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KEYNOTE AND
PLENARY SESSIONS
Session: Keynote lecture 1

Detection, management, challenges and innovations in the clinical care of Fetal Growth Restriction (FGA/SGA)

Dr. Francesc Figueras

Hospital Clinic and University of Barcelona, Spain

Fetal growth restriction (FGR) is among the most common complications of pregnancy. FGR is associated with placental insufficiency and poor perinatal outcomes (remarkably, perinatal mortality). Clinical management is challenging because of variability in clinical presentation. Fetal smallness (estimated fetal weight <10th centile for gestational age) remains the best clinical surrogate for FGR. However, it is commonly accepted that not all forms of fetal smallness represent true FGR. In a significant subset of small fetuses, there is no evidence of placental involvement, perinatal outcomes are nearly normal, and they are clinically referred to as “only” small for gestational age (SGA). Doppler may improve the clinical management of FGR; however, the need to use several parameters sometimes results in a number of combinations that may render interpretation challenging when translating into clinical decisions. We propose that the management of FGR can be simplified using a sequential approach based on three steps: (1) identification of the “small fetus,” (2) differentiation between FGR and SGA, and (3) timing of delivery according to a protocol based on stages of fetal deterioration. This stepwise approach has the potential to prevent adverse outcomes.

Ethics statement: N/A

Conflicts of interest: None

Keywords: fetal growth restriction, screening, ultrasound

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Session: Keynote lecture 2

Investigation of perinatal death from a Pathologist's perspective (clinical aspects and interaction with parents)

Dr. Martha Cohen
Sheffield Children’s NHS FT and University of Sheffield, United Kingdom

A perinatal post-mortem (PM) is an important tool in the investigation of fetal & neonatal death. Central to parents and the health team is a complete understanding of the PM, what it entitles, its risks and benefits. The range of emotions that come with expecting a child is different for every family. Just as each pregnancy is unique, so too are the feelings and circumstances surrounding the loss of their child. Sensitive approach when communicating to parents about a PM includes the manner in which the offer of a PM examination is presented; trust the parents have on the health professional; openness and transparency; timing of the discussion and setting where this takes place. All these issues will have a profound impact on the parents and their decision. When discussing the perinatal PM, the health professional should discuss options available: full or limited PM, PM MRI, genetic and placental studies, consent or not to use the tissue for research. The staff should always listen to parents’ questions and perspectives; understanding their religious and cultural concerns. Once the PM results are available, a multidisciplinary discussion should take place. Findings should be fed back to the parents by the consultant, in a timely, clear and informative style, using a vocabulary that parents can understand. Women of deprived background are less likely to be offered, or consent to, a PM, and less likely to receive the results in a meeting with a consultant. Timing and sensitivity with which women are approached and the prolonged turnaround for the PM results are key. Some institutions now offer a PM MRI, which is seen as a good option for those parents and faith groups who object to an invasive approach; has a faster turnaround time of the body, and the images can be kept as memories. A perinatal PM should always be offered, tailored to parents culture. Barriers should be overcome with sensitivity, professionalism, and openness.

Ethics statement: N/A

Conflicts of interest: None

Keywords: bereavement, MRI, perinatal postmortem, stillbirth

Discovering novel predictors for fetal growth restriction

Prof. Gordon Smith

University of Cambridge and Cambridge University Hospitals NHS Foundation Trust, United Kingdom

We followed 4,212 women having first pregnancies from their dating scan to delivery, collecting serum and plasma at 12, 20, 28 and 36 weeks of gestational age. This cohort, the Pregnancy Outcome Prediction study, also involved serial ultrasonography at the same time intervals. Utero-placental Doppler flow velocimetry and third trimester biometry were blinded. At delivery, samples of placenta were collected and flash frozen as soon as possible for molecular analyses. We have applied multiple discovery based approaches to the identification of novel biomarkers and disease mechanisms for fetal growth restriction. These include: (1) maternal serum (i) proteomics and (ii) metabolomics; (2) maternal plasma (i) RNA-seq and (ii) DNA-seq using antibody capture of hydroxy-methylated DNA; and, (3) placental (i) RNA-seq, (ii) oxidative bisulphite DNA-seq, (iii) metagenomics using RNA-seq and DNA-seq; (iv) mutation analysis using laser capture microdissection and 30x and 120x depth DNA-seq. Results reveal the potential of discovery-based methods to yield clinically useful predictors of fetal growth restriction.

Ethics statement: N/A

Conflicts of interest: Gordon Smith receives/has received research support from GE (supply of two diagnostic ultrasound systems) and Roche (supply of equipment and reagents for biomarker studies). Gordon Smith has been paid to attend advisory boards by GSK and Roche. GS has acted as a paid consultant to GSK. Gordon Smith has received support to attend a scientific meeting from Chiesi. Gordon Smith is named as co-inventor in a patent submitted by Cambridge Enterprise (UK) in the national phase, for a novel treatment for preterm infants (US61/253936). Gordon Smith is named inventor in a patent submitted by GSK (UK), for novel application of an existing GSK compound for the prevention of preterm birth (PCT/EP2014/062602).

Keywords: fetal growth restriction, novel predictors, biomarkers

Session: Keynote lecture 3

Perinatal palliative care overview: U.S. Care from parent and care provider perspectives

Dr. Denise Côté-Arsenault
St. Louis University, United States

With routine antenatal testing parents may now learn that their wished-for child has anomalies, 2% of which are life-threatening. While the majority of parents choose to terminate the pregnancy, a growing number are choosing to continue. In the United States many of these parents are offered perinatal palliative care. Perinatal palliative care (PPC) is the newest type of palliative care in the United States, with the majority of programs being in existence 10 years or less. The goal of PPC is to provide interdisciplinary team support and comfort for pregnant women and their families when a life-threatening fetal condition is found and parents choose to continue the pregnancy. Although programs share some aspects of care there is no agreed upon standard of care or parent outcomes. Often it consists of early involvement, concurrent palliative and life-sustaining care, and caring for the infant with a serious condition. Poor parental outcomes after a perinatal loss are common, consisting of compromised physical and mental health, changes in the couple’s relationship, and decreased work productivity. However, some bereaved try to make sense of their loss through meaning-making and seek something positive from their tragedy may experience positive personal growth. This presentation will provide an overview of PPC, differentiate it from hospice care, and describe common aspects of care. Research findings on parents’ experience of continuing pregnancy will include decision-making, their revised tasks of pregnancy and their needs from care providers. Thoughts will be shared about possible approaches that may improve parent outcomes and facilitate positive growth. Perinatal palliative care is an increasingly available type of care in the United States. Although the fetus is the identified patient, during pregnancy care and support is provided through the mother, and often, the father. It is critically important to listen to the parents a

Ethics statement: N/A

Conflicts of interest: None

Keywords: perinatal loss, perinatal palliative care, fetal diagnosis, parent bereavement

Cite as: Perinatal palliative care overview: U.S. Care from parent and care provider perspectives. Denise Côté-Arsenault. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Providing respectful perinatal bereavement care: Reflections from EE.UU., Spain and Uganda

Sue Steen

Maple Grove Hospital and Bethel University, United States

Literature from many organizations around the world overwhelmingly supports the importance of respectful care for families experiencing the loss of a baby. Does respectful care look the same in low-income and high-income countries? What do parents tell us is important to them? How does the Health Care Professional ensure that families are receiving respectful care? International guidelines for perinatal bereavement care share common themes that can direct us in our care of bereaved families who experience perinatal loss in many parts of the world. One theme of respectful care is the presence of supportive and compassionate staff. Compassionate staff will respect and honor the family’s feelings, beliefs, and desires. They will provide presence and develop the supportive relationships that families deserve. Another theme of respectful care is that of sensitive and clear communication that allows families to understand their circumstance and make informed decisions. Families, who are fully informed, will know of their option to stay in the hospital with their deceased baby until they are ready to say good-bye. An informed family will know that they can have a cultural or religious ceremony with their stillborn baby. Informed families will be aware of support options and resources for the weeks and months following their baby’s death. Respectful care also allows time for planning, helping parents make decisions at a difficult and overwhelming moment in their lives. Providing privacy and time alone with extended family and friends allows families to honor and celebrate their baby. Respectful care involves good communication, honoring parent choices, and compassionate presence. Whether families are navigating through a neonatal loss, a stillbirth or a variety of perinatal bereavement situations around the world we must give them excellent, respectful care as they make this difficult journey.

Ethics statement: N/A

Conflicts of interest: None

Keywords: respectful, bereavement care, perinatal loss

Cite as: Providing respectful perinatal bereavement care: Reflections from EE.UU., Spain and Uganda, Sue Steen. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Keynote lecture 6

Stigma and stillbirth: how health messages impact on the experience of reproductive loss

Dr. Samantha Murphy

The Open University, United Kingdom

The concept of stigma (Goffman, 1963) will be outlined together with an explanation of how it can be applied to the experience of reproductive loss. Goffman’s concept of stigma is one that has been used in the social sciences over the last five decades and it continues to have currency. Here it will be drawn upon to explore the experiences of women who have experienced a stillbirth which for many women can induce feelings of guilt and shame. As such it will highlighted how the well-intentioned but proscriptive health messages that are relayed to pregnant women thus impact upon them deleteriously following a reproductive loss. Indeed, such negative feelings might, then, affect their social relationships as well as on their sense of wellbeing and confidence. This can be especially in the case where a stillbirth remains unexplained: the absence of a reason, leads some women to find one of their own and this is often where they will question their own behaviour during the pregnancy. In summing up the importance of reassuring women that the stillbirth was not their fault will be highlighted and that, where possible, an explanation for the stillbirth should be sought.

Ethics statement: N/A

Conflicts of interest: None

Keywords: stigma, stillbirth, pregnancy, health messages, women, qualitative research

Cite as: Stigma and stillbirth: how health messages impact on the experience of reproductive loss. Samantha Murphy. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Plenary session 1 Setting the agenda: Perinatal mortality and bereavement care

The Impact of perinatal death on society

Prof. Alexander Heazell

Maternal and Fetal Health Research Centre, University of Manchester and Manchester University NHS Foundation Trust, United Kingdom

There are over 5 million stillbirths and neonatal deaths worldwide each year. This loss of life causes significant adverse psychological effects for bereaved mothers, fathers and wider family members. Perinatal deaths also impact upon professionals working in maternity services. These psychological impacts have wide reaching social and economic consequences for bereaved families. Studies employing quantitative, qualitative and mixed methods designs have demonstrated the enduring psychological impact of perinatal death; it is estimated that over 4 million women have significant depressive symptoms due to stillbirth. Critically, the majority of data have been derived from low-burden settings with a paucity of studies from high-burden environments. Bereaved parents are often socially isolated due to the stigma associated with perinatal death, in some settings this may result in marital breakdown and partner violence. The death of a child is also associated with economic impact which is more often met by parents in higher burden settings where there is lower availability of state support. Including the economic impact of stillbirth significantly reduces the cost per life saved of interventions which reduce maternal and perinatal mortality. Therefore, a full appreciation of the cost of stillbirth is important so that the cost of interventions to prevent perinatal death can be appropriately evaluated. Some of the negative psychological and social impacts of perinatal death can be mitigated by care and strategies from the time of loss onwards including respectful maternity care and peer-support. Perinatal death is associated with psychological, social and economic impact. While this is primarily felt by bereaved parents the effects permeate to wider society. There is some evidence from low-burden settings for strategies to mitigate the negative effects, further studies are urgently needed in high-burden settings.

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, perinatal death, psychological consequences, perinatal mental health

Perinatal death from the perspective of the healthcare professional: caring for self while caring for others

Dr. Jane Warland
University of South Australia, Australia

There is no doubt that caring for bereaved families can be both challenging and rewarding. This is because when a maternity care provider (MCP) opens themselves to voluntarily engaging empathically with those encountering perinatal death they also open themselves to a deep personal transformation. While this transformation can include positive aspects such as personal growth and greater awareness of all aspects of life, there is also a darker side which includes unwanted changes to oneself that can parallel those experienced by the bereaved parents themselves, this is known as vicarious traumatization. This can have an impact on the MCP’s sense of self, world view, spirituality, affect tolerance, interpersonal relationships, and imagery system of memory. Likewise, emotional burnout i.e. a state of emotional, physical, and mental exhaustion caused by excessive and prolonged stress, can also be a consequence of working with bereaved families. Nevertheless, caring for families who have suffered the death of their baby can be deeply enriching for the care provider and certainly warrants the MCP taking time to care for themselves, so that they are best placed to empathetically care for all bereaved family members they encounter when a baby dies. In this presentation, Dr Warland will first share some of her own experiences of caring for bereaved parents at the time of or following a perinatal death. She will then outline some of the areas of one’s life that can be impacted by vicarious traumatization and suggests self-care strategies that apply to each area of disruption. She will finish with reviewing some strategies for avoiding burnout.

Ethics statement: N/A

Conflicts of interest: None

Keywords: vicarious trauma, burnout, caring for the carer

Cite as: Perinatal death from the perspective of the healthcare professional: caring for self while caring for others. Jane Warland. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Plenary session 2 Saving babies lives: Innovations in perinatal mortality reduction

Perinatal mortality: a global and regional scorecard

Dr. Hannah Blencowe

London School of Hygiene and Tropical Medicine, United Kingdom

Globally 5.1 million babies die between the 28th week of pregnancy and the 28th day after birth every year, accounting for nearly 60% of all childhood deaths (28th week of pregnancy to age 15). This is a massive burden on mothers and fathers, families, communities and societies. The majority of deaths occur in sub-Saharan Africa and Southern Asia, with around 2/3rd during pregnancy or on the day of birth. Infections and complications of labour and preterm birth remain the most important causes of neonatal deaths globally. Important causes of stillbirth include infections, labour complications, maternal chronic conditions and antepartum haemorrhage. The majority of these are preventable with low-cost, low-tech solutions. Recent increase in attention and investment has contributed to reductions in neonatal deaths. Global attention and investment for stillbirth remains insufficient to meet 2030 target of 12 or fewer stillbirths in every country. The Stillbirth Advocacy Working Group has created a scorecard to track progress against the Lancet Ending Preventable Stillbirth call to action highlighting areas for action, including quality of antenatal and intrapartum care, improving the counting of every baby, closing equity gaps, improved bereavement care and action to reduce stigma.

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, neonatal death, epidemiology, causes, global

Session: Plenary session 2 Saving babies lives: Innovations in perinatal mortality reduction

Women and parent focused stillbirth reduction and prevention strategies in low mortality countries

Dr. Jane Warland

University of South Australia, Australia

Stillbirth is not inevitable, in fact it is estimated that in high resource settings more than half of these deaths could be prevented through education and awareness. The problem is that stillbirth is not talked about and therefore pregnant mothers are often not aware that it can still happen. In this case ignorance is not bliss. There are some simple steps that every woman can take to reduce the chances of stillbirth happening to her, if she knows what to do. These are: get to know your baby’s normal, trust your instincts, monitor the strength, frequency and pattern of baby’s movements and settle to sleep on your side from 28 weeks. Furthermore, when it comes to reducing risk for stillbirth there are things that maternity care providers should know but often do not, and things that they should do that they may not. This underscores the urgent need to develop and test approaches to support optimal care in relation to stillbirth, particularly given the tragic scale and consequences of stillbirth. Maternity care providers have a significant role to play in detecting and managing the fetus at risk and when they do, research has shown that stillbirth rate can fall. The maternity care provider’s role is also to support and educate women during pregnancy as well as listen to her concerns, if and when they are raised. However, they often do not know how to deliver stillbirth awareness and reduction messages and often have a fear of provoking anxiety. However, it is possible to simply talk about stillbirth prevention in pregnancy.

Ethics statement: N/A

Conflicts of interest: None

Keywords: prevention, reduction, altered fetal activity, maternal intuition, sleep

Country case study: perinatal mortality reduction in South Africa

Dr. Salome Maswime

Associate Professor and Head of Global Surgery, University of Cape Town, South Africa

South Africa has a population of 57 million people, with over 1 million births annually. A stillborn is defined as a viable baby (28 weeks or more) born with no signs of life. The Perinatal Problem Identification Programme (PPIP) was implemented in 2000, and currently captures over 80% of all deliveries, births and perinatal deaths, and causes of death nationally. We reported on 3 years of PPIP data also available in the South African Saving Babies Report, from January 2014 to December 2016. There were 2,350,781 total births, 98% were born alive, with 44,153 stillbirths, and 24,929 (1%) neonatal deaths. The stillbirth rate was 31/1000 births. The highest number of perinatal deaths was in the 500-999g birthweight group, with the lowest number of deaths in babies born with a weight over 2,500g. Spontaneous preterm birth and unexplained stillbirth accounted for 45% of the causes of stillbirth. Five national recommendations were made to reduce stillbirths following data analysis, which focused on reducing deaths from prematurity and intrapartum asphyxia. Auditing stillbirths in South Africa has led to the implementation of national recommendations that have improved perinatal care, clinical practice and birth outcomes.

