

EXPERIENCING REPRODUCTIVE LOSS

Working together to change practice

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ABSTRACTS

Hiding Babies: Birth Professionals Making Sense of Death and Grief

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This paper explores how in narratives of both past and current Perinatal death practices birth professionals are making sense of death and grief. Receiving primarily attention from psychological and action-oriented scholars focusing on the individual griever rather than on social and cultural contexts, up to this day loss at the hour of birth has been totally neglected by historians. It nevertheless provides a multifaceted topic for the anthropological history of reproduction and endings, the body and emotions, identity and personhood. Following the historians' performative turn, the hiding of dead baby's bodies is suggested to have confirmed and generated specific cultural patterns of meaning and self images.

Drawing on open, qualitative interviews of Flemish gynaecologists, midwives and pastors making sense to personal experiences in small scale hospital environments, the paper demonstrates how in changing contexts the practice of hiding has been interwoven with differing, shifting and interconnected meanings of death and grief. It develops, in particular, two partially historical approaches of practicing and hence of making sense.

In the formerly common approach, that is called the 'distant' one, the hiding of the dead baby covered a strict and silent culture of rules aimed at avoiding the construction of a subject and thereby of grief. Reducing the baby into an object, not to remain hybrid and socially alive through proactive memories, parents were forbidden to see their baby in order to 'let go'. The currently regular 'intimate' approach, on the contrast, is encompassed by a more open and idiosyncratic way of decision making and making sense: parents, yet being encouraged to 'continue bonds', are given authority. Referring to the categories (metaphors) and narrative forms used by birth professionals this paper fleshes out both approaches and clarifies their evaluations. Highlighting 'normality' and 'otherness' it also hopes to increase understanding of making sense of 'good' death and grief.

Irish Midwives' needs when providing perinatal bereavement support for parents experiencing perinatal death

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Perinatal death is a traumatic experience for parents. Midwives, who are required to provide care for these women before, during and after the birth of the baby, may feel unprepared for this aspect of their role (Gardner, 1999; Chan et al, 2003; Nallen, 2004). The purpose of this study was to identify midwives' concerns and support needs when providing perinatal bereavement support and to ascertain the knowledge, practices and confidence levels of midwives when providing perinatal bereavement support.

A questionnaire was designed based on the literature reviewed. Ethical approval was obtained and a pilot study was undertaken. A self administered questionnaire was distributed to 190 midwives and neonatal nurses from two maternity hospitals in Ireland. The response rate was 63% (n=118). Descriptive and inferential statistics were used to analyse the data.

Over 69% of midwives (n=80) were concerned with the lack of time they were able to give to bereaved parents. Lack of support, knowledge and experience were other areas of concern. While midwives used informal peer support as a coping strategy they perceived that debriefing sessions would enable them to enhance care. The midwives reported using caring practices that parents find helpful to facilitate their grieving process, but lack of time and lack of continuity of carer inhibited them from providing psychological care. Over 90% of respondents reported moderate and/or high confidence levels when providing perinatal bereavement care. Length of midwifery experience correlated positively with levels of confidence ($r=.527$, $p=0.000$). 102 respondents reported that perinatal bereavement education was not adequately addressed in their midwifery education and all the participants identified a need for continuing education in this area.

Midwives need protected time when providing perinatal bereavement support. Continuity of midwifery care should be facilitated. Senior midwives could provide invaluable support and education for junior midwives. This study identifies pertinent issues for practice and education that could enhance the provision of perinatal bereavement support for women and their families.

Diversity and pregnancy loss: Implications for policy and practice

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Birth and death are culturally significant events in most societies. Birth is associated with new life which normally leads to the incorporation of an individual into a community. Death is associated with the loss of someone who has been part of a community. Pregnancy loss, however, is associated with neither. How individuals and communities deal with pregnancy loss may be dependent on the way in which the loss is represented.

Midwives, doctors and nurses base their practice in relation to pregnancy loss on guidelines produced by user groups. These guidelines encourage the pregnancy loss to be seen as the loss of a

baby, irrespective of the gestational age at which the loss occurred. Such policies may suggest a number of ritualistic activities to reinforce the parental caring role, including holding the dead baby.

Some cultures attribute human status only to babies which show signs of life at birth. Within these cultures pregnancy loss may be ignored or even feared. The physical remains of pregnancy loss may be regarded as polluting or evil. This aspect is missing from policy and practice literature relating to pregnancy loss.

Equality and diversity are emphasised as being at the heart of health services policy. Current policies relating to pregnancy loss fail to acknowledge the diversity of views that exist. Some service users may therefore receive care that conflicts with their personal belief systems. This presentation will address how policies may be developed to meet the diverse needs of maternity service users experiencing pregnancy loss.

Public Spaces, Private Thoughts: Creating Remembrance and Identity Using Graves and Newspaper Notices

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Social theorists, such as Anthony Giddens, have propounded the idea that individuals create their own identities. People choose who they want to be, and one of the tools in the identity construction kit is that of storytelling. Through ongoing narration people can both make sense of their own lives, and also tell others about themselves.

