2. Invited commentary: The impact of stillbirth

In the developed world, one in 200 infants is stillborn. This is a devastating outcome of pregnancy for parents and for the healthcare professionals who look after them. Stillbirth is still 10 times more common than sudden infant death syndrome and accounts for 70% of all perinatal deaths. This latest Perinatal Mortality Annual Report from NPEC describes 301 infants who were stillborn in 2013.

Many stillbirths do remain unexplained, but an unexplained death may in reality be an un-investigated one. Stillbirths deserve the same systematic evaluation as adult deaths, yet the study of specific causes of stillbirth has been historically hindered by the absence of uniform protocols of investigation, lack of agreement on definitive classification systems, as well as the extent of post-mortem assessment performed. In general, the most common causes of stillbirth are investigated, as well as those conditions that might predispose couples to recurrent stillbirth. Understanding reasons helps parents recover, but may also identify recurrence risks and even identifying a sporadic cause has merit as it can bring closure and provide reassurance. An important national advancement has been NPEC's development and implementation in 2011 of a comprehensive data collection tool and classification system for perinatal deaths.

Falling post-mortem rates, related to public concerns regarding perinatal autopsy, has prompted a search for non-invasive alternatives, including post-mortem imaging, and for predictive markers of placental dysfunction and incipient fetal growth restriction. Despite this, the conventional post-mortem examination or autopsy remains the gold standard for determining the cause of death. Clinicians should continue to advocate for this rather than inferring a cause and the important role of specialist perinatal pathology within maternity services needs greater focus. Many of the broad categories of cause of death, including unexplained stillbirth, are thought to be related to placental function, and while placental abnormalities are estimated to occur in over 50% of stillbirths, they are still poorly understood and sometimes variously reported. Internationally, several risk factors have now been associated with stillbirth, including advanced maternal age, high body mass index, maternal ethnicity, fetal growth restriction but understanding of the epidemiology remains limited. Numerous social, behavioural and lifestyle risk factors are reported to be associated with stillbirth, but these links are complex, and psychosocial and biological factors may interact together to increase the risk.

The death of an infant is one of the most stressful life events that an adult experiences. There is significant psychological morbidity associated with prenatal loss at any gestation and effects on physical and emotional wellbeing may be long-lasting. Provision of an empathetic environment with psychological support at the time of loss is now an accepted part of care, albeit without much evidence yet of improved health outcomes. Only a few studies have addressed the lived experience of stillbirth and there is still relatively little qualitative research showing how bereaved parents make sense of their loss. In addition to the impact on parents and their families, stillbirth has also been demonstrated to have a considerable impact on healthcare professionals. Studies reveal a consistent account of personal and professional burden following stillbirth. Given the extensive impact of stillbirth on all involved, it is imperative to understand the underlying causes. Further, identification of mothers at risk for pregnancy loss is a necessary step to effective intervention and prevention, and the intensity of prenatal care can then be matched to each woman's risk profile.

Impact on parents and families

The recognition of stillbirth as a significant bereavement is relatively new, but the death of an infant is now acknowledged as a hugely stressful life event. Perinatal grief is a distinctive grief with lasting and lifelong impact for parents, who often have complex emotional and psychological needs following stillbirth.

Many short and long-term negative outcomes for parents have been reported in the aftermath of stillbirth, including anxiety, depressive symptoms, post-traumatic stress, suicidal ideation, guilt, social phobia and remorse. Studies have demonstrated that the impact of stillbirth contributes significantly to relationship strain and breakdown. Factors which have been suggested to increase the risk of adverse psychological outcomes for parents after stillbirth include: inadequate social support, traumatic circumstances surrounding the death, difficulties in coping with a crisis in the past, problematic relationships and the presence of other life crises. Of concern is the extensive literature regarding the ongoing morbidity and mortality that exists for families who have experienced infant bereavement, including significantly higher levels of anxiety and depression in pregnant mothers who had previously had a perinatal loss with a negative impact on attachment to the subsequent child, as well as evidence of increased mortality in bereaved parents. Stillbirth has also been shown to have a negative impact on siblings, grandparents, and other family members.

Bereavement care following stillbirth has developed over the last twenty years to reflect the increasing understanding of grief. Traditional models encouraged a focus on cutting ties with the loved one and moving on, whereas modern models recognise the value of continuing bonds and creating meaning. Stillbirth bereavement care now aims to support these grieving tasks by facilitating the parents' expression of grief, through ensuring a sensitive non-traumatising experience during which they spend time as parents with their baby, supporting them in creating memories and helping them with understanding through investigation.

The provision of support for parents following stillbirth is therefore a key part of overall care from the maternity services. This support should be initiated from the time of diagnosis and extend through the care provided in hospital and then following discharge for as long as is necessary. Dedicated bereavement teams contribute much to the support offered to parents, where trained professionals can provide specialised and appropriate person-centred care and follow-up investigations. There is however continuing inconsistency in the availability of bereavement support across the Irish maternity services in 2015, and a heavy reliance on the voluntary charitable sector to meet the needs of bereaved parents and families.