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, causes, prevention, reducing mortality, trends

Session: Plenary session 2 Saving babies lives: Innovations in perinatal mortality reduction

Country case study: stillbirth reduction in the Netherlands

Dr. Jan Jaap Erwich
University Medical Center Groningen, Netherlands

The European Peristat reports from data on 2004 and 2010 showed the Netherlands having one of the highest perinatal mortality rates as compared to similar countries (about 9/1000 on 170,000 births annually). After initial disbelief and denial, as “we had the best obstetric system in the world”, reality and common sense persisted and a full National task-force from the Ministry of Health was directed to investigate and to propose actions. Over the years up to now perinatal mortality has substantially decreased (4/1000), however still not as much as other high income-countries in Europe. Fetal mortality however, showed the largest decrease over time ever, also when compared to other countries. Although it is difficult to allocate one specific cause for this decrease due to many changes in Obstetric care in the Netherlands in the years 2008-2018, several elements have contributed without doubt to the decrease of our Perinatal mortality rate. These are: Introduction of routine fetal anomaly scan; Better cooperation between primary care midwives and gynecologists in hospital; Faster referral and action protocols in case of obstetric emergencies (incl. home deliveries, 14%); Awareness on decreased fetal movements; Better, by education, fetal monitoring; Better detection and management of fetal growth restriction; Earlier induction of labour (without rise in Caesarean section rates); Structured perinatal mortality (and now morbidity) audits in all obstetric units in NL (about 83) which identified improvement-issues

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, perinatal mortality, prevention

Stillbirth and perinatal bereavement care: are professionals trained to address parents' needs?

Dr. Claudia Ravaldi

CiaoLapo and Department of Health Sciences, University of Florence, Florence, Italy

Many authors reported that health care providers (HCPs) play a pivotal role in the management of stillbirth and perinatal loss in order to prevent the onset of psychiatric complication and to improve wellbeing of bereaved parents and families. Moreover, stillbirth has a strong emotional impact on care providers, such as midwives, obstetricians, nurses and psychologists. Professionals’ attitudes in the management of the event (diagnosis, delivery, giving explanation and proceed to an appropriate follow up) and towards the baby could have a strong impact both on the decision-making process of parents and on their wellbeing during the entire grieving process. Despite their well-known importance in stillbirth management, professionals seem to have quite a different approach to this issue, more influenced by personal opinions and sympathy than professionals’ skills and empathy. This may be due to the lack of specific training programmes during university study courses and also to the absence of a shared knowledge on stillbirth and perinatal loss care. Stillbirth is still a neglected issue and stillborn babies are often perceived as a taboo objects: death is often a taboo, per se, and many professionals express a huge difficulty in managing death related issues. Despite their knowledge about the main guidelines, the communication with parents and the contact with the baby still remain critical. Cognition, behaviours and emotions of HCPs involved in perinatal loss care, play a pivotal role in determining their approach towards stillbirth and perinatal loss. Most HCPs perceive certain situations, particularly communicating the tragic news to the parents and meeting the stillborn baby after the delivery, as extremely difficult, and feel themselves inadequately trained to deal with these events. Specific training and regular focus groups play an important role in promoting a compassionate and supportive assistance.

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth perinatal loss professionals education

Cite as: Stillbirth and perinatal bereavement care: are professionals trained to address parents’ needs? Claudia Ravaldi. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Plenary session 3 Systemic approaches to improving perinatal bereavement care

Development and implementation of the iSAIL (Integrated Support After Infant Loss) Clinic in Sydney Local Health District

Dr. Adrienne Gordon

Royal Prince Alfred Hospital and University of Sydney, Australia

1) Background: The death of an infant is one of the most stressful and devastating life events an adult may experience. This is compounded by the lack of acknowledgement, validation, and support in the community. Around 80 families per year in Sydney Local Health District experience stillbirth or neonatal death. Our previous research and best practice guidelines demonstrated that hospital follow up for families could be improved with key themes of emotional support, environment and education.

2) Methods: A multidisciplinary clinic to support families after infant loss (the iSAIL clinic) was established with seed funding from a local grants program in June 2015 to provide integrated support for bereaved families. Key factors considered were location, continuity of care, specialised bereavement support and multidisciplinary staff. We used a patient centred, respectful and compassionate approach to provide an integrated service which provides the right care in the right place at the right time. We encourage open and honest feedback from both staff and parents with ongoing evaluation.

3) Results: Over 200 families have been supported through the iSAIL clinic since 2015 and there are high levels of satisfaction with the service. The clinic has received sustainable permanent funding from the health district, additional funds from the community and positive media attention. Additional support services have been added with time including pregnancy after loss support groups, Art Therapy and yoga workshops. Most recently the clinic was mentioned in one of the recommendations for health services in the Australian Senate Inquiry into Stillbirth.

4) Conclusions: Parents voices, passionate staff and political support can establish and maintain health services to support families after infant loss

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, neonatal death, bereavement support

Cite as: Development and implementation of the iSAIL (Integrated Support After Infant Loss) Clinic in Sydney Local Health District. Adrienne Gordon. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Plenary session 3 Systemic approaches to improving perinatal bereavement care

Atención psicológica y apoyo emocional a padres con duelo perinatal en el Instituto Nacional de Perinatología de la Ciudad de México (Implementing care guidelines for parents after perinatal loss in the Mexican National Institute of Perinatology)

Dr. Cecilia Mota González

Instituto Nacional de Perinatología and Universidad Nacional Autónoma de México, Mexico

La pérdida de un hijo al inicio de la vida constituye uno de los estresores emocionales más intensos que puede experimentar una mujer. Para la gran mayoría de las mujeres mexicanas, ser madres representa su realización personal y social, tal situación puede explicarse por el hecho de que en México al igual que otros países de Latinoamérica hay una gran cantidad de personas que pertenecen a estratos socioeconómicos bajos en los que las mujeres tienen pocas oportunidades de realizarse en otras áreas de la vida, por lo que la maternidad constituye la única posibilidad de tener alcanzar un estatus, ser valoradas y tomadas en cuenta por la sociedad. El no llegar a concretar su deseo de ser madres a causa de pérdidas perinatales puede vulnerar seriamente su condición emocional. De acuerdo con los resultados de la investigación que hemos realizado con padres en duelo, hemos observado que las mujeres manifiestan un gran dolor y la mayoría viven duelos complejos, independientemente de la edad gestacional en la que ocurra la pérdida y del número de meses transcurridos desde el acontecimiento. Es por ello que en el Instituto Nacional de Perinatología desde hace dos años se estableció un protocolo de atención a la muerte fetal con una atención multidisciplinaria, en la cual intervienen Obstetras, Perinatólogos, Neonatólogos, Patólogos, Enfermeras perinatales, Trabajadoras Sociales y el equipo de Psicólogos del Instituto; con el fin de brindar a estos padres una atención con calidad y calidez en la que sientan que su dolor y su pena es reconocido y válido y tengan la posibilidad de contar con asistencia psicológica a lo largo del proceso de duelo que permita reducir los factores de riesgo para el desarrollo de duelos patológicos o no resueltos.

Ethics statement: N/A

Conflicts of interest: None

Keywords: muerte perinatal, duelo, impacto psicológico, guía de atención

Cite as: Atención psicológica y apoyo emocional a padres con duelo perinatal en el Instituto Nacional de Perinatología de la Ciudad de México, Cecilia Mota González. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
TOP 5 ABSTRACTS
Session: Top 5 Abstracts

Understanding differential patterns in perinatal mortality epidemiology to facilitate actions to reduce stillbirths and early neonatal deaths in India


(1) Public Health Foundation of India; Institute for Health Metrics and Evaluation and University of Washington, (2) Bill and Melinda Gates Foundation, (3) Public Health Foundation of India; Institute for Health Metrics and Evaluation, University of Washington

1) Background: The objectives of this study were to understand perinatal mortality (PM) by exploring the differences in risk factors for PM in subgroups of stillbirths, and 0-2 and 3-7 day neonatal deaths, and in cause of death distribution in the two neonatal age groups to inform programmatic decision-making in the Indian state of Bihar, a large state with a high burden of perinatal mortality.

2) Methods: Detailed interviews were conducted in a representative sample of 23,940 births from 189,800 households in Bihar in 2016. We estimated rates for PM, stillbirth, and 0-2 and 3-7 days deaths per 1,000 births, and explored the associations with a variety of risk factors using a hierarchical logistic regression model approach. Verbal autopsy was conducted and cause of death assigned for neonatal deaths using the SmartVA automated algorithm.

3) Results: The PMR in 2016 was 34 (95% CI 30.8-37.5) for Bihar state. Stillbirths (15.4) accounted for 45.2% of PM. The 0-2 day mortality rate (13.0) was 2.3 times higher than the 3-7 days rate (5.6). Gestation period of <8 months, pregnancies with multiple foetuses, breech presentation of baby, forceful push/pull during the delivery by health provider, and birth in private facilities or at home were significantly associated with the risk for overall PM and all the sub-groups. Previous history of stillbirth and not receiving tetanus injections during pregnancy was associated with overall PM but not with any subgroup. Being a boy baby was significantly associated with overall PM and 0-2 day deaths. Deferred deliveries and primi births were associated with overall PM and stillbirths. Birth asphyxia (61.1%) and preterm delivery (22.1%) accounted for most of 0-2 day deaths; pneumonia (34.5%), preterm delivery (33.7%), and meningitis/sepsis (20.1%) for the majority of 3-7 day deaths.

4) Conclusions: These data on perinatal mortality epidemiology by sub-groups can inform more effective programming to reduce perinatal deaths in India.

Ethics statement: This research was approved by the Ethics Committee of Public Health Foundation of India (approval number TRC-IEC-327/17).

Conflicts of interest: None

Keywords: stillbirth, neonatal mortality, perinatal mortality, india, epidemiology


*Presenting author
Rethinking the concept of disenfranchised grief in the context of perinatal death: a qualitative study

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(1) University of Ottawa; (2) Université du Québec en Outaouais, Canada

1) Background: The concept of disenfranchised grief (Doka, 1989) has been largely called upon in the literature on perinatal grief. Despite this concept shedding light on the social norms that regulate perinatal grief, its static and binary nature nevertheless prevents us from fully grasping the complexity underlying the social (non)acknowledgment of perinatal grief. Moreover, having been uncritically overused, it can lead us to think of disenfranchisement as an invariable and as an unvarying component of perinatal grief. Objective: Stemming from a critical reflection on the concept of disenfranchised grief, this study examines the way social (non)acknowledgement unfolds in the context of perinatal death/grief. 2) Methods: Semi-structured interviews were conducted with 23 women in Quebec (Canada), who experienced a perinatal death (from the second trimester of pregnancy). Interviews were transcribed and coded with NVivo. Analyses were performed following the grounded theorization approach described in Paille et Mucchielli (2012). 3) Results: Two axes of mediation (temporal and spatial) were found to modulate the social (non)acknowledgment of perinatal grief, both in its contents and in its form. It was shown that acknowledgment tends to decrease as we move along the temporal axis (i.e. the further away we move from the time of the perinatal death), and as we move along the spatial axis (i.e. more homogeneous in the medical sphere, less so in the family and social sphere, and often absent in the professional sphere). Tangibility, social scripts and empathy are three notions that have been found to help us make sense of these results. 4) Conclusions: Pitfalls of the DG concept can be avoided by highlighting the coexistence of areas of acknowledgment and areas of non-acknowledgment on each of the two axes (spatial and temporal), as well as the variability of (non)acknowledgment across these two axes.

Ethics statement: This study was approved by the research ethics committee of the University of Ottawa (#04-17-06). Confidentiality, anonymity, and the right to withdraw at any time were assured. The names of the participants were changed to pseudonyms, and the data were stored in a secure location with restricted access.

Conflicts of interest: None

Keywords: perinatal death, perinatal grief, disenfranchised grief, social acknowledgment


*Presenting author
Cultural influences on parents’ experiences of care and support after stillbirth in Kenya, Uganda, Tanzania and Zambia: a qualitative study

E. Ayebare (1), T. Mills* (2), C. Bedwell (2), G. Omoni (3), S. Wakasioka (3), R. Laisser (4), C. Tembo Kasegele (5), T. Lavender (2)

(1) Department of Nursing, College of Health, Makerere University, (2) Division of Nursing Midwifery and Social Work, School of Health Sciences, The University of Manchester, (3) School of Nursing Sciences, University of Nairobi, (4) Catholic University of Health and Allied Sciences, Bugando, (5) Ministry of Health, Zambia

1) Background: Low and middle-income countries (LMICs) bear the highest burden of global stillbirths, 64% occur in Sub-Saharan Africa. Preventing stillbirth is a public health priority, but providing respectful support for bereaved families is also vital. Parents’ experiences are shaped by cultural and societal responses which influence grief processes and adjustment. Research in high-income settings demonstrates persistent stigma and limited public recognition of impacts, but experiences of parents in Sub-Saharan Africa have received little attention. Here, we explored parents’ views and experiences of cultural and societal responses after stillbirth in urban and rural settings in Kenya, Uganda, Tanzania, and Zambia.

2) Methods: Following consent, one to one, in-depth interviews were conducted with women (N=110) and male partners (N=90) who had experienced the stillbirth of their baby (≤1 year). Interviews were audio-recorded, transcribed, translated and analysed using an interpretive approach uncovering themes.

3) Results: Cultural and societal beliefs surrounding stillbirth featured strongly in parents’ narratives. For some women, fears surrounding impacts on future fertility acted as a barrier to seeing or holding their baby after birth. Although communities provided valuable support, several participants identified stigma arising from superstitions associating stillbirth with bad omens, evil spirits or curses. Partners often described feeling pressure to arrange burials rapidly, mothers were discouraged from attending and sometimes not aware that funerals had taken place.

4) Conclusions: Understanding cultural and social responses to bereaved parents in sub-Saharan Africa is key to improving care and support and reducing adverse outcomes. The findings of this study will be used to develop interventions to improve bereavement care e.g. fostering peer support and raising community awareness, which will be tested in future research.

Ethics statement: Approvals were obtained from University of Manchester (UREC: 2017-0233-4462,2018-4446-6653 ), University of Nairobi/KNH (P240/05/2017), Makerere University SHSREC/JUNCST (SS 4666), CUHAS/BMC Tanzania Research & Ethical Committee (CREC/287/2018), Independent Research Board, Zambia (2018-Jun-029). Parent participants were approached via clinical teams. Following, explanations and time to consider, written consent was obtained. Interviews were conducted at a venue of participants choice with pseudonyms used to protect identity. A study-specific distress policy was adhered to at all times.

Conflicts of interest: None

Keywords: bereavement care, cultural factors, IMICs, experiences


*Presenting author
In utero placental biometry and histological placental examination in systemic lupus erythematosus and subsequent pregnancy following a stillbirth

H. Kither* (1), A.E.P. Heazell (1,2), G. Batra (2), C. Tower (1,2), I. Crocker (1)

(1) University of Manchester, (2) Central Manchester Foundation Trust, United Kingdom

1) Background: Pregnancies affected by Systemic Lupus Erythematosus (SLE) or stillbirth have smaller placental size at delivery and increased prevalence of histologically abnormal features. We examined in-utero placental size and histology at delivery, including complement deposition in women with either: (i) SLE, (ii) prior stillbirth or (iii) uncomplicated pregnancies. 2) Methods: Women with singleton pregnancies with SLE (SP, n=51), prior stillbirth (PL, n=29) and healthy women (NP, n=44) were recruited. In-utero placental dimensions were measured using 2D ultrasound at 17 and 22 (+/- 2) weeks’ gestation and placentas collected at delivery (SP=13, PL=19, NP=9) for histopathological examination. Placentas from stillbirths were obtained from the Department of Histopathology, Royal Manchester Children’s Hospital. Four distinct histopathological groups, were identified: no histological abnormality (NSB, n=25), excess perivillous fibrin deposition (PF, n=16), villitis of unknown aetiology (VUE, n=16) and maternal vascular malperfusion (MVM, n=31). Placental samples were immunostained for anti-complement factor 4d (C4d) or anti-complement factor 3a receptor (C3aR). The area of positive staining was calculated by image analysis software. 3) Results: Second trimester in-utero placental widths were smallest in SP and largest in NP (p<0.05); this was reflected in a trend towards lower placental weight at delivery in SP. Some complement deposition differed from stillbirth to livebirth placentas. Overall, levels of C3aR were highest in livebirth placentas compared to stillbirths (p <0.001), with greatest deposition in MVM and NP, and lowest in SP. C4d deposition was highest in VUE and MVM placentas compared to NSB (p<0.01); there was no difference in C4d deposition between livebirth and stillbirth. 4) Conclusions: Complement deposition varied according to the underlying pathology of stillbirth, offering a potential pathological mechanism and therapeutic target for high risk women.

Ethics statement: Pregnant women with singleton pregnancies were recruited at St Mary’s Hospital, Manchester, UK. The study received a favourable opinion from a Research Ethics Committee (13/NW/0158 and 14/NW/1149). All women gave informed written consent before recruitment. In addition, retrospective identification of antepartum stillbirth placentas was also performed from historic placental histology reports from archive records within the Department of Histopathology, Royal Manchester Children’s Hospitals, for the timescale 01/01/2011-31/12/2013 (under ethical approval (14/LO/1352)).

