Perinatal loss – a life-changing experience

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EVERY YEAR THOUSANDS OF BABIES DIE during pregnancy or at, or around, the time of birth. In 2005 alone more than 7,500 babies were stillborn or suffered a neonatal death in the UK (Office of National Statistics 2007). These statistics do not include many other deaths referred to as perinatal loss, including 'ectopic or tubal pregnancy; spontaneous abortion (miscarriage, in lay terms); or late-pregnancy loss' (Woods & Woods, 1997). This means thousands of families bereaved of someone whom they have not yet had a chance to get to know, although many will actually have formed an intimate relationship with this unborn person.

In my work as a chaplain in an acute hospital with particular responsibility for the maternity unit, I have had a number of experiences with older female patients still grieving for the loss of a baby, sometimes 60 years or more after the event. Esther Shreeve (2005) recounts a similar story:

> She wanted to tell me about the stillborn child she had had at home, over 60 years before, who had been taken from her at birth, wrapped in newspaper, and put out with the rubbish. She needed to talk, because she had not been allowed to grieve at the time. She had been expected to get on with her life as if nothing had happened.

Having suffered a pregnancy loss where I was barely able to see the unborn infant on a scan, and certainly not able to feel the foetus move, I was shocked to find how much I minded not having given this life a name, how much I mourned after the next baby arrived, how upset I always am (even more than 20 years on) when revisiting the place where the pregnancy was lost. This and other personal experiences, entwined with that of working for five years alongside many parents who have suffered a peri- or neonatal loss, added to the stories of the elderly women needing help with their own similar loss, have led to my particular interest in this area of bereavement care.

ABSTRACT

This article looks at the influence of the bereavement culture of the 20th century, compares this with more recent research and grief theory, and relates these to current practice with families after miscarriage, stillbirth or perinatal death. It considers the importance of memory-making and maintaining continuing bonds, alongside the need to adjust one's life around such a loss. The author is a hospital chaplain and mother of four who has both a personal and professional interest in the changing nature of perinatal bereavement care.

Hiding death away

Even as few years ago as the 1980s, pregnancy losses, including stillbirth at full term, were not considered in the same light as other bereavements. The babies were removed quickly from parents; many did not even see their infants, let alone have a chance to hold them, name them or have an end-of-life ceremony for them. Miscarriages and other forms of earlier pregnancy loss were viewed as even less significant and women encouraged to 'get over it' or 'try again' or told 'you have other children so that's ok'. This is reflected in words written by a mother following the death of her infant:

> When this most blessed and unique person dies, everyone acts like its nothing: 'Oh well, better luck next time'; 'It's better he died before you got to know him'; 'You'll have more babies' (Klass *et al* 1996: 203).

During the 20th century England, particularly, developed systems for hiding death away. Increasing numbers of people died in hospital, as opposed to at home, and funeral homes grew in number, taking the deceased out of the family environment. In the scientific world, making people better at all costs was paramount – death was seen as failure. Darian Leader in *The New Black: Mourning, Melancholia and Depression* suggests that 'the 20th century saw a gradual erosion of public mourning rituals'.

However, over the last couple of decades these attitudes have started to change and people have become more aware of the need to grieve, to mourn and to understand more about the process of bereavement. There has been new thinking and increased activity in research and, following on from that, in implementing practices and procedures to facilitate the grieving process.

When the expected becomes the unexpected

It is possible today to know about a pregnancy almost from conception. Women can find out even before missing a menstrual period that a life is

Ultrasound scan of Natasha, baby of Helen and Richard Burrows

growing within, and most of the women with whom I have had contact do not wait for another 38 weeks to meet their baby. They are communicating, having a relationship with him or her at once. Parents see their unborn child growing, hear the heart beating, see flailing limbs, thumb sucking. Even the gender of the foetus can be known and parents begin to reflect on who the baby looks like. Society is programmed to expect perfection, to expect everything to go well, for the baby to be all right.

