbirth, I probed to find out whether they had ever carried out any services in this context and for details.

#### Difficulties and contradictions

The religious professionals had all performed many funerals and spoke sensitively about what 'ought' to be done for stillbirths and miscarriages. But only the two Church of England hospital chaplains had actually performed funerals for stillborn and miscarried babies. The others admitted that in years of experience ranging from five-21 years they had rarely, if ever, performed such a service.

Within all religions, there are clearly set out rules, religious laws and procedures about what is to be done after the death of an adult, but there is usually a blank page when it comes to babies. Miscarriage and stillbirth are virtually unmentioned. My interviewees had difficulties in quoting chapter and verse, exemplified by an Anglican chaplain who performs about 50 funerals a year for babies lost neonatally and during pregnancy, but who could only recall that '[St Paul] talks of the difficulties of his life as if he were untimely born'.

Organisational factors often shape whether there is a funeral for a miscarriage or whether the loss is interpreted as fetal remains to be disposed of:

The policy here is determined by whether the mother comes to the maternity unit or the gynae ward. If...maternity, she'll be around 16 weeks... anybody in that category is offered a...funeral of some kind if they go to gynae, prior to 16 weeks...there is no policy or protocol and we're struggling with it at the moment...the maternity staff are very aware of the people going through a bereavement...in a gynae ward...their approach is much less about a baby.

This hospital has a bereavement counselling service and maternity ward and staff

refer women to it after miscarriage. However, if they are sent to the gynaecology ward there is little likelihood of referral for counselling. Further, although the hospital draws from a local population comprising a high proportion of Asians and Afro-Caribbeans, the staff said: 'We don't get many Asians nor other cultures. Mainly Christians and non-Orthodox Jews come.' The counsellors and chaplaincy arrange memorial services but, although ostensibly non-denominational, the 'fairly ecumenical' service is held in a Christian chapel.

A Humanist celebrant described practice at a London cemetery: 'Once a month, a local hospital comes along with all the fetuses for a month...they are given a Christian service...parents are told this is going to happen it's not an individual ceremony...the fetuses arrive in one coffin... individually wrapped with paperwork attached.' This illustrates how the needs and wishes of non-Christians (as well as of the non-religious) are overlooked.

There were contradictions surrounding baptism. A Roman Catholic priest, in 21 years' experience, remembered only one neonatal baby's funeral. He had never conducted a funeral for a stillborn or miscarried baby: '...we know that only baptism forgives sins...a child who is not baptised...various theories are put forward about them in theology but nothing very definite is said.' He believed they are in limbo, which he regarded as a happy place, inferior to heaven but not desolate. A Church of England minister regarded baptism of a stillborn or miscarried baby as 'a pastoral gesture': 'It doesn't make sense...It's a nonsense. When the baby has died, as far as I'm concerned, the baby is in God's care.'

According to article 601 in *Articles of Islam Acts*<sup>23</sup>, '...offering prayers for the dead body of a stillborn child is not recommended. It is obligatory to offer prayers for every Muslim including children aged six or more. My interviewee explained: '...children are not considered to have any sins. In Islam, they believe you have a reward...you lost the child...this child could help you go to heaven...you respect what God decides for you...the saying is that the child you lost will stand in front of the door of heaven and won't go in unless I take my parents with me'.

At one Hindu temple, the priest explained that adults are cremated but: 'We do not do cremations or last rituals or funerals for miscarried and stillborn babies.

Usually the women comfort the mother'.

At a Sikh Temple, when a new baby is born, a name is normally given in the presence of the congregation. However, a miscarried or stillborn baby 'doesn't need a name. A name is to communicate with each other'. There had been no requests at any time from parents wanting to give a name. After adult deaths, '...hymns are recited in a very sombre fashion and the whole congregation joins the family...to console them and help accept the inevitability of it all...a stillbirth or miscarriage is not normally a matter people bring to the Temple...they are done within the family at the house'.

Within Orthodox Judaism, mourning practices such as the Shiva are not observed for a baby who dies within 30 days. This is related to the viability of human life: 'In its time, this was very enlightened. They were trying to stop...limit the grief...it was saying this wasn't quite a person yet...wasn't a human being yet.' The Liberal rabbi had never carried out funerals for miscarried or stillborn babies, but remembered a funeral of a 12-day-old baby: 'I did a truncated funeral service...to respect Jewish tradition which doesn't have a funeral for a neonate...and respect modern knowledge which is to say we need to facilitate the mourning process.'