Conflicts of interest: None

Keywords: placental pathology stillbirth


*Presenting author
**Session:** Top 5 Abstracts

**My Baby's Movements: a stepped wedge cluster randomised controlled trial to raise maternal awareness of fetal movements during pregnancy study protocol**

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1) **Background:** Late gestation stillbirth has been linked to both sub-optimal maternal perception, and untimely reporting of decreased fetal movements (DFM) and remains a topic of interest in preventing stillbirth. The My Baby’s Movements (MBM) trial aims to reduce stillbirth rates through offering a mobile phone application (app) to women in the third trimester for the purpose of improving knowledge and awareness of fetal movements (FM) and to encourage timely reporting of concerns. 2) **Methods:** The MBM trial is a stepped-wedge, cluster-randomised trial conducted across 26 maternity hospitals in Australia and New Zealand from 3 years from August 2016 to May 2019. Women attending for maternity care at each of these hospitals were invited to download the app. Data were obtained from a survey embedded within the MBM app which was provided once the woman had birthed. 3) **Results:** Of the 18,273 women who downloaded the MBM app by April 2019, 23% (4,156) have birthed and completed the MBM app survey. Nearly half of these women (46%; n=1922) reported having concerns about FM in the third trimester and 64% of them (n=1224) said they used the MBM app when they felt concerned. Almost one-third (n=1234, 29.7%) of the MBM app survey completer's reported seeking care at their maternity hospital for FM concerns. Of these women, 533 (43.2%) reported doing so based upon prompting from the app and 440 (35.6%) reported using the app to inform discussion with their health care provider. 4) **Conclusions:** For a sizeable number of women, the MBM app appears to be a useful tool for promoting awareness, health care seeking, and interactions with health care providers around FM concerns.

**Ethics statement:** Primary ethical approval was obtained from Mater Misericordiae Ltd Human Research Ethics Committee (EC00332) (MML HREC) in 2015. Further jurisdictional ethics approval was obtained from seven participating HRECs across Australia and New Zealand. Governance clearance was obtained for each of the 26 facilities involved in the trial.

**Conflicts of interest:** None

**Keywords:** stillbirth, prevention, decreased fetal movements, mobile application


*Presenting author*
BREAKOUT SESSIONS
Risk based induction of labor as a strategy to prevent stillbirth: friend or foe?

Dr. Bob Silver
University of Utah, United States

All stillbirths are tragic but it is especially difficult when healthy babies die at term gestations. There is no medical benefit with regard to fetal development and maturity after 39 weeks gestation, and in theory, stillbirths after 39 weeks gestation could be prevented with a strategy of induction of labor. Each week that pregnancy progresses past 39 weeks gestation leads to an increased risk of fetal and neonatal morbidity and mortality. Risks increase for stillbirth, neonatal death, brain injury, meconium aspiration, neonatal intensive care admission, etc. The same is true for maternal morbidity. Elective induction of labor has been avoided in the past owing to concerns for increasing the cesarean delivery rate. Indeed, the odds of cesarean delivery are double for both medically indicated and elective inductions compared to spontaneous labor. However, spontaneous labor is not a "strategy" or a choice that can be made by clinicians and pregnant women. Instead, management options are limited to induction of labor and expectant management. Expectant management refers to simply waiting and hoping the woman has spontaneous labor. Some women will labor spontaneously with a high chance of vaginal birth. In contrast, others will not labor, and will ultimately undergo induction with less favorable chances for vaginal delivery. Moreover, there is a small, but real chance of stillbirth during the expectant management period. Recently, a large randomized trial conducted in over 6,000 low risk nulliparous women compared elective induction of labor at 39 weeks gestation to expectant management (ARRIVE trial). Induction of labor was associated with a lower chance of cesarean delivery, a lower rate of gestational hypertensive disorders and a lower rate of neonatal pulmonary problems. Secondary analyses indicate similar resource utilization and cost for both strategies and women in the induction arm had higher satisfaction scores. It is conservatively estimated that about 1,000 to 1,500 inductions of low risk women are needed at 39 weeks gestation in order to prevent one stillbirth. Based on these data, it is reasonable to consider elective induction of labor in any patient who wishes at or beyond 39 weeks gestation. It is critical to note that in low risk women, induction is optional but not mandatory. The absolute risks of expectant management are low and individual women may highly value the option of expectant care in hopes of spontaneous labor. Decisions regarding induction are best made collaboratively using shared decisions making. Finally, the pros and cons of induction of labor prior to 39 weeks gestation should be the focus of ongoing research. Small risks of prematurity are justified in women at increased risk of stillbirth, but not in low risk women. Improved risk stratification at near term gestations has the potential to further reduce the risk of stillbirth without increasing neonatal harm.

Ethics statement: N/A

Conflicts of interest: None

Keywords:

Cite as: Risk based induction of labor as a strategy to prevent stillbirth: friend or foe? Bob Silver. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Still Aware: role of parents’ groups/advocates in the prevention of stillbirth

Claire Foord

Still Aware, Australia

Still Aware was founded out of adversity by Claire Foord, who learnt of stillbirth in the cruellest of ways, at the birth of her own daughter, Alfie Foord-Heath. Wanting to ensure that others did not see the same fate, she began Still Aware. Under the direction of the Still Aware Board and with advice from the charity’s own Consumer and Clinical Advisory Boards, she runs the organisation: dedicated to raising awareness of stillbirth and saving lives. The role of parents and stillbirth advocates is crucial in sharing life saving information. Translating research into practice is more than just putting the knowledge out there. In order to create a safe and uplifting environment for change and education for women, families and care providers throughout pregnancy, it is critical that the consumer themselves are at the coalface. She will share empowered, informed and improved pregnancy information informed and led by expectant parents and bereaved families. The information formed from families is critical to help bring an end to preventable stillbirth. Hearing their stories and building from their experiences helps to inform quality pregnancy care. Parent groups and safe pregnancy advocates can help inform education delivery. Working together with clinicians to help inform messaging with clarity to ensure adequate action for prevention. In a unified approach we can effectively communicate and promote empowerment of women and the role that they too play in the management of a safer pregnancy. Parent groups and advocates are integral to empowered education and awareness. In sharing messaging derived from the consumer themselves we can share actions and methods for expectant families to actively use throughout pregnancy. Messaging with sensitivity and understanding to bereaved parents, which supports effective and open communication and promotes empowered pregnancy care for prevention of stillbirth.

Ethics statement: N/A

Conflicts of interest: None

Keywords: parents, mortality prevention, advocacy, stillbirth

Session: Breakout 1.1 Perinatal mortality prevention strategies - oral abstract communication

Mindfetalness and pregnancy outcomes: a randomized controlled trial including 39,337 women

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(1) Sophiahemmet University, (2) Karolinska Institutet, Sweden

1) Background: Researchers suggest that women's awareness of fetal movements may decrease the proportion of babies born with low Apgar score by reducing pre-hospital delay and others that it increases the prevalence of interventions. 2) Methods: By cluster-randomization we allocated pregnant women registered at 66 maternity clinics in Stockholm, Sweden to be given information about Mindfetalness (daily monitoring character, strength and frequency of fetal movements, but not count each movement) or to routine care. Outcome data were collected from population-based registers among women giving birth after 32 gestational weeks. As primary endpoint, we used Apgar score at five minutes after birth. A secondary endpoint was number of times women presented with decreased fetal movements. 3) Results: No differences (RR 1.0, CI 0.8-1.2) were found for the primary outcome Apgar score <7 at five minutes. Women in the Mindfetalness group contacted healthcare more often due to decreased fetal movements (6.5% versus 3.7%, RR 1.76, CI 1.61-1.92) and started labor to a higher extent spontaneously (71% versus 69.6%, RR 1.02, CI 1.01-1.03) followed by reduced proportion of cesarean section (19.0% versus 20.0%, RR 0.95, CI 0.91-0.99). Fewer newborns in the Mindfetalness group were transferred to neonatal intensive care unit (NICU) (6.3% versus 6.8%, RR 0.93, CI 0.86-1.0) and fewer of the children were born after gestational week 41+6 (5.2% versus 5.7%, RR 0.9, CI 0.83-0.98). 4) Conclusions: Mindfetalness did not decrease the proportion of children born with Apgar scores below 7 but Mindfetalness reduced the proportion of cesarean section, children born after gestational week 41+6 and babies transferred to neonatal intensive care unit. Mindfetalness increased the number of woman contacting healthcare due to decreased fetal movements.

Ethics statement: Ethics approval was obtained from the The Regional Ethic committee in Stockholm, Sweden (Dnr 2015/2105-31/1).

Conflicts of interest: None

Keywords: mindfetalness, decreased fetal movements, randomized controlled trial, outcomes

Cite as: Mindfetalness and pregnancy outcomes: a randomized controlled trial including 39,337 women. A. Akselsson. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 1.1 Perinatal mortality prevention strategies - oral abstract communication

Qualitative assessment of the community and healthcare system related determining factors of perinatal mortality in Sindh, Pakistan

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(1) Arabian Gulf University Bahrain, (2) University of Sydney, (3) School of Public Health, The University of Sydney, (4) School of Public Health, Faculty of Medicine and Health and The University of Sydney

1) Background: Previous studies from Pakistan have rarely focussed upon understanding the healthcare access and utilisation experience of women with a perinatal loss. We examined cultural influences on perinatal loss and the intersection of these with antenatal and birth service provision to determine the main factors, as perceived and experienced by women, leading to the perinatal loss.

2) Methods: In-depth interviews with 37 mothers, their family members and health care officials and 2 focus group discussions with 17 lady health workers were done in a rural district of Sindh province in Pakistan in 2018. The women who had a perinatal death in the year preceding the date of the interview were identified and requested to participate through lady health workers in their areas. The interviews were performed by a trained data collector within the homes of mothers. Data were analysed using inductive and deductive coding and thematic analysis.

3) Results: Mothers with perinatal deaths reported a high utilisation of antenatal care but most of them were not satisfied with the staff attitude and services in public sector hospitals. They preferred to give birth in private centres and attributed their perinatal loss to mishandling of their labour and staff negligence. Others believed a delay in their decision to seek health provider care, led to home births with traditional birth attendants. Caesarean delivery, and newborn care services did not exist in the public-sector facilities; and if available in private, were not affordable to the women.

4) Conclusions: Improvement in the quality of, and access to antenatal and perinatal care and availability, and affordability of caesarean delivery and newborn care facilities within districts is pivotal to any perinatal mortality prevention strategy. Since most women still prefer to deliver with ever expanding private sector health providers, it is necessary to regulate the sector to ensure enhanced quality of care.

Ethics statement: Ethical review for the study was obtained from the Ethical review committee of Health Services Academy Islamabad (F. No. 7-82/2017-IERB). Verbal consent was given by most and written by some participants after the interviewer read them the research details.

Conflicts of interest: None

Keywords: antenatal care, perinatal mortality, stillbirth, early neonatal mortality


*Presenting author
Educating maternity care providers about stillbirth prevention strategies: evaluating the effectiveness of a half-day workshop.

J. Warland* (1), J. Dorrian (1), D. Pollock (1), C. Foord (2)

(1) University of South Australia, (2) StillAware, Australia

1) Background: There are a number of existing programs delivering maternity care provider education focussed on managing stillbirth once it has occurred. However, stillbirth education and training for health professionals, is also an important strategy for reducing stillbirth. We conducted and evaluated the effectiveness of a four hour stillbirth awareness for prevention, education workshop for midwives and obstetricians providing antenatal care. The workshop focussed on up-to-date knowledge in relation to stillbirth prevention, as well as strategies for communicating these risks to pregnant mothers and empowering them with knowledge to advocate for their unborn baby. 2) Methods: A pre and post education intervention study. 55 midwives and obstetricians attended one of two half day workshops in Tasmania in late 2018. Analysis was conducted on the 30 participants who completed both pre and post workshop survey. Differences in total knowledge scores (78) pre and post workshop were tested used a paired t-test for repeated measures. 3) Results: Preliminary results indicate that knowledge scores (total of 8 points) significantly increased following the workshop (pre mean =2.9 ± 1.5; post: mean=4.7 ± 1.4 points, t 29 =7.9, <0.001). Before the workshop only 20% of participants responded that they “always” or usually” discussed the possibility stillbirth occurring with pregnant women in their care whereas after the workshop, nearly all (88.57 %) indicated that they planned to “always” discuss stillbirth with their clients. 4) Conclusions: Providing a targeted education to a group of Australian maternity care providers resulted in significant knowledge improvement and self-reported intention to change practice. While these results are promising, further study is needed to determine the extent of actual practice change following such education.

Ethics statement: This study was approved September 2018 by the University of South Australia Human Research Ethics Committee. Protocol number 201227. Participants were informed that participation was voluntary and they could stop the survey at any time and still fully participate in the workshop.

Conflicts of interest: None

Keywords: clinician education, stillbirth awareness, stillbirth prevention


*Presenting author
Session: Breakout 1.1 Perinatal mortality prevention strategies - oral abstract communication

Improving intrapartum quality of care to increase neonatal survival in Indonesia: mentoring embedded in a clinical governance approach

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(1) DAI Global Health, (2) DAI-Jalin USAID, (3) Ministry of Health, Indonesia, (4) Family Health Directorate, Ministry of Health, Indonesia

Indonesia’s perinatal and neonatal mortality rates had remained stagnant since 2002 at around 26 per 1000 pregnancies and 19 per 1000 live births respectively, according to the Indonesia Demographic & Health Survey 2012. The main causes of neonatal deaths are complications of prematurity (36%), intrapartum-related events (22%), congenital abnormalities (18%) and infections (14%). The 2016 registration system sampling shows that 68% of neonatal deaths occur in health facilities. Hence, the national strategy has focused on emergency obstetric and neonatal care in district hospitals. Mentoring was the main approach used. Mentors played various roles as needed, such as facilitator, coordinator, supervisor, coach, counsellor, collaborator and role model to support the mentee(s). Clinical governance includes conducting death and near-miss audits, promoting principles of good care, using clinical dashboards, supporting institutional readiness for obstetric and neonatal emergencies by instituting emergency drills and compliance to standard practices, and ensuring availability of proper equipment and supplies. The local Health Office led the mentoring process, including improving the referral system, and was supported by other stakeholders, including civil society. The national Ministry of Health led the development of the Indonesia Newborn Action Plan to provide direction and guidance for neonatal health care. Mentoring implemented within a clinical governance approach strengthened accountability within the health system and contributed to improved quality of maternal and newborn care interventions. Although evaluation of the mentoring has shown the benefit of the approach, it remains mainly donor-funded. By 2017 the neonatal mortality rate in Indonesia had fallen to 15 per 1000 live births. The current focus of efforts is on stimulating greater domestic ownership and funding so that the approach is fully embedded in a national system.

Ethics statement: This study is a summary of experiences in Indonesia, therefore, ethics approval was not sought.

Conflicts of interest: None

Keywords: neonatal survival, mentoring, Indonesia, quality of care, intrapartum


*Presenting author
Circulating SPINT1 is a biomarker of pregnancies with poor placental function, fetal growth restriction, and at higher risk of stillbirth.

S. Tong* (12), T. MacDonald (1), R. Hiscock (3), N. Haan (4), J. Myers (5), R. Hastie (1), A. Middleton (2), A. Sferruzzi-Perri (6), N. Hannan (1), N. Crinis (7), L. Hui (1), T. Kaitu'u-Lino (1)

(1) University of Melbourne, (2) Mercy Hospital for Women, (3) Mercy Hospital for Women, (4) Foresight Health, (5) University of Manchester, (2) Mercy Hospital for Women, (6) Cambridge University, (7) Austin Pathology

1) Background: Placental insufficiency can cause fetal growth restriction and stillbirth. There are no reliable screening tests for placental insufficiency, especially near term when the risk of stillbirth rises. 2) Methods: We prospectively collected plasma from 1996 participants at 36 weeks' gestation to identify new biomarkers of placental insufficiency. We divided the cohort to discover, then validate biomarkers (997 in cohort 1; 999 in cohort 2). 3) Results: By screening 22 proteins in cohort 1 we identified a strong association between low circulating serine peptidase inhibitor, Kunitz type-1 (SPINT1) and low birthweight (<10th centile), which we validated in cohort 2. Using cohort 2, we generated a 4-tier risk model based on circulating SPINT1 concentrations. The highest tier of risk (7.1% of cohort 2) had 14.1%, 19.7%, 28.2% and 46.5% risk of women delivering neonates with birthweights <3rd, <5th, <10th and <20th centiles respectively. In contrast, those within the lowest tier of risk (9.1% of cohort 2) had 0.0-6.6% risk of birthing neonates at these fetal weight centiles. The 4-tier model validated in cohort 1 with similar diagnostic performance. Low SPINT1 concentrations were also strongly associated with other clinical indicators of placental insufficiency, including increased uterine artery Doppler resistance, low placental weight and low lean body mass of the newborn. The association between low circulating SPINT1 and placental insufficiency validated in an independent cohort of high-risk pregnancies (n=291) from the United Kingdom. Mechanistically, hypoxia in vitro and in vivo reduced placental SPINT1 expression, silencing SPINT1 reduced placental cellular proliferation and a SPINT1 mimic enhanced proliferation. 4) Conclusions: Low-circulating SPINT1 is a marker of placental insufficiency. Circulating levels at 36 weeks gestation may identify pregnancies with fetuses at very high risk of being at a low weight centile and at elevated risk of stillbirth.