Research has suggested that the role of practitioners in the handling of death and their interaction with the bereaved from the moment of breaking the news of death influences the intensity of grief and has the potential to positively impact on the grief experience of bereaved parents. However, poor communication can add to parental distress and increase dissatisfaction with care. There is, thankfully, increasing recognition of the need to offer guidance and training to health-care professionals involved in communicating bad news. Creation of an empathetic, caring environment, and strategies to enable the family to accept the reality of stillbirth, are now an accepted part of standard care and social support. Further, provision of interventions such as psychological support or counselling, or both, has been suggested to improve outcomes for families after a perinatal death, although evidence for this is still limited.

Surveys of bereaved parents highlight the critical importance of the quality of parents' interactions with staff. While the specialised role of bereavement midwives in particular, and other members of the bereavement team is always acknowledged, it is clear that parents expect the importance of kindness and sensitivity to extend to all hospital staff including clerical, security, catering, medical, chaplaincy and midwifery. The use of an alert

or 'bereavement' sticker on the cover of the hand held patient file, as used in several UK and Irish hospitals, has the potential to remind staff to be sensitive, as does the display of a similar symbol in clinical areas. A study on bereaved parents' experience of stillbirth in UK hospitals agreed that, "positive memories and outcomes depend as much on genuinely caring staff attitudes and behaviours as on high-quality clinical procedures". In this way it can be seen that empathic care and sensitive communication from the bereavement team alone is not sufficient. The entire hospital must adopt a considerate and supportive approach toward parents and families bereaved by stillbirth. The conclusion of Soo Downe's 2013 paper on bereaved parents experience of stillbirth is a worthwhile one to remember: "*all staff who encounter parents in this situation need to see each meeting as their one chance to get it right.*"

Impact on staff

The lived experiences of bereaved parents have contributed much to the published literature on stillbirth. However, it is increasingly recognised that stillbirth has a considerable impact on the personal and professional wellbeing of healthcare professionals. The impact of this emotional burden in the wider healthcare field is now being openly documented. In a questionnaire study of US obstetricians in 2008 seventy-five percent of respondents acknowledged that caring for women following stillbirth took a large emotional toll on the obstetrician. A recent Irish study confirmed that the emotional burden associated with stillbirth is considerable and revealed the complexity for medical consultants within the multi-disciplinary team. Despite the impact of stillbirth, no consultant had received formal training in perinatal bereavement care. This study highlighted both a gap in training and the implications of stillbirth on obstetricians professionally and personally, recommending the provision of support, ongoing education and the need for self-care.

In a meta-analysis of studies (n=20) published between 2000-2015, conducted for the upcoming 2015 Lancet stillbirth series, all of the studies reviewed reported substantial personal and professional impacts on staff following stillbirth. Four major qualitative themes emerged from the review of these papers: psychological impact, professional impact, need for support, and positive effects for staff. Psychological impact was most frequently reported with somatic effects such as trauma symptomatology, diminished emotional availability, stress, and affective states such as grief, guilt, anger, self-blame, self-doubt, anxiety and sadness. The professional impact of stillbirth was characterised by fear of litigation or loss of livelihood as well as fear of disciplinary action. The majority of studies highlighted the need for further education and professional support for staff in psychosocial care and communication skills. Lack of institutional and structured peer support was also highlighted, and many studies found that peer support, although valuable, was too informal. Interestingly, staff who felt they had received adequate training in stillbirth care reported less guilt and less fear of litigation. Only six studies noted the positive outcomes reported by staff such as a sense of 'privilege', 'personal growth' and the development of a 'special bond' with parents. In four studies, staff reported more confidence with fewer negative effects, where they had more direct clinical experience of stillbirth.

The Irish Medical Council's 2014 report "*Your training counts*" states that there is ample evidence to show that "good health and wellbeing contribute to good professional practice". It is acknowledged therein that healthcare professionals must provide safe effective and compassionate care for patients and families at times of great distress, in a demanding healthcare context, while trying to maintain professional competence. However, historically, healthcare professionals, and doctors in particular, have been slow to recognize the profound effect adverse medical outcomes, such as the death of a patient, can have on their mental and physical health. Doctors have higher rates of mental health disorders, including depression, anxiety, substance misuse, and "burn out" than other

occupational groups yet are reluctant to access services that might help.

There is now an increasing body of research looking at burnout and compassion fatigue in healthcare, although for reasons that are unclear very little of this to date has focused specifically on the maternity services. Compassion fatigue, defined in the literature as the reduced capacity for empathy toward patients resulting from repeated exposure to their trauma, has been linked with maladaptive coping mechanisms to stress, chronic exhaustion, absence of appropriate debriefing after adverse events and lack of training in dealing with death. Burnout, a concern in fields dealing with trauma and acute stress, also develops in response to intense interpersonal situations with high emotional and cognitive demands. It has been linked to longer working hours and is experienced more often by those who work in specialties with proportionally higher direct patient contact.