However, what happens when this living being dies? Everything that was expected and prepared for, the hopes and dreams already planned for years ahead are gone. There has not even been a chance to get to know the person properly, yet they have been alive for months and real to the parents, especially the mother who has usually felt their presence as well as seen it on a screen. In the past parents would not have known about the impending arrival so soon, would not have had so many scans (if any), and awareness of any potential health issues with the growing foetus were much less.

Because of this increased parental involvement in pregnancy, changing views about the grieving process, and an awareness that procedures used in the past may not always have been helpful, attitudes to peri- and neonatal bereavement have begun to change. Capitulo (2005) observes:

> In the case of stillbirth or infant death, lack of validation of that loss (by discouraging parents from seeing their deceased child or denying mourning rites) can disenfranchise grief...make the tragedy a 'nonevent' and the loss a 'nondeath'.

Making memories

Currently most hospitals suggest that parents (and other family/friends if appropriate) see, hold, bath and dress the baby. The 1985 guidelines of the UK Royal College of Obstetricians and Gynaecologists recommended that:

> ...staff should create an atmosphere which encourages parents to see and hold their baby...[they] need to be informed that if they do not see their baby...it could make mourning more difficult.

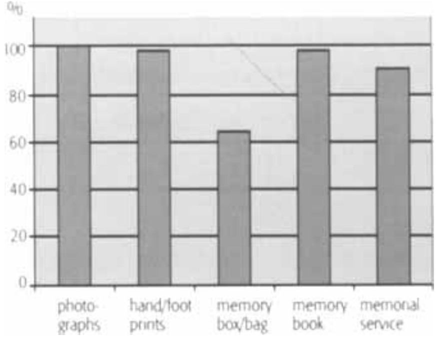
Parents are encouraged to name the baby, possibly with the involvement of a member of the multidisciplinary health team, often a chaplain, or their own minister or faith leader.

This does not happen in all cases as sometimes the gender of a prematurely born infant is unclear or, for some cultures/faith groups, naming an infant who has not breathed outside the womb is not possible. However most families want to give their child a name, usually one they have been using for some weeks or months, to acknowledge the tiny infant as a real person, someone to grieve for, someone to tell the story of and for others to speak about. For some it is important that the baby is baptised and this can be done by any staff member in extremis, although most would call the chaplain to help or to perform the ceremony.

Parents bereaved in this way will have very few 'memories' so hospital staff will take photographs of the baby (with or without the parents/extended family), make hand and foot prints, and keep a lock of hair, if possible. Some hospitals offer 'imprints', framed moulds of the child's feet and hands in clay with the name and date of birth/death. Anything that has been used in the care of the baby – name tags, feeding tubes etc – can also be added to a box (or bag) of memories. Naming, blessing or baptism service sheets or certificates are also important, as is putting the baby's name in a book of remembrance or having it read out at a memorial service.

Hand and footprint of baby Katie, aged two weeks

Graph showing memory aids offered to parents after a neonatal bereavement by UK hospitals who responded to a questionnaire (n=102)



> Sometimes... babies are literally 'born dying'...What little time these families have to spend with their newborn babies is precious; if it is missed, it is gone forever. When families haven't had time to plan for these moments, health professionals must be ready to guide them. (Stokowski 2004)

A review of neonatal bereavement services in UK hospitals was undertaken by the author in 2007. Questionnaires were sent to three different members of staff (a nurse, doctor and chaplain) in over 200 hospitals. The response rate averaged 51% and the data on what hospitals provided by way of making memories is shown in the table above (Aldridge 2007).

Questioning current practice

There is very little research on the longer-term effects of encouraging parents to make memories of their dead child for the future in this way, but a recent controversial study by Hughes *et al* (2002) concluded, 'Our findings do not support good-practice guidelines, which state that failure to see and hold the dead child could have adverse effects on parents' mourning'. These researchers studied a group of 65 women who were pregnant subsequent to a stillbirth alongside a control group of equal number. They found that mothers who had held their stillborn infant were more likely to be more depressed during a subsequent pregnancy and to have more difficulty attaching to the new baby up to a year after the live birth. They did not conclude that having mementoes or a funeral service had further adverse affects.