Ethics statement: We obtained ethics approval for all studies described: Cohort study: Mercy Health Research Ethics Committee (Ethics Approval Number RH12) and written informed consent was obtained from all participants. Mouse study: We obtained approved from the Ethical Review Committee of the University of Cambridge (Cambridge, UK) and were carried out in accordance with UK Animals (Scientific Procedures) Act 1986.

Conflicts of interest: TKL, TM, SW and ST hold a provisional patent (# 2018901813) relating to the use of SPINT1 and syndecan as diagnostic markers in pregnancy. N. Haan is the owner of Foresight Health, which has a research and commercialisation agreement with The University of Melbourne relating to the development of diagnostic markers of placental insufficiency, and rights to the patent.

Keywords: biomarker, placental insufficiency, stillbirth, diagnostics

Cite as: Circulating SPINT1 is a biomarker of pregnancies with poor placental function, fetal growth restriction, and at higher risk of stillbirth. S. Tong, T. MacDonald, R. Hiscock, N. Haan, J. Myers, R. Hastie, A. Middleton, A. Sferruzzi-Perri, N. Hannan, N. Crinis, L. Hui, T. Kaitu'u-Lino. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.

*Presenting author
Materialities and perinatal bereavement

Dr. Samantha Murphy

The Open University, United Kingdom

Following a stillbirth or other type of reproductive loss, memories of the event can often be hazy for parents – especially in cases where people are reluctant to acknowledge that a loss has occurred. Over the last few decades, particularly in Western countries, the keeping of objects related to the pregnancy, such as the ultrasound scan phot, and the creation of memorabilia following a death of a baby has become important. Such objects, like a photograph following the death, or bought mementos such as jewellery, serve to allow parents to consider that their child remains with them in some form and as part of their lives. As such, they allow parents to continue a bond with their baby which can be important to the grieving process. Healthcare providers need to suggest to parents to consider creating objects and memorabilia following a reproductive loss in a timely and sensitive manner which allows parent(s) to choose whether this is an appropriate activity for themselves.

Ethics statement: N/A

Conflicts of interest: None

Keywords: objects, reproductive loss, parents, grieving, continuing bonds

Cite as: Materialities and perinatal bereavement. Samantha Murphy. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 1.2 Grief experiences (psychological and socio-anthropological perspectives on grief) - Invited speaker

Muslim women’s experience of perinatal loss

Asoc. Prof. Rosnah Sutan

National University of Malaysia, Malaysia

Scarce literature is available on knowledge, attitude and practice of Muslim’s women following perinatal loss. The way people react and adjust is diverse and closely determined by their environment social support, beliefs and social cultural practice. Religion is one of the important domain at root level needed in facing grief situation. Routine Muslim education is based on Muslim scripture which focuses on accepting grief as a test in life. Internalization of its information needs a proper guidance from scholars and those who can elaborate its means. The aim of this paper is to explain the psycho-social support and coping mechanism among the Muslim women in facing perinatal loss. Muslim mothers who had perinatal loss experienced psychological difficulties including feelings of confusion, emptiness and anxiety at initial recruitment with high score EPDS and noted a reduction in scores at 1 months. However, on the follow up monitoring, the scores were fluctuated by presence of emotional disturbance. The majority of Muslims agreed that the decision makers were husbands and families instead of themselves. Repetitive reminder of whatever happened was a test from God, has improved their sense of self-worth. They appreciated this reminder especially when it came from husband, family or friends close to them. Variety of Muslims practices for coping to overcome grief is written in the scripture. Muslim mothers who had experienced perinatal loss showed some level of adverse psycho-social impact which affected their feelings. Husbands and family members were the main decision makers for Muslim women. Healthcare providers should provide psycho-social support during antenatal, delivery and postnatal care. On-going support involving husband should be available where needed.

Ethics statement: N/A

Conflicts of interest: None

Keywords: psycho-social support, coping approach, perinatal loss, grief, Muslim

Cite as: Muslim women’s experience of perinatal loss. Rosnah Sutan. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 1.2 Grief experiences (psychological and socio-anthropological perspectives on grief) - Invited speaker

Perinatal death from the perspective of siblings

Dr. Jane Warland

University of South Australia, Australia

When Jane Warland’s daughter Emma was stillborn she had three children, Greg aged 9, Pete aged 8 and Cate aged 3. This meant that not only did she, and her husband Mike, need to deal with their own trauma and grief but also, they had to help her children manage theirs. One way she managed this was to engage them in writing a book for families called “Our Baby died.” Then when her ‘Rainbow’ baby Sarah was born Jane realized that her parenting had been forever changed and she wondered if her experiences were echoed by others. This led her to conduct a series of small qualitative studies with bereaved parents and their children. The findings of these studies has resulted in describing a paradoxical style of parenting where parents at once describe two contradictory styles that they try to do together for example, holding their children emotionally close and emotionally distant. Findings from her studies with children alive at the time of the loss and born subsequent to it also reveal important understandings for both bereaved parents themselves and those caring for them. In this presentation, Dr Warland will first share her own experiences of helping her children alive at the time and born subsequently to her daughter Emma’s death. Then she will discuss findings from some of the research she has conducted with bereaved children and their parents. Finally, she will show some of the written resources that are available for both bereaved children and their parents.

Ethics statement: N/A

Conflicts of interest: None

Keywords: children and grief, siblings, rainbow, parenting

Cite as: Perinatal death from the perspective of siblings. Jane Warland. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
**Session**: Breakout 1.2 Grief experiences (psychological and socio-anthropological perspectives on grief) - Invited speaker

**Grief and complicated grief: clinical and emotional reactions**

Dr. Manuel Fernández Alcántara

*Department of Health Psychology, University of Alicante, Spain*

The grieving process following the death of a loved one is a period of great emotional stress where psychological and emotional intervention is a fundamental pillar. This presentation will define adaptive grief and outlines the principal current debates in regard to the diagnosis of complicated or prolonged grief, the use of appropriate assessment instruments, and different therapeutic approaches. In addition, we will explore the peculiarities of certain disenfranchised griefs and the impact they have on bereaved families. Finally, we will focus on perinatal grief, which occur following a fetal death or the death of a baby during their first days of life. In these cases, the loss includes a loss of promises and expectations that will never be realized, as well as a shift in parents' identity. Recent theoretical models to explain the intensity of perinatal bereavement will be discussed.

**Ethics statement**: N/A

**Conflicts of interest**: None

**Keywords**: bereavement, complicated grief, perinatal loss, family care

**Cite as**: Grief and complicated grief: clinical and emotional reactions. Manuel Fernández Alcántara. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Voices of the unheard: an international qualitative survey exploring bereaved parents experiences of stillbirth stigma

D. Pollock* (1), T. Ziaian (1), E. Pearson (1), M. Cooper (1), C. Foord (2), J. Warland (1)

(1) University of South Australia, (2) Still Aware, Australia

1) Background: Every year, 2.6 million babies are stillborn worldwide. Despite these figures, stillbirth remains a relatively ignored public health issue. The wider literature suggests that this is due to the stigma associated with stillbirth. The stigma of stillbirth is seen as possibly one of the greatest barriers in reducing stagnant stillbirth rates and supporting bereaved parents. However, empirical evidence on the extent, type, and experiences of stillbirth stigma remain scarce. Therefore, this study aimed to explore the stigma experiences of bereaved parents who have endured a stillbirth. 2) Methods: An online survey of closed and open-questions with 817 participants (n=796 female; n=17 male) was conducted in high-income countries. 3) Results: Based on self-perception, 38% (n=313) of bereaved parents believed they had been stigmatised due to their stillbirth. A further 96.1% (n=785) believed that there was a silence surrounding stillbirth. Thematic data analysis of the open-ended responses revealed several themes consistent with Link and Phelan’s stigma theory- labelling, stereotyping, status loss, discrimination, separation, and power. One more theme outside of this theory- bereaved parents as agents of change was also discovered. 4) Conclusions: Bereaved parents after stillbirth may experience stigma. Common experiences included feelings of shame, blame, devaluation of motherhood and discrimination. Bereaved parents also reported the silence of stillbirth occurred during their antenatal care with many health care providers not informing them about the possibility of stillbirth. Further research needs to be undertaken to explore further the extent and type of stigma felt by bereaved parents after stillbirth, and how stigma is impacting the health care professional.

Ethics statement: This study was approved on the 5/12/2016 by the University of South Australia Human Research Ethics Committee. Protocol number 0000036017. The survey was developed by bereaved parents and reviewed by obstetricians, midwives and organisations which specialise in stillbirth to ensure its safety. Participants were informed prior to completing the survey that participation was voluntary, and they were able to stop at any time. Services which specialises in bereavement care of each targeted country were listed prior to the start and the end of the survey to provide support for participants.

Conflicts of interest: None

Keywords: social stigma, bereavement, stillbirth, social psychology, advocacy


*Presenting author
Men's grief following pregnancy loss and neonatal loss: a systematic review and emerging theoretical model

K. Obst* (1), C. Due (1), M. Oxlad (1), P. Middleton (2)

(1) University of Adelaide, Australia (2) Healthy Mothers, Babies and Children and South Australian Health and Medical Research Institute

1) Background: Emotional distress following pregnancy loss and neonatal loss is common, with enduring grief occurring for many parents. However, care guidelines focus largely on heterosexual women's experiences, with limited research pertaining to men's grief and psychological outcomes. To develop a comprehensive theory of men's grief, this systematic review sought to summarise and appraise the literature focusing on men's experiences of grief following pregnancy loss and neonatal loss.

2) Methods: Systematic searches across PsycINFO, PubMed, Embase and CINAHL were guided by two research questions: 1) what are men's experiences of grief following pregnancy/neonatal loss; and 2) what are the predictors of men's grief following loss? Eligible articles were qualitative, quantitative or mixed methods empirical studies including primary data on men's grief, published between 1998 and October 2018. Eligibility for loss type included any definition of miscarriage or stillbirth, and neonatal death up to 28 days after a live birth.

3) Results: A final sample of 47 articles were identified, of which 27 were qualitative, 19 quantitative, and one mixed methods. Findings indicate that men's grief experiences are highly varied, and current grief measures may not capture all of the complexities involved. Qualitative studies revealed the nuanced ways through which men express and navigate their grief. In comparison to women, men may face additional challenges including expectations to 'support' their female partner, and a lack of social recognition for fathers' grief and subsequent needs. As such, men seem to face a type of double-disenfranchised grief in relation to the pregnancy/neonatal loss experience.

4) Conclusions: To refine an emerging theoretical model of men's grief, cohort studies are needed among varied samples of bereaved men to confirm grief-predictor relationships. There remains a need to promote engagement of fathers throughout pregnancy, and early in their grief following loss.

Ethics statement: Ethical approval was not required for the purposes of a systematic review, as there was no participant involvement. Data comprised solely of previously published work.

Conflicts of interest: None

Keywords: men, grief, stillbirth, miscarriage, neonatal loss, systematic review


*Presenting author
Society’s attitude towards stillbirth

N. Sharabidze* (1), M. Abuladze (1), S. Lomashvili (1), N. Chkheidze (2)

(1) Women’s Rehabilitation Association, Obstetric-gynecological Clinic “Venus Georgia”, (2) Endocrinology, Women's Rehabilitation Association

1) Background: Stillbirth is one of the most evident health problems faced by the developing countries. It is connected not only to health but also social issues. The urgency and importance to conduct a sociological study on this topic was reinforced by our five-year experience in this field of research. We have seen that in Georgia there is a stigma in the society concerning the topic of stillbirth. Mission: To assess the attitudes of the society towards the issue of stillbirth.

2) Methods: Research design involved creation of a questionnaire and distributing it to respondents living in the capital city of Tbilisi, Georgia. Several locations were chosen near metro stations, data was collected via iPad and the sample was randomized by choosing every 4-5th respondent on the street. On a daily basis the average number of respondents questioned was 30 and the study consisted of 502 respondents in total. Collected information was written down and analyzed.

3) Results: Sociological study showed how the community perceives the issue of stillbirth. 43.1% of the respondents believe that parents should not discuss their lost newborn, 17.9% believe that this is a course of nature, only 39% agrees to the idea that parents who suffered from stillbirth have to confront the topic and openly speak about it, lastly 17.9% has made no comment regarding this topic. 84.8% of the respondents believe that families who suffered from stillbirth have to continue trying having a healthy child.

4) Conclusions: Results of the study once again confirm the argument that majority of the society perceives the issue of stillbirth as a stigma and a topic which should not be discussed. The presence of stigma towards the topic, prolongs the recovery process which families undergo and further aggravates the issue.

Ethics statement: Informed consent document (IRB00002150 NCDC IRB#1). The study is anonymous and questionnaire is designed carefully, to avoid emotional impact. The topic of stillbirth is sensitive and during interview the only risk is individual emotional response. Based on the sociological study results will be possible to create bereavement care strategies after stillbirth. Data entered in the database are confidential. The level of risk of this research is minimal. During the interview the participant can terminate at any time without penalty.

Conflicts of interest: None

Keywords: stillbirth, stigma, sociological study

Cite as: Society’s attitude towards stillbirth. N. Sharabidze, M. Abuladze, S. Lomashvili, N. Chkheidze. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.

*Presenting author
Session: Breakout 1.3 Parents’ experiences of care: listening to parents and understanding their needs - Invited speaker

Supporting parenthood when a baby is stillborn

Prof. Ingela Radestad

Sophiahemmet University, Sweden

Health-care professionals play a central role when a baby is stillborn. The degree to which the professionals promote the parents’ parenthood of their stillborn baby will have a major influence of the parents’ future life. We certainly have come a long way over the last few decades in terms of supporting parents’ possibilities to parent their new-born but dead baby, but much more can be done to move forward. In addition, sadly enough, we still see examples of active hindrance of promoting parenthood when a baby is stillborn. Parents’ stories, experiences from health-care professionals and results from research have taken us from routines that obstruct parents from all contact with their baby to today’s evidence-based care. In the early 1980s, health-care professionals began to realize that, if parents are deprived of the opportunity to meet their baby, grief is complicated and further complicates recovery after the loss. In today’s standard of care, which is offered in many countries, the parents receive support to meet their baby and their parenting is affirmed. This is not the case in all parts of the world, where care is still dominated by the belief that parents should be protected from any contact with their baby. In this presentation, I will introduce the concept of dialectic proactivity. Evidence-based care after a stillbirth is based on the fact that the staff should be proactive but at the same time attentive. That means that the dialogue, logical argument and reasoning as well as the nursing of the stillborn baby, support parenthood. Dialectic proactivity is based on an ethical approach that relates to the current state of knowledge. In this presentation, key issues in parents’ ability to meet their stillborn baby will be described and highlighted based on an ethical analysis. The presentation will also focus on how we should care for the dead baby’s body in a dignified manner so that the baby should be as intact as possible prior to cremation or burial.

Ethics statement: N/A

Conflicts of interest: Prof. Ingela Radestad has invented Cubitus baby and is awarded royalties from the company that produces the tool.

Keywords: stillbirth, parenthood, dialectic proactivity

Cite as: Supporting parenthood when a baby is stillborn. Ingela Radestad. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 1.3 Parents' experiences of care: listening to parents and understanding their needs - Invited speaker

What parents want from best practice perinatal bereavement care: a case study of Italy

Prof. Alfredo Vannacci

Department of Neurosciences, Psychology, Drug Research and Child Health (NEUROFARBA), University of Florence and CiaoLapo, Italy

Stillbirth is a severe stressful life event with a deep impact both on families and on professionals. In the past years, several guidelines have been developed in order to allow the best care for bereaved parents and to enable professionals to have an active role in the management of this traumatic event. Unfortunately, despite the increasing body of literature, in some countries only a small number of bereaved parents receive support as suggested by international guidelines. Here we report results of our case study in Italy, where national guidelines on stillbirth and perinatal loss management are absent and international guidelines are scarcely known and applied in hospitals. CiaoLapo Charity, after a revision of the guidelines adopted in several countries, developed a simple checklist, called CLASS (CiaoLapo Stillbirth Support checklist), a practical instrument based on more than ten years of work with both Italian professionals and bereaved parents. In CLASS checklist, recommendations are divided in six sections: Respect, Information and Communication, Birth Options, Hospital Stay, Collecting Memories, Aftercare. Results from CLASS survey, conducted on a sample of 280 Italian women who had a stillbirth, recruited by a web-based platform, showed that correct application of international guidelines is very rare in Italy. In particular, each section of guidelines was respected in less than 50% of cases, and only 2 items out of 59 were respected in slightly more than 75% of cases (i.e. “allowing staying with partner” and “using a simple language”). Many guidelines share the same indications showing that there are some important issues that need to be assessed and managed. CLASS checklist resume all this pivotal issues in six different sections, in order to enable professionals to improve their knowledge on stillbirth management and on bereaved parents’ needs.