#### **ISSUES RAISED BY TERMINATIONS**

An Anglican hospital chaplain who heads a multi-faith team carries out funerals for babies who die before or soon after birth, but spends the majority of his time looking after the staff. He set up a counselling service in direct response to their needs:

We were doing quite considerable numbers of late terminations for social reasons...extremely distressing for the staff and they needed some support and so the ward sister...asked me to facilitate a group. As a result of what came out, we then explored the possibility of creating a better system of disposal.

The distress of the professionals highlighted the importance of acknowledging caregivers' needs, as well as paving the way for something to be done for the parents. However, it also addressed the knotty issue of abortion – a topic which cannot be ignored and which may shed further light on why miscarriage has been overlooked and, in particular, why feminist movements have kept relatively quiet about it. Focusing attention on the 'personhood' of the baby lost through miscarriage might be perceived as fuelling the anti-abortion debates.

#### **IMPLICATIONS OF THE STUDIES**

The qualitative findings of these studies<sup>2,3,4</sup> have implications for religious and health professionals. The changing identities of miscarriage and stillbirth hinge on technicalities and organisational factors which do not necessarily reflect personal experience. The invisibility of miscarriage and stillbirth in liturgical texts means that bereaved parents slip through the spiritual net which takes little account of their grief. The explanations about why in some religions there is no funeral or mourning prayers are inconclusive. It may be because of the precarious existence of the baby or fetus; another justification is that pleas to the deities for redemption are redundant: the evidence is fragmented. Religious functionaries, like medical professionals, work within male-dominated contexts. Rituals are written in or excluded from the texts but who writes the scripts, and why have pregnancy losses been so neglected?

It is not the weeks of gestation but the personal significance of the loss which determines the extent of parents' bereavement and their need to grieve. Individual needs and emotions do not necessarily fit in with changing medico-legal definitions or religious liturgy. The caring professionals, as well as the community at large, need to bear this in mind when dealing with miscarriage and stillbirth.

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### BOOK REVIEW

#### **LAST RITES**

## The work of the modern funeral director

#### Glennys Howarth

Amityville, New York: Baywood Publishing Company, 1996, \$42.95 hb, 224pp. ISBN 0 895 03134 5

In Last Rites Glennys Howarth provides us with an 'ethnographic snapshot' of the funeral industry based on a year of observations and interviews with staff and others associated with a small, family-owned funeral company in the East End of London. It is probably the most comprehensive account of modern undertaking practice, or to use her term, 'deathwork', that has ever been written. Using a method known as dramaturgical analysis in which 'social life is seen as analogous to the theatre', Howarth explores in minute detail the social world of funeral directors as they manage the 'theatrical production' of the funeral.

Howarth begins with a broad historical and sociological analysis of the funeral ritual and a meticulous account of the day-to-day workings of the funeral company chosen for the study. She covers every facet of the work from the physical handling of dead bodies, the legal and bureaucratic procedures, to dealing with grief-stricken relatives. The stigma associated with this work and the defences that staff develop to cope with the psychological onslaught of repeated exposure to death are also discussed.

This is a fascinating book which illuminates a subject that continues to be a source of mystery, fear and suspicion. Howarth has left no historical, sociological nor psychological stone unturned. However, there is an air of cynicism about the book that I found disappointing. Having worked alongside funeral directors for seven years as a

social worker in an Australian funeral company (which had its origins in England) I felt that Howarth's portrayal of funeral directors as 'experts at making a drama out of crisis' who 'aspire to theatrical presentation' was rather unfair. Death is by its very nature, dramatic and disturbing – the drama is not necessarily manufactured. Rather than 'deathworkers', most funeral directors would see themselves as 'lifeworkers' serving the living – the bereaved who are left behind after a death – offering competent and efficient care and safe passage through an often overwhelming, traumatic and unfamiliar event.

As for the claim that funeral directors deliberately humanise the corpse through embalming and cosmetics, I have seen the enormous benefit and comfort that the bandaging of a severely damaged head or the softening of extreme discolouration through decomposition can bring to the bereaved. Rather than seeing this as a pseudo-professional role which usurps traditional family involvement, I see this intervention as necessary and humane. Although the study is based on one small English funeral company, I also think that Howarth could have said more about the enormous contribution that funeral directors have made throughout the world over the past two decades in bereavement support and community education. Last Rites is nonetheless a book that all those concerned with death, bereavement and ritual will value and find useful as a basis for discussion of these sensitive issues.

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