However, firstly the research group in this study was small. Secondly, it is possible that those mothers who did not cuddle/see their baby and who were apparently coping better may have still been in the initial stage of grief (in shock), even after a subsequent pregnancy and live birth. It is the experience of some bereavement counsellors that one cannot grieve during pregnancy: the group who did not see their babies may not yet have begun to mourn. Thirdly, the study only ran for only one year after the birth of the live infant. Bearing in mind Shreeve's account (2005) of much older women still deeply grieving infants whom they never saw or held, a much longer study would be needed over, say, five, 10, 20 or more years, in order to fully understand and make informed judgements about positive or negative effects on the grieving process of holding dead infants.

The comments of women of all ages who I have worked with over the years suggest they would have preferred to see and cuddle their baby and take part in mourning rites. Perhaps some longer-term research, or a larger study involving women of various ages (including the very elderly who speak of such losses as if they happened yesterday) would help to clarify the situation.

Staying connected or moving on?

Every year at Addenbrooke's hospital we hold services to remember those babies who have died, and these are well attended and appreciated (Aldridge 2006). The annual remembrance service for those bereaved of a child, which is held in a local city church, draws many back year after year, as does a similar event held by the local children's hospice. This appears to be at odds with 20th century grief theory which suggested 'people whose loved one has died needed to work through the loss, with the final outcome being to detach emotionally and let go of hopes' (*Family Journal* 2007: 6). Psychologists, affected by the prevailing medical model of healing, have tried to fit grief into patterns which resulted in resolution. Kubler-Ross (1969), Bowlby and Parkes (1970) and Worden (1982) all attempted to categorise the process, with the ultimate aim of the bereaved being able to let go and move on.

It is significant, however, that despite trying to find systems to explain grief, the researchers' own life experiences did not follow the patterns they were suggesting. This meant that they began to change their research findings; Worden, in particular, changed his stance and replaced his final task of grieving, withdrawal of 'emotional energy from the deceased' (Worden 1982: 15) with 'to relocate the dead person within one's life and find ways to memorialise the person' (Worden 1996: 15). In their later work Kübler-Ross and Kessler (2005: 203) also acknowledged their change in understanding: 'Grief is not just a series of events, stages, or timelines...The loss happens in time, in fact in a moment, but its aftermath lasts a lifetime'.

Klass, in *Continuing Bonds* (1966), looks at the idea that bereaved people remain connected in some way to the deceased because 'Remaining connected seemed to facilitate...[the] ability to cope with the loss...these connections provided solace, comfort and support and eased the transition from the past to the future'. Davies (2004) cites multiple data which suggests that dead children become 'central to the conversational life of parents' and that through their sharing of memories 'they were able to reconstruct their relationships with them...in a way that was meaningful'.

This is particularly relevant to the peri- and neonatal setting and to those who provide bereavement care. It signifies the need to create memories, sometimes where there are none, and the importance of bereavement care that continues after the family has left the hospital. In light of current population patterns where families are distanced from each other, work needs also to be done to consider how best to support those who were once supported by networks of blood relations.

In perinatal death this has been addressed through increasing provision of groups and organisations providing post-death support. These actively encourage sharing of the story, including the feelings, and acknowledging the baby as having been, and continuing to be, in the memories of each family. Organisations such as SANDS (Stillbirth and Neonatal Death Society), ARC (Antenatal Results and Choices) and the Miscarriage Association offer this kind of support in the UK, as well as information, chat rooms and pages for memorials internationally via the internet. A brief glimpse of some of the poems or comments on these pages demonstrates the depth of feeling that remains many years later (eg www.aheartbreakingchoice.com/personal.html).