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, parents, guidelines

Parents experiences of perinatal bereavement care in Tamil Nadu, India

Dr. Sudharshini Subramaniam

Institute of Community Medicine, Madras Medical College and NODAL Point, Chennai, India

Stillbirth has serious psycho-social consequences on the parents and on the family. The psychological impact of stillbirth is strongly influenced by the social and cultural context. A qualitative study was conducted in Tamilnadu, South India to understand the psycho-social impact, aggravating factors, coping styles and health system response to stillbirths. Women who experienced stillbirths suffered from serious forms of grief and guilt. These emotions were aggravated by the insensitive health system, health care providers, friends, and neighbours, as well as strained marital relationship and financial burdens. The women and their families were disturbed by the ‘suddenness’ of the stillbirth and frantically searched for the cause. They were frustrated when they couldn’t find the cause and blamed various people in their lives. The women and their families perceived poor quality of services provided in the health system and reported that the health care providers were inconsiderate and insensitive. On the other hand, the health care providers reported that they were over-worked, and the health facilities were under-staffed. The community health workers reported that they felt caught in the crossfire between the health facility staff and the family who suffered the stillbirth. The women reported several coping mechanisms including isolation, immersion in work, placing maternal love on other children, the anticipation of next pregnancy and religiosity. Stillbirth, though a biomedical problem, is a significant psycho-social phenomenon that has potential to change the life of a family. Therefore, care for mothers who suffer stillbirth should include a thorough attention to the psycho-socio-cultural aspects of the event. Health systems should be sensitive to such psycho-social needs of women who suffer stillbirths and their families.

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, psycho-social impact, coping

Cite as: Parents experiences of perinatal bereavement care in Tamil Nadu, India. Sudharshini Subramaniam. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 1.3 Parents’ experiences of care: listening to parents and understanding their needs - Invited speaker

Agency, control and decision-making processes in perinatal bereavement care

Paul Cassidy

Universidad Complutense de Madrid and Umamanita, Spain

It is well established within qualitative research that hospital care has a lasting impact on perinatal grief, producing what may be called “good” or “bad” deaths. Bad perinatal deaths are often associated with interactions with unempathetic healthcare personnel and regrets about decision-making, in particular in relation to the care of the baby following the birth or death. This is of particular concern because lack of control over decision-making can impact grieving in two ways. Firstly, the institution takes a dominant role in how the narrative of the death in constructed and secondly, decisions taken in the hospital play an important role in configuring the bond between the living and the dead. Based on qualitative and quantitative fieldwork, the research identifies a number of contextual and social mechanisms that act to reduce control over decision-making. Firstly, the research identifies how women can be uniquely vulnerable following a perinatal death: they experience shock, fear for their own safety, and guilt, as well as having few discursive resources on which to draw to understand what is happening and to demand appropriate care. Taking this as a context, asymmetry in relations with health professionals can be further amplified by: lack of or poor information provision; non-censal and autocratic decision-making; provision of single-option care pathways; coercion and pressuring (infantilising, invalidation of women’s knowledge of their bodies, use of sedation, threats, imposition of protocols); lack of privacy; and naturalisation and collusion in paternalism. The consequences of care process that embody some or all of these characteristics are: i) deconstruction of the self as a capable and empowered person, ii) the dispossession of the social role of mother/parent, the person who decides what should happen to their child, and the need for justifications of actions taken in the hospital that contradict the responsibilities and moral obligations associated with such roles, iii) the introduction of toxic narratives into the relationship between mother/child that complicate the grieving process. An already bad death becomes an even worse death.

Ethics statement: N/A

Conflicts of interest: None

Keywords: perinatal bereavement care, control, agency, stillbirth, TOPFA

Session: Breakout 1.3 Parents’ experiences of care: listening to parents and understanding their needs - oral abstract communication

Irish inquiry reports on pregnancy loss services: recommendations on management of information and maternity services governance

Ä. Helps* (1-3), S. Leitao (2), L. O’Byrne (1), R. Greene (2), K. O’Donoghue (1,3)

(1) Pregnancy Loss Research Group, Department of Obstetrics and Gynaecology, University College Cork, Ireland, (2) National Perinatal Epidemiology Centre (NPEC), University College Cork, Ireland, (3) The Irish Centre for Fetal and Neonatal Translational Research (INFANT), University College Cork, Ireland

1) Background: External inquiries are carried out following specific adverse maternal events and aim to identify issues in the maternity care provided to pregnant women and make recommendations to improve standards of care. This study, presents the analysis of two of the domains identified in these reports: management of information and maternity services governance. 2) Methods: Ten publically-available national health-service-commissioned inquiry reports on pregnancy loss services from inquiries into the Irish maternity services (published between 2005 and 2018) were analysed. Qualitative data was collected by 2 clinicians, separately, using a specifically designed review tool. Thematic analysis of the findings and recommendations was carried out. 3) Results: Communication with families should be clear, open and timely, especially relating to pregnancy loss care. For effective continuity of care, it was advised that each patient should have a clear plan of care, and that clinical results be followed-up promptly. Three reports encouraged the introduction of a national early warning chart to identify the deteriorating maternity patient early. Collecting data (e.g. through audit) for national benchmarking and monitoring maternity outcomes was recommended in 90% of reports. Further development of national guidelines for maternity care was advocated. All reports made recommendations in relation to maternity service clinical governance, including the need for effective leadership and management, with adequate human resources. 4) Conclusions: Standardised or structured communication procedures are useful to transfer patient information between staff effectively. Communicating sensitively with families, especially after a bereavement can significantly reduce their distress. Relevant recommendations made within inquiry reports, can have a profound impact on maternity services if implemented appropriately.

Ethics statement: Only publicly-available reports were analysed, therefore no ethics approval was required.

Conflicts of interest: None

Keywords: communication during pregnancy loss, national inquiry reports, data collection

Cite as: Irish inquiry reports on pregnancy loss services: recommendations on management of information and maternity services governance. Ä. Helps, S. Leitao, L. O’Byrne, R. Greene, K. O’Donoghue. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.

*Presenting author
Session: Breakout 1.3 Parents' experiences of care: listening to parents and understanding their needs - oral abstract communication

"I should have seen her face at least once": parent's and health providers' experiences and practices of care following stillbirth in Afghanistan


(1) University of Sydney, Australia (2) Afghanistan National Public Health Institute, Ministry of Public Health, (3) World Health Organization, Afghanistan, (4) Management Sciences for Health (MSH), Afghanistan, (5) Sydney School of Public Health, University of Sydney, Australia

1) Background: Stillbirth is devastating for parents and families and associated with long-term psychological and social consequences. Care and treatment of parents and their baby after stillbirth can have a profound impact on parent's wellbeing. This study aimed to understand bereaved parent's experiences following stillbirth in Afghanistan. 2) Methods: In-depth interviews were done with women and men that experienced stillbirth, female elders, community health workers, and healthcare providers in Kabul province, Afghanistan. 3) Results: Practices varied across health facilities and providers around their interactions with parents following stillbirth. Inadequate communication was a recurring theme. Insensitive practices included avoiding or delaying disclosing the death, not receiving information directly from healthcare providers, and insufficient communication about the circumstances or reasons for their baby's death. There was a disconnect between what women and their husbands desired and what healthcare providers thought was best for the mother. Parents were frequently not asked or given the chance or adequate time to see/hold their baby and there was no opportunity for memory making which manifested as profound regret. Facilities were not equipped to separate women who had a stillbirth, and women who had not undergone surgery were discharged within a few hours after birth. Healthcare providers acknowledged that psychological support would be beneficial, but the lack of trained personnel and resource constraints prevented any provision of support. 4) Conclusions: These findings can inform improvements to bereavement care in health facilities and minimise actions that may exacerbate parent's grief and have long-lasting effects. Given resource constraints in this setting communication training and improved practices for women experiencing a stillbirth can be considered with longer term goals to develop and implement context-appropriate bereavement care guidelines.

Ethics statement: Ethical approval for the study was provided by the institutional review board of the Afghanistan National Public Health Institute, Afghanistan (no.43831) and the ethical review committee of the University of Sydney (no.2017/566). All participants provided written or verbal informed consent prior to participating in the study.

Conflicts of interest: None

Keywords: stillbirth, bereavement care, health services research, Afghanistan

Cite as: "I should have seen her face at least once": parent's and health providers' experiences and practices of care following stillbirth in Afghanistan. A. Christou, S.M.S. Hofiani, A. Mubasher, M.H. Rasooly, M.K. Rashidi, A. Alam, C. Raynes-Greenow. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.

*Presenting author
By virtue of their own bereavement, parents become experts in their own experience of grief and have much to offer in shaping developments in bereavement care, policy and service provision. As part of Ireland’s new National Standards for Bereavement Care, a parents’ forum was established in collaboration with the national implementation team as part of the implementation process. The stated purpose of the parents’ forum was to: • Represent the parent voice and facilitate their opinions and experiences when implementing the Standards; • Provide opportunities for parents to contribute to developing guidelines, care pathways and services that aim to meet the needs of bereaved families in the future; • Inform the National Implementation Group (NIG) about the needs of parents and provide feedback and constructive challenge to outputs from the NIG. Ten parents participated in the forum which also comprised of the NIG Clinical Lead, the NIG Project Manager and a Bereavement Clinical Midwife Specialist. While parents were advised that they could access bereavement support as a result of their involvement, parents were required to be able to see beyond their own experience of loss and consider the aim of the Standards for bereaved parents in the future. The forum met four times over eighteen months: parents also received documents by email to provide feedback. Collaboration with bereaved parents provided valuable expertise and insights into the implementation process. Commitment and courage were required from parents and the NIG to facilitate an open and mutually respectful environment that was productive and of value. Collaboration was also evidenced in a plenary presentation by a parent at national bereavement forum at the end of the implementation process. The process provided rich mutual learning for both professionals and parents alike, and has much to offer as a model for planning and implementation of perinatal bereavement care developments.

Ethics statement: Ethical approval was not required for this consultative process

Conflicts of interest: None

Keywords: stillbirth, bereavement care, patient engagement, pregnancy loss,


*Presenting author
Session: Breakout 1.4 Respectful disposition: practices and bioethics in disposition of the body and handling of remains/tissue - Invited speaker

Understanding, informing, and supporting the choices regarding disposal of pregnancy remains (pre 24 weeks) in England and Wales.

Dr. Sheelagh McGuinness

Centre for Health, Law, and Society, University of Bristol Law School, United Kingdom

This talk provides an overview of findings from a research project entitled ‘Death before Birth: Understanding, informing and supporting the choices made by people who have experienced miscarriage, termination, and stillbirth’ conducted by academics from the Universities of Birmingham and Bristol and funded by the Economic and Social Research Council (UK) [see: deathbeforebirthproject.org]. The overall aim of this project was to examine the law surrounding the disposal of the remains of pregnancy and the ways in which it is interpreted, and to examine the narratives of women and those who support them, focusing on metaphor as a commonly-used resource for expressing the inexpressible. The specific focus of this paper will be on the legal framework which governs disposal of pregnancy remains, specifically Guidance issued by the Human Tissue Authority Guidance (2015). This guidance outlines the following options for disposal: a. Hospital-arranged cremation [shared/individual]; burial [shared/individual]; and (sensitive) incineration; b. Possibility for making private arrangements; c. Burial outside a cemetery/burial. Key general recommendations: that there be a move towards a standardised approach to provision of information about options for disposal of pregnancy remains. This could be achieved with specific patient information leaflets on disposal and standardised consent forms like those provided by Sands for post mortem. Such an approach could help ensure that women are being provided with a range of options for disposal of pregnancy remains; that consideration be given as to whether disposal of remains of pregnancy be integrated into miscarriage care pathway, potentially within the meaning of treatment and as such discussed as part of the consent process.

Ethics statement: N/A

Conflicts of interest: None

Keywords: pregnancy remains, burial, cremation, sensitive incineration

Cite as: Understanding, informing, and supporting the choices regarding disposal of pregnancy remains (pre 24 weeks) in England and Wales, Sheelagh McGuinness. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Sensitive disposal of fetal remains: are Spanish hospitals and funerary services meeting parents needs?

Dr. Sonia Pastor Montero

Hospital Universitario Juan Ramón Jiménez, Spain

Perinatal death causes a great emotional impact not only on parents but also on health professionals. Providing care that allows parents and family members to prepare a healthy grief is a great challenge. In cases of gestational death, the professionals involved in the care must offer to the woman and her partner the different options for the sensitive and safe disposal of the fetal remains, regardless of the weeks of gestation, respecting the decision they make. In this sense, it is difficult to talk with the woman and her partner about the respectful elimination of fetal remains and a combination of knowledge, skills and attitudes is required. In addition, hospital care protocols do not take this good practice into account. Summary: a) Offer quality information to women and their partners, providing them in writing and verbally, with a compressible and sensitive language on the different options for the respectful management of fetal remains; b) Allow time to assimilate information, ask questions, express their concerns and needs. Facilitating informed decision making according to your values and beliefs; c) Professionals must update their knowledge regarding the legal aspects and issues in the field of mortuary health in force in their country with regard to the management of fetal remains; d) Guarantee this good practice in the protocols of action. It is recommended to use a document such as the Birth Plan, to facilitate communication between professionals, women and their partners, inform and record decision making; e) Providing human and evidence-based care in an informed decision-making environment that respects and supports the decision of the woman and her partner regarding the management of fetal remains positively influences the process of perinatal grief.

Ethics statement: N/A

Conflicts of interest: None

Keywords: mortuary practice, cremation, burial, perinatal loss, medical waste disposal

Cite as: Sensitive disposal of fetal remains: are Spanish hospitals and funerary services meeting parents needs? Sonia Pastor Montero. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
La búsqueda y localización de restos mortales de los bebés fallecidos antes de nacer (Finding the burial sites of stillborn babies in Spain)

Rocío Cuéllar

Plataforma para la dignidad del nasciturus fallecido "Madres Libélula", Spain

La búsqueda y localización de restos mortales de los bebés fallecidos antes de nacer no está absolutamente regulada legalmente, por lo que el destino final de estos cuerpos, va a depender de la buena fe, protocolos y prácticas en cada hospital y/o cementerio. El nacimiento de las Madres Libélula viene determinado por esta dificultad, y por la necesidad personal de encontrar los cuerpos de nuestros hijos como un ritual necesario, y del cual carecen muchas familias con el sistema actual. El objetivo principal del proyecto es encontrar esos cuerpos. Para ello nuestro trabajo debe comenzar necesariamente por el estudio y análisis de las normas troncales del estado, la legislación autonómica, pasando por la normativa específica y por las costumbres de cada hospital, cementerio o crematorio. Cada proceso de búsqueda se convierte en algo personalizado, dificultando el hecho en sí de la investigación y de la localización de los restos; en el cual en las últimas gestiones no obedece a parámetros legales mínimamente garantistas, sino a decisiones arbitrarias de los organismos que las gestionan en última instancia. En unos casos podemos terminar encontrando unos restos sin incinerar en un nicho compartiendo ataúd, en una fosa común, un jardín de cenizas, inmersión en aguas profundas marinas o en el peor de los casos, en plantas de gestión de residuos sólidos urbanos. Cuando no hay una disposición privada del cadáver por parte de las familias, nos enfrentamos a un abanico de posibilidades muy amplio. Nuestro trabajo y estudio tienen como finalidad, no solo la asistencia a las familias, sino el estudio pormenorizado de la legislación, protocolos, usos y costumbres en cada territorio, hasta completar el mapa de todo el estado español, y que ello nos sirva como base para una propuesta de cambio legislativo y protocolar, en aras de conseguir unas condiciones más dignas y humanas.

Ethics statement: N/A

Conflicts of interest: None

Keywords: mortal remains of the stillborn, stillborn rights, search stillborn bodies

Cite as: La búsqueda y localización de restos mortales de los bebés fallecidos antes de nacer (Finding the burial sites of stillborn babies in Spain). Rocío Cuéllar. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 1.4 The political and legal environment of perinatal death - Invited speaker

Derecho y burocracia en la muerte perinatal (Law and bureaucracy in perinatal death)

Francisca Fernández Guillén

Francisco Fernández Guillén Law Office, Observatorio de la Violencia Obstétrica, Spain

La muerte a veces se presenta por sorpresa, y encuentra a los padres sin lápiz y papel y sin fotocopia del DNI. O es avisada pero la tristeza no permite pensar en formularios y solicitudes en el Registro Civil. Quienes se enfrentan a la pérdida en su dimensión física y espiritual, pueden no estar preparados para consecuencias civiles y administrativas. Aun así, de repente, la inexistencia jurídica puede resultar hiriente e inscribir al hijo perdido en el libro de familia convertirse en una necesidad. Y en ocasiones la sospecha de que la muerte pudo evitarse irrumpe en el duelo y nadie sabe dónde buscar respuestas, si pedir una autopsia y a quién o cuánto tardará y si se podrá recuperar el cuerpo. Como añadido, la medicina defensiva sumada a la dificultad de dar males noticias puede producir reacciones extrañas en los profesionales. Esta ponencia describe las cuestiones legales y administrativas que con más frecuencia surgen en torno a la muerte perinatal y ofrece una orientación práctica sobre cómo abordarlas.