Over the past decade, system changes in healthcare have necessarily focused on disclosure, reporting, and the patient safety culture. However, little attention has been paid to creating systems that help the healthcare providers, who are involved as the 'second victims' after an adverse event such as stillbirth represents. The literature highlights the importance of staff education and professional support as gaps in existing service provision and as areas that require increased attention in healthcare systems. Further research on support interventions for staff and the effect of this staff support on patient care outcomes are needed. Finally, as colleagues in palliative care medicine have written: "the idea of 'self-care' may seem a selfish irrelevance and an unjustifiable luxury. In fact, self-care is an essential part of the therapeutic mandate."

Impact on society

The impact of stillbirth on society ranges from the obvious loss of a valued human life to the effect of this loss directly on families, healthcare systems, welfare systems and the workplace. There is a paucity of information in the published literature to quantify the exact economic cost of stillbirth to society, but these costs can be loosely described as direct and indirect. Direct costs associated with stillbirth include those related to its management and the associated medical investigations, costs of funerals and burial arrangements, as well as the increased costs of care for subsequent pregnancies following stillbirth. Indirect costs are more difficult to quantify and include the longer-term costs to society following the grief and psychological symptoms that occur as part of the impact of stillbirth on parents. Other indirect costs include lack of productivity through employment absence and reduction in working hours. Acknowledgement of the personal and professional cost of stillbirth on staff raises important issues of staff wellbeing and governance, which in turn directly affect both the financial and human costs of providing care and families' experiences.

How to make a difference

Healthcare Systems

Sands, the UK Stillbirth and Neonatal Death Society founded in 1978, recommends five key ways in which maternity units can improve the care for parents whose baby dies before, during or after birth (https://www.uk-sands.org/professionals/principles-of-care/5-ways-to-improve-care). These are (1) bereavement care training for all staff, (2) access to trained bereavement care midwives for bereaved parents and staff support, (3) at least one dedicated bereavement room, (4) bereavement care literature and (5) post mortem consent information for parents and staff training in consent. This is because "the quality of care that bereaved families receive when their baby dies has long-lasting effects. Good care cannot remove parents' pain and grief, but poor care can and does make things much worse."

National clinical guidelines on the Investigation and Management of Late Fetal Intrauterine Death and Stillbirth were published in 2011, with 22 key recommendations setting out the expectation of standards of care in all Irish hospitals (http://www.rcpi.ie/article.php?locID=1.5.71.492). The guideline highlights that skilled, sensitive and caring treatment in the time surrounding

pregnancy loss can positively impact on the grief experience of bereaved parents and recommends that supportive care should be made available to all. The introduction and, it is expected, implementation of these stillbirth guidelines ensures that, at a very minimum, parents should expect to receive comprehensive care, thorough investigation, and bereavement support from diagnosis to delivery and postnatally following stillbirth.

The HSE has recently launched a national public consultation process on draft Bereavement Care Standards following Pregnancy Loss & Perinatal Death, which, it is hoped, will be published in 2016 (http://www.hse.ie/bereavementcarestandards/). These Standards are important to ensure improvements in key aspects of bereavement care for women, parents and families who experience stillbirth in Ireland, including the development of bereavement specialist teams in all maternity units and the provision of training and support for all healthcare professionals involved in caring for the bereaved.

Stillbirth Research, Confidential Enquiries and Clinical Audit

Stillbirth is a highly significant topic of research. While stillbirth has been for decades a largely under-prioritised and under-researched problem, stillbirth research – that is, the investigation of causes of stillbirth as well as development of effective interventions to prevent stillbirth - has now been classified as a specific global research priority.

Stillbirth has become an international focus of interest and concern as a preventable death, with the Global Alliance to Prevent Prematurity and Stillbirth (GAPPS) and the World Health Organization naming reduction in stillbirth rates as a key goal to improve pregnancy outcome. The Lancet's Stillbirths Series listed stillbirth research priorities in 2011. These included: (i) developing repositories of human samples from stillbirths (ii) defining pathophysiological pathways leading to stillbirth associated with maternal disease, fetal growth restriction or placental dysfunction, (iii) investigating maternal lifestyle consumptions associated with stillbirth and (iv) determining optimal antenatal surveillance with interventions to reduce stillbirth. There has already been a significant increase in stillbirth research output commensurate with this attention, assisted by the increasing public awareness of the impact of perinatal grief.

Consideration should be given to establishing a Confidential Enquiry into Perinatal Death in Ireland, in the same way as the Maternal Death Enquiry (MDE) Ireland has conducted confidential reviews into maternal deaths since 2009. Confidential Enquiries focus on improving health care by collecting evidence on aspects of care, identifying any shortfalls in this, and disseminating recommendations based on these findings. In this process, enquiry panels comprise clinicians from relevant specialties, who are independent of the hospital where the patient died and who are unaware of the clinicians concerned with the patient's care. The purpose of a Confidential Enquiry is specific; identifying suboptimal patterns of practice and service provision related to the deaths, making recommendations for improvements in clinical care and suggesting directions for future research and audit.

Finally, robust perinatal audit is increasingly established throughout the developed world and aims to identify antecedent conditions and risk factors associated with stillbirth. It has proved an important tool for reduction of perinatal mortality and assessment of quality of perinatal care. The work of the National Perinatal Epidemiology Centre in presenting the results of clinical audit in successive annual Perinatal Mortality Reports is therefore to be commended.

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