When pregnant, parents will often think and talk about their child, who thus becomes part of their family and ongoing story. If the child dies, either before or soon after birth, the parents need to grieve. But who is this lost child for whom they are mourning?

Parents in this situation may make use of public, as well as private spaces. Babies' graves, often in a special section of the cemetery, are accepted as sites of remembrance. These graves can also be sites of identity creation. Artefacts placed on, and visits to the grave play a part in the parents' telling of their baby's story, and thus in the creation of their baby's identity.

Newspapers are another public site that parents are beginning to utilise. Death and In Memoriam notices are sometimes used to speak about the dead child in a public forum.

This paper explores, with particular reference to Scottish experience, the ways in which graves and newspaper notices can be used as a public means of creating both memory and identity simultaneously.

Words and Pictures: Moving on while maintaining bonds through remembrance and memorialisation

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In England and Wales*, nearly 194000 legal abortions were performed in 2006, one in four pregnancies ended in miscarriage, while the perinatal mortality rate (2005) was 8.0 deaths per 1000 live births. Gray and Lassance in *Grieving Reproductive Loss* (2003), acknowledge the human beings beneath such bare statistics who are both directly and indirectly affected, commenting that ‘The grief associated with such reproductive losses is often minimized, denied, and considered to be outside the normal “grieving rules” of society’. Yet individuals who have suffered these losses can experience profound grief and emotional pain. Their grief needs to be acknowledged by themselves and by others’. They may become what Doka (1989) describes as ‘disenfranchised grievers’, experiencing a sense of disempowerment within themselves and alienation from the community in which they exist.

One way in which those affected by grief may reclaim a sense of re-empowerment and autonomy, assisting them to move through the tasks of mourning, is by the pro-active process of remembrance and memorialisation, through which they can both acknowledge the reality of their loss – (not only of their child, but also of part of themselves and their future dreams) - and also maintain continuing bonds with the deceased. This paper will look at some practical ways in which this can be therapeutically facilitated, through the use of written text and visual images, particularly in the creation of journals, memory books and memorial websites.

Doka, K. (Ed.). (1989). *Disenfranchised Grief: Recognising Hidden Sorrow*. Lexington, MA, USA: Lexington

Gray, K. and Lassance, A. (2003) *Grieving Reproductive Loss: The Healing Process* New York Baywood

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The Disposal of Foetal Remains

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This paper considers the sensitive disposal of foetal remains, through examining developments that have taken place over the past 10 years and how further improvements may be made in the future.

Drawing upon research into the burial, cremation and disposal of foetal remains carried out in the mid 1990s by the Institute of Cemetery and Crematorium Management (ICCM), the paper charts the history of the disposal of foetal remains in the UK up to the beginning of the twenty first century. It is since this time that there have been vast improvements: from the turn of the century, when approximately only 9000 foetal remains were disposed of via cremation or burial (the rest being disposed of as clinical waste), the figure is now in excess of 30,000.

The paper reflects on the work the ICCM has undertaken over the last decade in conjunction with the Royal College of Nursing that has led to this increase. Their collaboration, culminating in a national policy document in 2001, alongside pressure on local authorities and other factors that will be explored in this paper, has resulted in fewer and fewer foetal remains now being disposed of as clinical waste. However, there remain inconsistencies in services offered, which will be highlighted here, alongside suggestions for improvement(s).

Diversity and discretion in experiences related to reproductive loss

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There is variation in the kinds of health care offered to parents who experience reproductive loss, as this important life experience can fall within the remit of several medical specialties through which care provision is structured (such as Obstetrics, Fetal Medicine, Gynaecology and Neonatology). Drawing on the experience of involvement in sociological research in three key areas of reproductive loss (termination of pregnancy, neonatal withdrawal of life sustaining intervention, and miscarriage), I begin this paper by mapping out some of the ways in which diversity of experience is created by the organisation of formal health care. I then go on to explore in more detail the diversity that exists beyond such structural factors, by focusing on the case study of feticide prior to termination of pregnancy for fetal anomaly. The findings from three studies on this topic are sampled heuristically to provide an insight into the diversity of views and experiences of reproductive loss in this context, and to highlight the implications of such diversity for the role of clinical discretion in care provision.

The liturgical response to stillbirth and pregnancy loss

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The last few decades have seen considerable change in attitudes towards stillbirth and miscarriage in this country. The pastoral support offered to parents has increased considerably, but there is also a need to mark reproductive loss ritually. The Church of England has now produced an official service for the funeral of a child dying near the time of birth, while in many places there are regular memorial services specifically for stillbirths and neonatal deaths. As technology increases our knowledge and awareness of the unborn foetus, so provision is requested and offered at increasingly early stages in pregnancy, often before the medical and legal limits of viability. This paper considers the appropriateness of available material and its use, and what other liturgical resources might best meet the needs of those affected.