Ethics statement: N/A

Conflicts of interest: None

Keywords: muerte perinatal, derecho, medicina defensiva, trámites

Cite as: Derecho y burocracia en la muerte perinatal (Law and bureaucracy in perinatal death), Francisca Fernández Guillén. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Stillbirth and United States Tort Law

J. Lens (1,2)

(1) University of Arkansas School of Law, U.S. (2) Bereaved Mother

Every year, mothers throughout the world bury their stillborn children. These women are both bereaved and blindsided—blindsided as doctors rarely mention the word “stillbirth” until after the child dies. In many countries, what information doctors must disclose to their patients is governed by informed consent law, a tort law doctrine. Traditionally, the required disclosure was based on what doctors customarily disclosed, a “doctor knows best” standard. Most courts, including courts in the USA, the UK, Canada, and Australia, however, have rejected that paternalistic standard instead requiring disclosure of material risks to empower patient self-determination. No study indicates exactly why doctors do not disclose the risk of stillbirth, but the believed reasons include that the risk is low, that it will cause women anxiety, and that stillbirth is unpreventable, all of which are inconsistent with the materiality standard. Even a small risk can be material when the risk is the child’s death. The anxiety myth reflects a paternalistic view of an emotional pregnant woman, not a competent adult. Last, self-determination requires disclosure of even unpreventable risks. More importantly, though, stillbirth is not unpreventable; doctors frequently advise women to sleep on their side and monitor fetal movements, although they fail to explain that the purpose of those measures is to help prevent stillbirth. Disclosure of the risk of stillbirth—including saying the word “stillbirth”—also has other benefits. Many countries believe that informing women will decrease the frequency of stillbirths. Disclosure of the risk also can reduce the shock if stillbirth does occur, decrease a woman’s likelihood of blaming (and suing) her doctor, and increase public awareness of stillbirth. A pregnant woman, just like any other patient, has a right to self-determination and doctors should inform women of the risk of stillbirth.

Ethics statement: N/A

Conflicts of interest: None

Keywords: disclosing risk of stillbirth, tort law, informed consent, medical paternalism

Variation in stillbirth rates between and within countries suggests that a significant proportion of stillbirths are preventable. Prevention of stillbirth requires understanding of women at greatest risk in order that strategies to reduce stillbirth can be developed and tested. Risk factors for stillbirth have been investigated using various epidemiological approaches including birth registries, cohort or case-control designs. In some cases, it has been possible to conduct meta-analyses of observational studies to better understand these risk factors. Risk factors for stillbirth can be divided into those which are present prior to or in early pregnancy and those which develop during pregnancy. The effect of some risk factors can be modified either by changes in maternal behaviour or by changes to maternity care (e.g. more frequent antenatal visits). Some factors evident in early pregnancy which are associated with stillbirth in all settings including extremes of maternal age, cigarette smoking, maternal obesity, maternal medical disorders such as diabetes or hypertension and having had a prior stillbirth, whereas others are restricted to high-burden countries such as malaria, syphilis and HIV infections. Factors which may develop during pregnancy which are associated with stillbirth include a small for gestational age fetus, gestational diabetes, obstetric cholestasis, reduced fetal movements, prolonged pregnancy and access to skilled maternity care. In some cases, these associations are supported by understanding of underpinning biological mechanisms or appreciation of clinical effectiveness. This presentation will consider the impact of intervention for risk factors and potential effects on stillbirth e.g. induction of labour to prevent prolonged pregnancy or following maternal perception of reduced fetal movements. In other cases, strategies to reduce stillbirths have been combined into “care bundles” and their effects eva

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, prevention, risk factors, care bundle

Session: Breakout 2.2 Risk factors and causes of perinatal death - Invited speaker

HIV, antiretroviral therapy and stillbirths in South Africa

Dr. Salome Maswime

Associate Professor and Head of Global Surgery, University of Cape Town, South Africa

1) Background: South Africa has the highest prevalence of HIV in the world. Thirty percent of pregnant women are infected with HIV. Pregnant women living with HIV have an increased risk of maternal mortality, stillbirth, preterm birth and low birth weight. Anti-retroviral therapy reduces prevention of mother to child transmission of HIV, but has also been associated with adverse perinatal outcomes. 2) Methods: We did a secondary analysis of data from the Perinatal Problem Identification Programme, a national programme which audits over 80% of births and perinatal in South Africa from 2008 to 2010. South Africa has had 3 different national regimens in the 10-year period. 3) Results: There were 7 454 172 deliveries, and 40 177 stillbirths delivered by women living with HIV. The HIV testing rate in pregnant women increased from 52% to 93% in, and ART use increased from 11% in women living with HIV to 86%. The stillbirth rate was highest (47/1000 births) in HIV positive women who were not on ART. 4) Conclusions: Women who had not received ART had the highest stillbirth rates. HIV testing and treatment has improved dramatically in South Africa.

Ethics statement: N/A

Conflicts of interest: None

Keywords: HIV, stillbirth, ART

Cite as: HIV, antiretroviral therapy and stillbirths in South Africa. Salome Maswime. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
**Session:** Breakout 2.2 Risk factors and causes of perinatal death - oral abstract communication

**Understanding pathways leading to stillbirth: the role of care-seeking and care received during pregnancy and childbirth in Afghanistan**


(1) University of Sydney, (2) Afghanistan National Public Health Institute, Ministry of Public Health, (3) World Health Organization, Afghanistan, (4) Management Sciences for Health (MSH), Afghanistan

1) **Background:** The underlying pathways leading to stillbirth in LMICs are not well understood. Context specific understanding of stillbirth is needed to prioritise interventions and identify barriers to implementation and uptake. We explored stillbirth experiences of parents and healthcare providers in Afghanistan to investigate the contribution of contextual, individual, household and health system factors. 2) **Methods:** In-depth interviews were done with bereaved parents, female elders, healthcare providers, and government health officials in Kabul province, Afghanistan. We used thematic analysis to identify contributing factors and develop a conceptual map describing pathways leading to stillbirth. 3) **Results:** Low levels of healthcare utilisation was a critical factor contributing to stillbirth underscored by women’s lack of decision making power, sociocultural barriers to access, lack of perceived need and benefit of care, and low knowledge of pregnancy self-care. Perceptions of quality of care and providers’ behaviour also affected health service use. Unmanaged maternal conditions heightened women’s risk for stillbirth. Socio-cultural factors including perceptions about caesarean sections led to refusal of medical intervention and then stillbirth. Low quality of care particularly inadequate detection of maternal conditions, advice during pregnancy, and harmful provider practices contributed to stillbirth. Inappropriate referral and inadequately equipped facilities led to delays in receipt of life saving care. The impact of the conflict created barriers to accessing care and exposed pregnant women to substances with detrimental effects on the fetus. 4) **Conclusions:** There are multiple and complex pathways to stillbirth in Afghanistan. Efforts are needed at the community level to facilitate care seeking and raise awareness of risk factors, and at the facility level to strengthen quality of antenatal and childbirth care, ensure respectful care, and reduce treatment delays.

**Ethics statement:** Ethical approval for the study was provided by the institutional review board of the Afghanistan National Public Health Institute, Afghanistan (no. 43831) and the ethical review committee of the University of Sydney (no. 2017/566). All participants provided written or verbal informed consent prior to participating in the study.

**Conflicts of interest:** None

**Keywords:** stillbirth, health services access, quality of care, health system, care-seeking


*Presenting author*
Predicting and preventing stillbirths in Zimbabwe: a cross-sectional study

R. Smyth* (1), A.E.P. Heazell (1), K. Dube (2), G. Dando (2), Sikhululekile. Mremi (2), C. Sutton (1), T. Lavender (1)

(1) University of Manchester, United Kingdom, (2) Mpilo Central Hospital, Zimbabwe

1) Background: Annually, it is estimated there are at least 2.6 million stillbirths worldwide; 98% occur in low and middle income countries of which a vast majority are preventable. In order to make any real advances in stillbirth prevention in high-burden countries, Zimbabwe being one, it is crucial to understand the causes and contributory factors which can be challenging in low-resource settings. Currently, there is a paucity of data regarding risk factors for stillbirth in Zimbabwe.

2) Methods: A cross-sectional hospital-based study was designed in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines. Data were collected by reviewing finished episodes of health records for each woman delivering at the study site, Mpilo Hospital, Bulawayo, Zimbabwe. The sample size calculation was based using binary multivariable logistic regression for the main analysis to identify factors having an impact on stillbirth when adjusted for each other (demographic/social status details, information regarding pregnancy progress and care, labour and birth, details of the death (if baby stillborn) and critical delays and modifiable factors). Assuming a stillbirth rate of 33.3 per 1000, the number of participants required to fit a model with a given number of risk factor variables is at least 1802 participants, including about 60 stillbirths.

3) Results: An interim analysis has been performed from the first 1,000 cases of which 43 stillbirths occurred giving a rate of 32.6 per 1,000 births. In these cases stillbirth is associated with poor antenatal clinic attendance (≥4 visits: LB 48% vs SB 17%), un-booked (LB 6.3% vs SB 26.8%) and previous stillbirth (LB 1.53% vs SB 73.17%).

4) Conclusions: A systematic analysis of mortality trends and events leading to stillbirths can help identify risk factors and provide information to develop local solutions to address deficiencies in service delivery.

Ethics statement: Ethical approval has been gained from The University of Manchester UK, 17/07/18 (20018-4229-6699) and the Medical Research Council of Zimbabwe, 28/09/2018 (MRCZ/E/203).

Conflicts of interest: None

Keywords: stillbirth, cause of death, low-income setting, cross-sectional

Session: Breakout 2.3 Pregnancy after loss - Invited speaker

Parental experiences of pregnancy after loss

Dr. Margaret Murphy
University College Cork and Cork University Maternity Hospital, Ireland

Globally an estimated 2.6 million babies are stillborn each year at or before their birth. The majority of these deaths (98%) occur in low and middle-income countries, stillbirth affects 1:200 pregnancies in high-income countries also. There are profound physical, psychological, social and economic effects of stillbirth that are often unrecognized. The majority of couples who experience stillbirth will progress to a subsequent pregnancy, often within a very short time frame of their index loss. Results from a qualitative phenomenological study with couples who are pregnant after stillbirth will be presented. Perinatal death, the grief of these losses, and experiences of subsequent pregnancies all affect the couple dynamic with gender differences often apparent. Healthcare professionals and society need to be aware of the particular needs of women and men who are pregnant again after stillbirth. These include increased physical, psychological, and social needs in the aftermath of stillbirth and in the pregnancy that follows. Appropriate support and continuity of care can assist couples throughout their stillbirth and pregnancy after loss journey.

Ethics statement: N/A

Conflicts of interest: None

Keywords: pregnancy after loss, support, couples

Cite as: Parental experiences of pregnancy after loss. Margaret Murphy. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
**Session:** Breakout 2.3 Pregnancy after loss - Invited speaker

**Decision-making, clinical management and care during subsequent pregnancies**

Dr. Elizabeth McCarthy

Mercy Hospital for Women and University of Melbourne, Australia

Grief following pregnancy loss is profound and far reaching. It differs in some ways from grief after losing a loved one who has shared a longer, child or adult relationship with a bereaved parent. One distinguishing feature is that pregnancy often occurs again, mixing ideas of life, hope, death, sorrow, joy and birth. About 65% of couples conceive another pregnancy within 1 year of perinatal loss. Whenever it occurs, the next pregnancy presents biopsychosocial challenges. Biological tasks include phenotyping the previous loss, identifying causes, risks, predicting and preventing recurrence. Many currently used tests, surveillance and interventions lack high level evidence for benefit. In trying to help, we must strive not to make women's experience and outcome worse. Psychosocial tasks include validating the woman's experience, range of emotions and providing individualised care. Excessive attention on biomedical factors can detract from normal parenting tasks, joys and challenges. Excessive emphasis that the next pregnancy will probably result in livebirth (97+% overall) can seem to invalidate the woman's ongoing bereavement and love of her lost baby and detract from efforts to reduce stillbirth for this women and others. Multi-disciplinary care which includes obstetrician/perinatologist, midwife, pastoral care/bereavement workers and ready access to other clinical, laboratory and research specialists aims to balance these emphases. Those of us caring for women during pregnancy after loss need to be responsive to (a) the woman and the (b) research. Encourage and explore women's questions: they have thought about pregnancy loss a lot and might be the catalyst for stillbirth-preventing research. Care which is individualised, responsive, multi-disciplinary, evidence-guided, (despite a currently imperfect evidence-base) offers balance, safety and usually, good biopsychosocial outcomes for women who are pregnant after

**Ethics statement:** N/A

**Conflicts of interest:** None

**Keywords:** grief, stillbirth, miscarriage, placental insufficiency, congenital abnormalities

**Cite as:** Decision-making, clinical management and care during subsequent pregnancies. Elizabeth McCarthy. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 2.3 Pregnancy after loss - oral abstract communication

Generating evidence to inform clinical practice in pregnancies after stillbirth: what next?

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(1) NHMRC Centre of Research Excellence in Stillbirth; Mater Research Institute and The University of Queensland (MRI-UQ), (2) Maternal and Fetal Health Research Centre and Faculty of Biology Medicine and Health, University of Manchester, (3) Division of Obstetrics, St Mary’s Hospital, Manchester, (4) South Australian Health and Medical Research Institute (SAHMRI), (5) Griffith University and Gold Coast University Hospital, (6) Department of Obstetrics and Gynecology, University of Utah, U.S.

1) Background: Evidence to inform clinical practice in pregnancies after stillbirth is sparse. While more research is required, there are myriad potential avenues to pursue in terms of specific research topics and proposed methodologies, of which some may pose significant ethical and logistical challenges. This study aimed to canvas such views and establish future research directions to inform care.

2) Methods: A web-based survey was administered to an international, multidisciplinary panel of 79 individuals involved in stillbirth research, clinical practice, and/or advocacy (response rate = 64%). The survey assessed the importance of 16 candidate research topics, and the perceived utility and appropriateness of randomised-controlled trial (RCT) methodologies for four selected intervention categories: (1) medical therapies for placental dysfunction; (2) additional antepartum fetal surveillance; (3) early planned birth; and (4) different forms of psychosocial support. Data were analysed using descriptive statistics in aggregate form.

3) Results: Medical therapies for placental dysfunction was considered the most pressing future research topic, rated as “important and urgent” by 81%. Whether RCT methodologies were deemed appropriate for such future research varied, depending on the intervention and given criterion. For example, while 72% felt that RCTs were ‘the best way’ to evaluate medical therapies, fewer respondents (63%) deemed RCTs ethical in this context, and only half (52%) felt that RCTs were feasible. There was considerably less support for RCT methodology for the evaluation of psychosocial support interventions, which was reinforced in by free-text comments.

4) Conclusions: Candidate future research topics for care in pregnancies after stillbirth were identified. In general, there was more support than not for conducting RCTs in this area, but respondents were divided on issues of ethics and feasibility. Engaging with parents and families is a critical next step.

Ethics statement: This study was approved by the Mater Health Services Human Research Ethics Committee on 22 June 2018 (Ref Reference No: HREC/18/MHS/85), within the guidelines of the Australian National Statement on Ethical Conduct in Human Research (2007) updated 2015.

Conflicts of interest: None

Keywords: stillbirth, subsequent pregnancy, priority setting, implementation, RCTS


*Presenting author
Navigating an uncertain journey of pregnancy after perinatal loss

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(1) St. Louis University, United States, (2) Cone Health Alamance Regional Medical Center, U.S.

1) **Background:** Women with a perinatal loss history desire to both get pregnant again and maintain a connection to their dead child. However, many women realize that pregnancy does not always equal a live baby, they fear of another loss, and distrust of their bodies. Thus these women fluctuate between worry and confidence resulting in pregnancy-specific anxiety. 2) **Methods:** The purpose of this qualitative data analysis was to gain insights into women’s experiences over the course of pregnancy after perinatal loss documented in pregnancy diaries. Inductive thematic analysis of pregnancy diary entries from 19 pregnant women who participated in an intervention study were the data source. 3) **Results:** The participants were primarily Caucasian, 23 to 41 years old, with history of 1 to 6 prior losses, high school to graduate school education, and a wide range of incomes. A metaphor of navigating a pregnancy journey that feels scary and uncertain, towards the goal of reaching their desired destination, a healthy infant, was identified from women’s personal accounts. Six themes were identified: 1) Staying Alert: Noting Physical Symptoms, 2) Dealing with Uncertainty: Expressing Emotions, 3) Dreaming of the Destination: Evolving Thoughts of Baby, 4) Traveling Together: Connecting with Others, and 5) Moving Forward: Reflecting on Sense of Self. The interaction of several themes is described as 6) Staying on Track: Navigating through Pregnancy. 4) **Conclusions:** Women may find journaling helpful in dealing with the anxiety and fear that characterize pregnancy after loss. Viewing pregnancy after perinatal loss as similar to navigating an uncertain journey may provide greater understanding of the emotional, physical, and social challenges that women may experience. Recognition that women with a history of perinatal loss may be anxious and fearful during pregnancy will increase sensitive care.

**Ethics statement:** Approval for this study was received from the University of North Carolina Greensboro (Approval number 13-0224). Informed consent was received from the participants when they participated in the original study; the data used here were de-identified and thus was exempt from additional consent.

**Conflicts of interest:** None

**Keywords:** pregnancy after loss, pregnancy, diary, journals, bereavement

**Cite as:** Navigating an uncertain journey of pregnancy after perinatal loss. D. Côté-Arsenault, S. Moore. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.