Many families struggle at anniversaries or birthdays or when a sibling goes to university or gets married. The baby who died is still part of their life. Most people adjust to living with the loss; it becomes part of their story that they revisit on occasions when they choose to do so, but also sometimes when they are caught unawares. The memory-making right at the outset – the naming, the seeing, the saying 'hello' in order then to be able to say 'goodbye', the photographs, handprints – all these make for a sense of normality where there is none and provide resources on which to draw in years to come.

Many hospitals now continue to explore how best to involve the whole family in the grieving process: firstly by encouraging all family members to be involved at the end of a life (and this is particularly true for the neonatal setting); secondly by helping them to organise their own, individualised funeral services; and thirdly by the continued remembering in annual services where families are invited to share feelings and to shape the event by adding their own ideas.

Thoughts for the future

It seems to me from both a personal and professional perspective that parents want an ongoing relationship with their deceased infant, something that health carers this time last century would have thought outrageous. There has not been sufficient time to establish whether current practice provides the best long term outcomes, because it is over a lifetime that grief emerges for a death that is hidden, and often not until the parents are in old age.

There is not space here to do more than touch briefly on the theory, but researchers and grief theorists do now seem to have as common ground in that there is a sense in which every bereavement is life-affecting, life-changing and, in some way, lifelong.

Elderly women who speak whilst in hospital of babies they did not feel able to mourn, are encountering other bereavements – loss of health, of independence, sometimes of home or family – and often looking towards their own demise. All of this highlights for them other significant previous losses, and particularly those for which there appears to have been no closure.

Recently the Faculty of Health and Social Care at Aberdeen University (Wimpenny *et al* 2006: 8) carried out a literature review on bereavement and bereavement care and concluded:

> A compassionate approach by all professional and non-professional staff [in hospitals] is consistently reported by the bereaved as having a positive impact on their bereavement. Conversely, approaches which do not relay such compassion can impact negatively.

Those who are perinatally bereaved need to have good care provided by all with whom they have contact. This necessitates closer interaction between the caring agencies: hospitals, primary care trusts and other external organisations. There is an urgent need for some joined-up thinking, a plan that is understood by all those involved, since 'Bereavement is a universal phenomenon that needs multiagency/professional involvement to ensure coverage across health and social care, education and work place settings' (Wimpenny *et al* 2006: 10). ●

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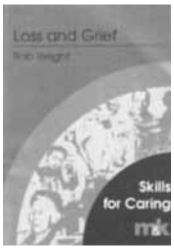
BOOK REVIEW

Loss and Grief

Bob Wright



Keswick, Cumbria, UK
M and K Publishing
2007, 72pp
ISBN: 1 90553 943 7
£16.00 pb

Working in health care means that we will inevitably meet patients who are experiencing loss in one way or another. This book sets out to guide and help professionals involved with those who are undergoing loss in its various forms, not only from bereavement but from other major changes in their lives.

The opening section gives a good grounding for understanding separation and loss. It is followed by chapters on grief and different types of death. Although there are several theories of loss and grief mentioned here, it would have been helpful to have included more of the current thinking, such as the dual process model (Stroebe, Schut 1999), continuing bonds (Klass *et al* 1996) and families making sense of death (Nadeau 1998).

A chapter on dying covers physical pain well, but does not include the spiritual or social aspects of grieving, both of which can give rise to mental anxiety and discomfort and can, in their turn, influence physical pain. The last section on bereavement and loss takes in a wide range of issues, including altered body image after surgery, cancer, dementia and miscarriage, ending with a short piece on funerals and rituals. Both the references and suggestions for further reading given at the end of the book are somewhat dated.

The text is well laid out, easy to read and follow. There are good experiential exercises throughout, designed to give the reader a better understanding of the psychological impact on their patients when a loss occurs. For professionals new to the field of dying and bereavement, and for those involved with initial training, this workbook could be a useful tool. ●

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