Death at the beginning of life: stillbirth and perinatal loss - the need for education and training for health care professionals

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Childbearing loss affects all social groups and impacts on professionals who may be involved in the care and well-being of women and their families. A loss during pregnancy or around the time of birth is complex and unique (Hutti 2005). The literature suggests that health care professionals are at the front line of care when a baby dies. Yet they remain ill prepared to deal with the grief and loss experienced by parents and families at this challenging time (Maguire and Faulkner (1988), Fallowfield (1993) and Garg et al (1997).

This paper will present a discussion on the human consequences of stillbirth, perinatal loss and early infancy death as these affect the mother, her partner and those who care for her at this time. It will highlight the extent and significance of losses such as these in the UK as well as touch on the global issues and cultural issues surrounding the topic of death and the beginning of life. The paper proposes to explore knowledge and best practice in caring for, and working with individuals at this time and, as the literature suggests that doctors and nurses may benefit from increased training in bereavement support, the paper strongly proposes that health care professionals' contemporary education and training curricula accommodate this appropriately in programme syllabuses.

Silent miscarriage and deafening heteronormativity: An experiential and critical feminist account

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In this paper we provide a critical feminist analysis of 'silent' miscarriage using our experiential accounts as a catalyst to explore both the academic and 'lay' literatures surrounding pregnancy loss. We delineate the similarities and differences in our own experiences before focusing on relational context as a prime site of diversity and difference. Through an examination of scholarly and 'self-help' writing on miscarriage we argue that pervasive heteronormativity doubly marginalises the experiences of lesbians – and women otherwise located outside the realm of heterosexual relationships. In conclusion, we suggest a more thorough engagement with 'non-normative' experiences of pregnancy loss will substantially enhance our understandings of miscarriage. Moreover, placing marginalised experience at the centre of pregnancy loss scholarship could significantly augment critical, feminist and social scientific theorising and contribute to pregnancy loss being more firmly located on reproductive health agendas.

Searching for Wholeness? An Autoethnography

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In the form of an autoethnography which connects the personal and the cultural and where the self is made vulnerable (Ellis 2004), this paper explores the author's personal experiences of pregnancy loss in the 80s and early 90s. Drawing on a range of artefacts that aided in the creation of memories of liminal lives during that time, it partly reflects on the struggle to have these losses and ensuing grief and mourning recognised as legitimate. However, its overall focus is Western discourse which upholds an imperative to create positive meaning or 'a sense of wholeness' from traumatic life experiences, where the favoured outcome is personal progress and 'triumph over adversity' (Stacey 1997). In presenting an alternative, messier and more ambiguous story the author highlights the difficulties in voicing experience which resists such a conceptualisation and ultimately remains 'unwhole'.

Post mortems after perinatal death: can we research parental decision-making?

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After late miscarriage, stillbirth or termination for fetal abnormality a post-mortem carried out by a specialist perinatal pathologist may explain the cause of death or pregnancy loss and improve future parental and medical decision-making. Rates of perinatal post-mortems are falling in the UK, in part because parents decline consent and also because doctors may not even discuss the potential value of a post-mortem for fear of causing additional distress after bereavement.

It may be that fear of causing additional distress has also inhibited research into parents' decision-making about post mortems: data are limited and mostly retrospective. As a multi-disciplinary group comprising obstetricians, a perinatal pathologist and a social scientist we sought to investigate, prospectively, parental decision-making about post-mortem in the aftermath of recent organ retention scandals and revised consent protocols.

In this paper we will discuss:

- our experiences of seeking to undertake research with newly bereaved parents making decisions about whether or not to have a post-mortem
- findings related to parents' attitudes to research participation
- findings related to decision-making

Research Ethics Committees should be aware that sensitivity to parental distress does not preclude research. As one mother said: *Medical research is extremely important, and I think Drs should approach parents, however difficult it may be*. Having or not having a post-mortem appears to relate to desire for

information rather than concerns such as what happens to the baby's body. In-depth discussion of post-mortems can enable parents to feel better about the decision they make.

To see or not to see: should parents hold their stillborn baby?

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For every 200 live births in the UK, one pregnancy results in stillbirth. The question of whether or not it is beneficial for parents to see and hold their stillborn baby remains hotly controversial. Recent NICE guidelines state: 'It is now considered unhelpful for women to see and hold their babies (after stillbirth), unless they particularly wish to do so.' At the same time, new guidelines for professionals published by the Stillbirth and Neonatal Death Society advocate 'suggesting to parents that they might want to see and to hold their baby'.

These unfortunate contradictions are profoundly unhelpful to both parents and midwives. They appear to derive from common discrepancies between different kinds of evidence and different kinds of experience. On the one hand, systematic research has shown that experience of contact with the dead infant is associated with significantly elevated symptoms of maternal depression, anxiety and post-traumatic stress disorder in the subsequent pregnancy and with insecure disorganised attachment in the next-born child. Longer-term adverse outcomes include continuing symptoms of PTSD and increased risk of family breakdown. On the other hand there is a strong body of qualitative data demonstrating that some – although by no means all - parents greatly value having time and contact with their stillborn baby and believe this is important to recovery.

These paradoxical findings will be discussed. Developments in policy and practice will be suggested that may empower parents to make more informed choices.