*Presenting author
The effects of stillbirth on the reproductive future and medical interventions in subsequent pregnancy

L. Leupen*, P. van Rijn, J.J. Erwich

University Medical Center Groningen, Netherlands

1) Background: There were 2.6 million cases of stillbirth globally in 2015. Stillbirth has an emotional effect and an effect on the subsequent pregnancy. The aim of this study is to improve clinical guidelines in subsequent pregnancies following a stillbirth. 2) Methods: This study is a retrospective case study, on 345 cases extracted from an earlier study on stillbirth (ZOBAS study 2002-2008), from 9 hospitals in the Netherlands. The patient files were examined using a case report form and the data was stored using RedCap and analyzed using IBM SPSS. Relevant information for comparison with the general population were obtained from earlier research on this subject. 3) Results: Of the 345 cases examined, 241 (69.9%) cases became pregnant again, from which 229 files were available. Time between the stillbirth and the subsequent birth had a mean of 19.4 months. A mean of 15 prenatal controls and a mean of 9.4 ultrasounds were done in the subsequent pregnancy. In 116 (50.7%) cases, this was unknown. In 163 cases, the mode of delivery was spontaneous. In 65 cases, instrumental delivery was necessary, respectively 29 elective C-sections, 19 emergency C-sections and 17 ventouse were performed. Unfortunately, 9 (4.0%) cases did experience another perinatal death, respectively 7 antenatal deaths and 2 postnatal deaths. The causes of these deaths were 1 congenital anomaly, 3 prematurity, 1 infection, 2 other causes and 2 of unknown cause. 4) Conclusions: Women who experience stillbirth have a higher subsequent pregnancy rate and conceive faster. In the subsequent pregnancy, there were also more ultrasounds and prenatal checks done. These women have a higher risk of delivering by C-section, of suffering from a complication and of experiencing another perinatal death. These findings can be useful in counseling of women who experienced stillbirth and will also be incorporated in a larger follow-up study.

Ethics statement: This study was assessed and deemed non-WMO by the Medical Ethics Test committee of the UMCG on the 15th of November 2017 with RefNo. M17.220789. The participants were not asked to consent because of the design of this study. The research committees and the board of directors of the participating hospitals gave permission to examine the files of the participants.

Conflicts of interest: None

Keywords: stillbirth, subsequent pregnancy, complication, counseling.


*Presenting author
Session: Breakout 2.3 Pregnancy after loss - oral abstract communication

The Tommy’s Rainbow Clinic Study: evaluating a specialist antenatal clinic for women following a stillbirth or neonatal death

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1) Background: The death of a baby has long-lasting emotional and psychological impact on a woman and her family, but the majority will embark on another pregnancy within a year of their baby’s death. A prior perinatal death increases parents’ anxiety, emotional vulnerability and decreases confidence in their next pregnancy. To address these additional needs our hospital hosts the Rainbow Clinic, a specialist antenatal service for women following a perinatal death. This study aimed to explore users’ experiences of care in the service and to assess its economic impact.

2) Methods: A mixed methods approach was used; validated questionnaires were used to measure psychological constructs at two time points during pregnancy and six weeks postnatally (n=83). Semi-structured interviews were conducted in a subset of women and analysed by thematic analysis (n=17). Hair cortisol was measured using ELISA to assess stress levels throughout pregnancy (n=10). Social Return on Investment (SROI) methodology was used to assess the economic value of the service.

3) Results: Women described a reduction in anxiety and improved experience; the Cambridge Worry Score and Generalised Anxiety Disorder-7 scores reduced over time (Postnatal 5.2 vs Late Pregnancy 5.9 vs. 8.1 Early Pregnancy); there was no change in Edinburgh Postnatal Depression Score, State-Trait Anxiety Index or EQ5D. The interview data further explained the women’s improved experiences, reduction in worry and anxiety and the relationship between worry and anxiety. There was large variation in hair cortisol between participants but there was a reduction from the first through to third trimester. The Rainbow clinic model gives a 6-fold return on capital invested, with the greatest emphasis placed on reduction of psychological distress and delivery of a healthy baby.

4) Conclusions: The Rainbow Clinic model of care is an effective, economically viable service which can improve families’ experience of a subsequent pregnancy after stillbirth.

Ethics statement: Ethical approval was obtained for this study (Ref 16/NW/0258). The wellbeing of the participants involved in this project was of high importance and as such steps were taken to ensure they had support during and after taking part in the study.

Conflicts of interest: None

Keywords: stillbirth, rainbow clinic, care in a subsequent pregnancy, perinatal death

Cite as: The Tommy’s Rainbow Clinic Study: evaluating a specialist antenatal clinic for women following a stillbirth or neonatal death. S. Thomas, T. Mills, D.M. Smith, C. Hughes, L. Stephens, A.E.P. Heazell. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.

*Presenting author
A community based approach to supporting women and their families following the loss of a baby

Wanjiru Kihusa

Still A Mum Trust, Kenya

The loss of a baby is often times seen as a private affair; something the immediate family should handle privately without the involvement of “outsiders”. This immediate family to most people usually comprises the woman, her partner, the baby’s siblings and the family members of the bereaved parents. This however is not an accurate representation of the support bereaved parents receive. Consider this, when a baby is born healthy and taken home we see a rallying of family, friends, neighbors, nannies, religious leaders among other community members participate in the parenting process. This should happen, and in most cases happens, when a woman loses a baby. Based on the author’s personal experience and that derived from running an organization that supports bereaved families in Africa, this work suggests that there is a community surrounding the bereaved family that is beyond the immediate family. Additionally, it looks into who exactly is included in this community and their unique role in supporting the bereaved woman and her family as well as how to specifically engage these community members. Each community member has a unique role in supporting a bereaved family; some being hands on help others being to provide a safe space for grief and healing to happen. The absence of even one aspect of community support can lead to delayed healing from the trauma of child loss.

Ethics statement: N/A

Conflicts of interest: None

Keywords: child loss, community support

Cite as: A community based approach to supporting women and their families following the loss of a baby. Wanjiru Kihusa. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 2.4 Community based care: follow-up care, support associations and support groups - Invited speaker

Traumatic deaths, the role of support associations in preventing complicated grief

Trine Kalstad

Norwegian SIDS and Stillbirth Society, Norway

The death of a child affects us deeply and grieving parents face high risk of increased mortality and illness including complicated grief. Even though grief is severe pain, the grief process serves a purpose; finding a way to live without the dead child. Many parents need both professional and non-professional help. As a support organization we offer different types of bereavement support. Through psychoeducation and different types of peer support, we facilitate a healthy and healing process by empowering the bereaved families to find their ways of coping with the different consequences of grief. Our method is peer support; rooted in having their own experience of loss this is a respectful and mutual understanding of the struggle to rebuilt a meaningful life. Peer support are based on three principles: We need to see the bereaved person by simply accepting their experiences. Secondly, we support them by identifying their daily life challenges and finally we need to empower the bereaved person in coping; what decisions need to be made in order to accept the complex consequences of the loss and move forward. Our peer supporters are trained and our work is based on the dual process model of grief by Stroebe and Schut (2010); coping is finding a balance between accepting and confronting the tasks of grief. Even though the support organization do not offer therapeutic treatment, we experience therapeutic effects. Our peer supporters accept the issue of time needed to restore and cover other needs than professionals. So we need to cooperate to utilize the potential of support, both from social network, peer supporters and health personal. Nevertheless, as a support organization we do have a normative role and we have to focus on quality and knowledge. This recognition makes us a competent and professional actor in preventive health and grief support in order to reduce the risk health problems in general and complicated grief specifically

Ethics statement: N/A

Conflicts of interest: None

Keywords: grief, bereavement support, coping, education, peer support

Cite as: Traumatic deaths, the role of support associations in preventing complicated grief Trine Kalstad. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 2.4 Community based care: follow-up care, support associations and support groups - oral abstract communication

Bereavement support groups for parents who lost a child during pregnancy, birth or shortly after birth

H. Himmelstrup*, J. Ammitzbøll, M. Egelund, M. Dorthea Bjerre

Regionshospitalet Randers, Fødeafsnittet, Denmark

Since August 2018 four maternity wards in the Region of Central Denmark in cooperation have provided bereavement support groups for parents, who lose a child during pregnancy, birth or shortly after birth. Due to the size of each maternity ward, local bereavement groups are not feasible and hence the Region has organized a mutual organization with a counselor from each hospital, working in pairs of two. The participants have evaluated the support groups as very helpful in their grief process. Especially getting together with others in the same situation has been rewarding, alongside grief theory and mindfulness. Parents with a spontaneous loss or termination of pregnancy due to fetal anomaly between gestational age 14 weeks to one week postpartum are invited to participate in the support groups. The parents are given written and verbal information about the groups before discharge from the hospital followed by a call from a counselor. Participation is free of charge. A support group typically comprises four to six couples who meet for three hours five consecutive weeks; two hours guided by the bereavement counselors and one hour assigned networking between the couples themselves. In the group sessions the parents are given the opportunity to reveal and reflect over their individual story. Grief theory is part of the program and furthermore the following themes are most often discussed: guilt, succeeding pregnancies, gender differences after a loss, the response of friends and colleagues, bodily changes, rituals, going back to work, etc. The purpose of the bereavement support groups is to offer a safe space for reflection after a traumatic experience. Emotions like loneliness, meaninglessness, sense of emptiness, anxiety, anger, guilt can be very difficult to carry alone. Without support there is an increased risk of developing adverse mental outcomes among the bereaved parents.

Ethics statement: Ethics approval wasn’t required and subject safety is protected via anonymization.

Conflicts of interest: None

Keywords: bereavement support groups

Cite as: Bereavement support groups for parents who lost a child during pregnancy, birth or shortly after birth. H. Himmelstrup, J. Ammitzbøll, M. Egelund, M. Dorthea Bjerre. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.

*Presenting author
When talk therapy is not enough: Alternative strategies to support the perinatally bereaved

K. Ludski*

Red Nose Australia, Peace of Mind Counselling Training and Supervision

Grief has the capacity to affect an individual psychologically, physically, spiritually, cognitively and emotionally. Clinicians often report the significant challenges that accompany supporting the perinatally bereaved and struggle to know what type of therapeutic intervention will be the most effective in their client's bereavement care. Sometimes traditional ‘talk’ therapy is not enough. Supporting the perinatally bereaved is often challenging. Mothers report strong feelings of guilt and shame that seem immovable. Fathers, on the other hand, often report a sense of helplessness and hopelessness in supporting their partners; whilst at that the same time trying to navigate their own grief experience. Within the supervision setting many clinicians have shared feelings of inadequacy and ineffectiveness in really creating any shifts in this cohort of bereaved parents. Years of practice have highlighted that bereaved families cannot be talked or reasoned out of their intense feelings and that the integration of logic has mixed results. In order to best support the perinatally bereaved, clinicians need to understand and acknowledge that people grieve differently. One’s grieving style will determine the most effective therapeutic interventions for that individual. For some people talk therapy may be overwhelming, traumatising and of no great benefit. This session will focus on alternate methods for supporting the perinatally bereaved that best meets their individual needs. These approaches include creative interventions, the use of ritual, mindfulness and grounding strategies. It will be an interactive session allowing clinicians to sample different interventions.

Ethics statement: No ethics approval was required for this abstract submission

Conflicts of interest: None

Keywords: perinatal bereavement, clinicians, therapeutic intervention, support

Cite as: When talk therapy is not enough: Alternative strategies to support the perinatally bereaved. K. Ludski. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.

*Presenting author
Session: Breakout 3.1 Improving care quality through the development of care standards, training and support structures for HPs - Invited speaker

In-hospital support groups for healthcare professionals at Val d’Hebron maternity hospital

Dr. Fatima Camba

Vall d’Hebron University Hospital, Spain

Perinatal death has a devastating effect on families, but it also affects the professional who attends them. Accompanying families who lose a child is a job of psychological risk, and professionals can be affected by compassion fatigue, post-traumatic stress, moral distress or burn-out. It is necessary to take care of the professionals, and for that there are different strategies, one of which may be the reflection groups. The Interdisciplinary Group of Reflection on perinatal grief (GIR) of the Vall d’Hebron hospital was created in 2012. It is formed by professionals from the neonatal service, who meet once a month to discuss how the death of patients affects them. The group is moderated by a psychologist and allows professionals to reflect on the experience of the death of their patients, talk about the link created between professionals / patients / parents, accept the questioning and recognize their own mournings and improve communication in the team (doctors-nurses). The professionals who form the group value their existence very positively, say that it helps them to feel better, and they would recommend the group to other professionals. In addition to personal benefits, the group has also contributed to improve perinatal grief care in the neonatal unit, since it has led improvements in end-of-life care and training in perinatal grief and perinatal palliative care. In our experience, the reflection groups for professionals (GIR) are a good strategy for supporting health professionals who accompany families in perinatal grief. The group has individual benefits for each professional, as well as for improving the attention to perinatal grief in the neonatal service.

Ethics statement: N/A

Conflicts of interest: None

Keywords: neonatal death, health professionals support

Cite as: In-hospital support groups for healthcare professionals at Val d’Hebron maternity hospital. Fatima Camba. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Participatory Action Research as best practice in the development of care standards and guidelines for perinatal bereavement care

Dr. Sonia Pastor Montero

Hospital Universitario Juan Ramón Jiménez, Spain

The large number of studies that have been conducted on perinatal death and grief have led to the development of clinical practice guidelines and the application of a series of good practices. However, between the production of knowledge and the decisions that professionals make in clinical practice, there is generally a reduction of knowledge in favor of beliefs and opinions. In this sense, overcoming the barriers that hinder the transfer of better knowledge to decision-making in clinical practice is a challenge for health professionals. Participatory Action Research (PAR) is emerging in the field of health as a great instrument for changing clinical practice. It is based on the generation of critical awareness, by promoting the participation of community members in the search for solutions to their problems as agents of change to transform the healthcare reality in which they are immersed. Summary: a) PAR articulates research, education and action; b) The transfer of knowledge to clinical practice requires professionals to change attitudes and reflect on their own healthcare practice; c) The PAR has a humanistic design, guaranteeing the participation of all those involved, who share their knowledge and experiences, select strategies adapted to their context, facilitating implementation, and give a sense of ownership and commitment to the actions put into practice. health professionals the agents of change themselves; d) PAR is an enriching methodological strategy for the empowerment of health professionals, which enables an innovative attitude of their clinical practice by recognizing the professional's ability to generate knowledge in an active, critical and reflective way in order to lead a transformative action in the field of death care and perinatal grief.

Ethics statement: N/A

Conflicts of interest: None

Keywords: perinatal loss, parental grief, participatory action research, practice guideline

Session: Breakout 3.1 Improving care quality through the development of care standards, training and support structures for HPs - Invited speaker

Education for perinatal bereavement care

Dr. Margaret Murphy

University College Cork, Ireland

How bereaved families are cared for at the time of their loss has been shown to affect experiences of that care, grief journeys, enduring relationship with deceased children, and physical and emotional well being. Families’ negative experiences of care are often the result of ill prepared healthcare staff who are uninformed about the specific challenges of caring for the perinatally bereaved. Healthcare staff too have identified training and education as key priorities for them in caring for bereaved families. In March 2019 Ireland completed a two year implementation of National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death (Health Service Executive, 2016) (2016). A feature of this implementation was the development of national bereavement education standards. The presentation will address the development of these standards and how they can be operationalised with healthcare professionals, including student midwives.

Ethics statement: N/A

Conflicts of interest: None

Keywords: bereavement, education, perinatal

Cite as: Education for perinatal bereavement care. Margaret Murphy. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Midwifery students' experiences of providing care to women following stillbirth in Papua New Guinea (PNG): Implications for education and practice

K. Cheer

James Cook University, Australia

1) Background: Providing care to a woman experiencing stillbirth affects the health and wellbeing of midwifery staff, including midwifery students. Understanding how midwifery students experience and manage stillbirth is essential to help midwifery students cope with this aspect of their work. This study was undertaken in Papua New Guinea (PNG), a South Pacific country with one of the highest stillbirth rates in the region. 2) Methods: Semi-structured interviews, focus group discussions and a participatory workshop were used to explore the perspectives of a cohort of midwifery students enrolled at a faith-based university in PNG. Data was analysed to identify codes and categories to inform a grounded theory. 3) Results: Midwifery students sought to provide the best possible care to women following stillbirth by balancing interconnecting social, cultural, spiritual and systemic factors. Students live and work in settings where diverse beliefs and customs influence the creation of meaning and determine individual and community behaviour. Students revealed the personal and professional consequences of caring for women following stillbirth that include guilt, self-doubt and blame. Social, cultural and spiritual systems provide meaning and resilience for students. 4) Conclusions: Midwifery students engage in layered discussions about religion, culture and social issues to improve health outcomes for women and their families. They also use these mechanisms to make sense of stillbirth for themselves. Students require specific support strategies to help build coping skills to deal with the emotions they experience in their complex and diverse setting.

Ethics statement: Ethical approval for this study was granted by James Cook University (H6344) and Pacific Adventist University (ECP0315). All participants gave their informed consent to participate in the study. Counselling services were available if participants required support.

Conflicts of interest: None

Keywords: stillbirth experiences, midwifery students, Papua New Guinea

Cite as: Midwifery students' experiences of providing care to women following stillbirth in Papua New Guinea (PNG): Implications for education and practice. K. Cheer. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Stillbirth: a healthcare provider perspective

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1) Background: Stillbirth is a major global health concern. Most stillbirth research has been conducted in high-income countries with few studies in low-middle income countries. An important step in understanding stillbirth, its management and support provided to mother and families who experience stillbirth is understanding health professionals’ perspectives. The purpose of this qualitative study was to investigate the experiences of health professionals involved in care after stillbirth in Lao People’s Democratic Republic, a lower-middle income country in South-East Asia.

2) Methods: In-depth face to face interviews were conducted with 33 health professionals at health facilities specialising in maternal and child health in Vientiane Province. Participants were doctors, midwives and nurses involved in the direct or indirect care of mothers who had experienced stillbirth. Data were transcribed with constant comparative techniques for thematic analysis.

3) Results: All participants recognised stillbirth as an issue of concern. However, absence of reporting systems, review processes and autopsy services meant that stillbirth frequency and causes remained undocumented and invisible. From the perspective of participants, under-resourcing of facilities influenced the quality of care provided to mothers and left health staff feeling frustrated, sad, in fear of being blamed and ill-equipped to support mothers. Participants highlighted the need for further training and reported that when mothers needed emotional support, they often faced stigma and blame from family members and the broader community.

4) Conclusions: These findings shed light on the personal experiences and impact of stillbirth on health professionals and mothers in a low-resource setting. Relatively low-cost interventions such as appropriate reporting systems and review processes, training for health professionals, and public education to reduce stigma and blame could help improve the management and support mechanisms.

Ethics statement: Ethics approval was obtained from the Human Research Ethics Committee at the University of Queensland (#2017000978) in accordance with the Australian National Statement on Ethical Conduct in Human Research (NHMRC, 2007). Local ethics approval was obtained from the Lao PDR University of Health Sciences Ethical Review Board following their review of translated copies of the research proposal executive summary, consent form and interview guidelines. Written informed consent was obtained from all study participants.

Conflicts of interest: None

Keywords: stillbirth, Lao PDF, bereavement care, low- and middle-income countries


*Presenting author
Making Memories: More than Footprints

Sue Steen

Maple Grove Hospital and Bethel University, United States

Studies have found that in high-income countries parenting time and making memories with their stillborn baby may help parents grieve. Many nurses encourage families to create keepsakes, take pictures, name their baby, and include family in the birth experience. In low-income settings, nurses may have a lack of resources that prevents them from creating keepsakes as well as cultural practices that may prevent a mother from seeing her stillborn baby. The health care professional's comfort level with stillbirth and knowledge of memory-making activities is critical for the provision of compassionate and comprehensive care. Being with a deceased baby after birth can be a frightening time for parents. They may need support as they determine how much time they want to spend with their baby. According to international guidelines, parents should be encouraged to stay with their baby for as long as they desire, making memories and allowing an opportunity for siblings, family, and friends to meet the baby. Photography may be invaluable during and after the crisis of a stillbirth or newborn’s death. Creating ceramic molds and footprints, taking a lock of hair, and providing a hand knit blanket are keepsakes that parents may find meaningful. Respect for families and culture, while introducing global standards, can direct our care in various settings around the world. Creating keepsakes and creating a safe space for parents as they make memories with their baby will assist parents as they move through their grief journey. Our role as health care professionals is to explain all options and choices that parents can make and support their decisions.

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, memory making, keepsakes, parenting

Management of perinatal death audit and review systems: overview and parental involvement

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Proper review of cases of perinatal mortality or morbidity (like asphyxia) has the power to determine where our care has been good and where our care needs to be improved. Methodology for setting up a system for audit is available (WHO), however this path can be determined by strengths and difficulties. With the input of all involved disciplines (nurses, midwives, obstetricians, pediatricians, pathologists, ambulance personnel, anesthetists etc) a case can be discussed in a meeting using root-cause analysis techniques for repetitively asking the “why” question if sub-standard care has been identified. If basic causes of the sub-standard care can be defined, suggestions for improvement including a pathway on how to implement them, should be the result. Talking about bad outcomes and about our possible role in those, like medical errors, can be difficult and hampered by barriers to be frank due to the fear of personal consequences, like litigation or institutional consequences. Prerequisites for audit are a training for the participants on the methodology, allocated motivated multidisciplinary personnel, complete documentation for the case, preparation with the involved caregivers before the meeting setting the possible lessons to be learned and an independent chairperson. Implementation of such regular meetings and of the lessons learned are vital for success and improving the quality of care. Important factors for this are: a strong chair (champion) person, a culture that is willing to change for the better, support like funds for meetings/secretary (management), a plan for monitoring and reporting the progress, an external force for support or check on the system as a whole. Currently, involving the parents is challenging. However, their experiences should be taken into the audit because they can point at sub-standard care items the professionals will not see for themselves. Proper feedback to the parents is just good clinical care.

Ethics statement: N/A

Conflicts of interest: None

Keywords: perinatal audit, case-review, PDCA cycle

Investigating perinatal death: optimal approach to placental pathology

Prof. Jane Dahlstrom

ACT Pathology, The Canberra Hospital, Canberra Health Services and ANU Medical School, College of Health and Medicine, Australian National University, Australia

In 2015 it was estimated that 2·6 million babies were stillborn. 90% of injuries to a baby happen before labour and hospital admission, are either utero-placental or placenta-fetal with the common element being the placenta. In 30% to 64% of cases an indication for the cause of the adverse outcome for a baby can be found in the placenta. A detailed placental pathological examination is thus one critical component of stillbirth evaluation given the placenta's essential role in maintaining the pregnancy and is recommended in clinical practice guidelines. In addition, certain placental pathologies are associated with an increased risk of recurrent stillbirth. These include high grade chronic villitis, chronic intervillitis, massive perivillous fibrin deposition, inherited thrombophilias, inherited metabolic disorders and certain infections. The optimal approach to placental pathology requires good communication and development of protocols with the obstetric and pathology teams. Use of standardised terminology is also essential. This talk is case based and discusses the current optimal approach to placental pathology in the context of a perinatal death.

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, perinatal death, placental examination, pathology, recurrence risk

Reviewing stillbirths by root cause analysis – a pilot study from tertiary care hospital of India

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PGIMER CHANDIGARH, India

1) Background: Stillbirth is one of the adverse outcomes of pregnancy leading to a huge burden on society and India has the highest position in the world in terms of total number with estimated Stillbirth rate of 23 per 1000 births. Now it has been realized that to reduce this huge burden of we need to have a better understanding of stillbirths, its causes, risk factors and contributory factors. This study was an attempt to determine the root causes of stillbirths using an RCA framework. 2) Methods: Each case of stillbirth was reviewed in detail and information was gathered from clinical records, open history and interviewing each woman and her relatives in detail and root cause analysis was performed. RCA mainly focussed on six factors - Organization, personnel, equipment related, barriers at personal/family level, maternal and foetal causes. 3) Results: In all hundred stillbirths lack of recognition of seriousness at personal level played an important role in almost 72% of the cases. The organization related factors were noted in 42% of cases and common factors were poor organization and poor system for sharing information and referrals. The analysis further revealed that failure to follow best practice guidelines and lack of knowledge of health care provider were also there. 4) Conclusions: Root cause analysis of stillbirth has highlighted the contributory factors and lapses at various levels viz. patient and family, lack of optimal antenatal care at the local health-care level, poor referral system, organization/systems, lack of sufficient personnel, equipment, proper knowledge of treatment protocols. Timely referral and proper communication with referral institute and development of a strong referral system, availability of standard treatment protocols, guidelines and sufficient facilities at tertiary care can go a long way in reducing these preventable stillbirths.

Ethics statement: Clearance from institutional ethical committee was taken before starting the study.

Conflicts of interest: None

Keywords: stillbirths, root cause analysis, stillbirth rate


*Presenting author
Contribution of cytogenetic study in a series of fetal losses. Genetic and autopsic correlation


Pathology Department, Parc Taulí Hospital Universitari; Institut d’Investigació i Innovació Parc Taulí (I3PT) and Universitat Autònoma de Barcelona, Spain

1) Background: Fetal loss is a major obstetric complication in pregnancy, sometimes poorly understood due to the difficulty or impossibility to determine the cause of fetal death. More than one condition may contribute in an individual case and there are conditions that may be associated with stillbirth without directly causing it. Our hospital offers the study of fetal losses since 1992, which includes radiological study, cytogenetic study, clinical autopsy and placental examination, in order to establish the cause of the death, to recognize genetic based on diseases and to offer genetic counselling. Our objective is to evaluate the contribution of the cytogenetic study to establish the cause of death and to correlate it with autopsy findings in a series of fetal losses. 2) Methods: This was a retrospective cohort analysis of spontaneous fetal losses from 12th to 40th gestational weeks that occurred from 1999 to 2018 in our institution. Analysed data included: gestational age, genetic studies, fetal autopsy and histopathological examination of the placenta. Cytogenetic study was made by chorion villi, amniotic fluid, placental tissue or fetal cartilage. Abnormal results of karyotype, fetus and placenta were classified using Tulip classification. 3) Results: During 19 years of the study period, there were 939 fetal losses. Successful karyotyping was possible in 754 cases (80.3%). In 72 cases (8%) karyotype was abnormal. Parents gave their consent for fetal autopsy in 39 cases (54.2%) of the 72 cases with abnormal karyotype. Karyotype results, autopsic and placental findings are detailed in Table . 4) Conclusions: Chromosomal abnormality has been the only finding detected in 11 cases (28.2%). Karyotype adds complementary information in the other 28 cases (71.8%) in which other cause has been found at autopsic study that justifies fetal loss by itself. Understanding the aetiology of fetal loss enables classification of recurrence risk and improves the management of future pregnancies.

Ethics statement: All procedures are made under informed consent of parents. Obtained data have been used anonymously. Ethics approval wasn’t considered.

Conflicts of interest: None

Keywords: fetal loss, cytogenetic study, clinical autopsy.


*Presenting author
Session: Breakout 3.4 Perinatal and neonatal palliative care - Invited speaker

End-of-life care before and after birth: the challenges of perinatal palliative care

Prof. Alison Kent

University of Rochester, Golisano Children’s Hospital, Rochester, USA and Australian National University, Australia

There is universal acceptance that perinatal palliative care requires dedicated and skilled multidisciplinary practitioners. However, despite this recognition, provision of palliative care within and across countries varies widely and may be affected by cultural and religious beliefs. Perinatal palliative care frequently commences before life has begun, particularly for neonates who will be born with life-limiting conditions. Perinatal palliative care focuses on improving quality of life and minimizing suffering. End-of-life care is one aspect of palliative care and supports a peaceful, dignified death of the infant, while at the same time providing support to the families. Importantly, support should also be provided to staff members caring for these families. Tools from checklists to care plans have been designed to facilitate staff working with families to improve and provide sensitive, supportive palliative care. WHO defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". Perinatal palliative care is uniquely different to paediatric or adult palliative care in that the process frequently begins before life has begun.

Ethics statement: N/A

Conflicts of interest: None

Keywords: perinatal, palliative care, neonatal, end of life

Session: Breakout 3.4 Perinatal and neonatal palliative care - Invited speaker

Neonatal care at the limit of viability: ethics and legal framework for decision-making in Norway

Dr. Janicke Syltern

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Owing to the advances in neonatal intensive care, the limit of viability is touching the limit of abortion in Norway, as in many countries in Europe. The mortality rate and the incidence of severe disabilities are, however, high, and so is the burden of treatment for both infants and parents. How should we approach these dilemmas, and promote an ethically sound and sensitive decision-making process for both parents and health care personnel? Both doctors and parents face difficult decisions with regard to infants born at the limit of viability. Are we obligated to go for a trial of life-saving treatment, knowing that such efforts are likely to be unsuccessful and carry a heavy burden of treatment and disability? Or should we provide only comfort care, knowing that by doing so, we will allow some babies to die who might have been saved. The prognostic uncertainty has led to guidelines advising resuscitation to be offered on an individual basis. Studies suggest that there is no shared European consensus in this difficult field, creating a dilemma for parents and clinicians within the European community. The decisions are not black or white; thus, this domain of clinical decision-making is referred to as the grey zone. The ethics of such a grey zone is complicated and controversial. Possible diverging approaches between different hospitals in Norway threatens the idea of an equal and fair health care service for this group. We will provide a review of the topic with a special focus on the Norwegian perspective and discuss the ethical and legal framework, and present empirical ethics data from interviews with Norwegian health care personnel and parents.

Ethics statement: N/A

Conflicts of interest: None

Keywords: ethics, extreme prematurity, shared decision-making

Session: Breakout 3.4 Perinatal and neonatal palliative care - Invited speaker

Developing perinatal bereavement care in the neonatal unit of Vall d’Hebron Hospital

Dr. Fatima Camba

Vall d’Hebron University Hospital, Spain

In recent years there has been a growing interest in our country to improve the support to families experiencing a perinatal loss. Several centers have developed programs for perinatal bereavement support or perinatal palliative care. We report our experience in the neonatal unit at Vall d’Hebron Hospital (Barcelona) with the development of a perinatal bereavement support program, initiated in 2011. We highlight aspects that have been key in the development, such as the formation of an interdisciplinary group including a psychologist; and the difficulties encountered. We also reflect on the challenges for the future. We believe that sharing experiences in the development of respectful and supportive perinatal bereavement care programs it could be useful in the process of implementing of these programs in our country.

Ethics statement: N/A

Conflicts of interest: None

Keywords: perinatal death, neonatal death, perinatal bereavement care, palliative care

Cite as: Developing perinatal bereavement care in the neonatal unit of Vall d’Hebron Hospital Fatima Camba. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 3.4 Perinatal and neonatal palliative care - oral abstract communication

Accompanying the dying, family centered care in a high complexity healthcare unit

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Hospital Sant Joan de Deu, Barcelona, Spain

1) Background: Neonatal death represents one third of child deaths. The majority of these deaths occur in the NICU and after Limitation of Therapeutic Effort (LTE). Aim: To examine the causes and manner of death and characteristics of the dying process in our NICU. 2) Methods: Retrospective and observational study. The study group included deceased patients (January 2009 to December 2016). Some of the variables registered: gestational age (GA), weight, sex, age, moment of death, main pathology, death cause, manner of death and characteristics of the dying process: application or not application of LTE, accompaniment and consent autopsy. 3) Results: 5267 admissions and 283 deceased. Average GA: 34.3 weeks. GA in 73.1% of deceased patients was ≥ 32. Average weight: 2.216g. Average age at the time of death: 14 days. Congenital malformations were the most frequent cause of death 167/360; followed by complications of extreme prematurity 80/360 and severe hypoxic ischemic encephalopathy (HIE) 66/360. Most patients died after LTE: 200/283. This LTE was settled in 60.6% of the deceased with congenital malformations and in 47/52 of the deceased with HIE. The types of LTE were withdrawing life-support in 146/200, and withholding new treatments or failing to resuscitate in 54/200. Some characteristics of the accompanying process were: 94/200 patients’ families were asked if they wanted to perform some type of ceremony or ritual. In 63/200 patients pictures were taken. In 80%, parents accompanied their children in the dying process. 20% of patients die outside the NICU after being transferred to a room. Necropsy was granted in 64.7%. 4) Conclusions: The most significant groups of newborns who died during admission to NICU are: severe congenital malformations, extremely premature newborns and severe HIE. The majority died after LTE. Most patients died accompanied by their parents. It has become increasingly common to transfer these patients to a room to provide family privacy.

Ethics statement: It is a retrospective observational study based on the review of medical charts

Conflicts of interest: None

Keywords: neonatal death, limitation effort

A retrospective review of the Perinatal Palliative Care Programme at Cork University Maternity Hospital (CUMH)

C. Healy*, (1,2), A.M. Verling (3), R. Cotter (3), K. O'Donoghue (1,2,3)

(1) Cork University Maternity Hospital, (2) School of Medicine, University College Cork, (3) Pregnancy Loss Research Group and Cork University Maternity Hospital

1) Background: Perinatal Palliative Care (PPC) is a philosophy of care for women and families following antenatal diagnosis and expected delivery of a baby with a life-limiting condition. Within this environment medical science, technology, ethics, and faith intermingle in ways that affect everybody differently – there is one chance to get it right. Time parents have to spend with their baby can be brief and precious, so there must be a comprehensive yet individualised approach to care. The Health Service Executive (HSE) introduced the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death (NSBC) with the purpose of enhancing bereavement care (BC) services for families experiencing perinatal loss.

2) Methods: E-charts retrospectively reviewed against the NSBC. Data were supplemented by members of the CUMH Bereavement Specialist Team and National Implementation Team. Statistical analysis was conducted with IBM SPSS Statistics 25.

3) Results: 38 PPC referrals were received between 2017-2018. 36.8% pregnancies resulted in stillbirth, 28.9% second-trimester miscarriage and 34.2% early neonatal death. All pregnancies were cared for in dedicated rooms with the pregnancy loss symbol used and displayed clearly when appropriate. The time spent on the PPC Pathway ranged from 3-20 weeks. All points of care from the NSBC were observed to a very high standard. Some inconsistencies were noted in GP correspondence, and in the provision of written information around antenatal diagnoses. CUMH appears varied in its efforts to ensure educational staff programmes in BC are available and/or mandatory. CUMH is working on a formal policy on staff support services.

4) Conclusions: This review provides a platform for development of an audit tool for the NSBC. It is evident from this review that formalised and mandatory educational structures are needed to combat inconsistencies in staff training in BC. Comprehensive documentation by staff is also lacking and needs improving.

Ethics statement: Ethical approval was received from the Clinical Research & Ethics Committee (CREC) in June 2018 and from the South/South West Hospital Group Maternity Services – Local Information Governance Group (SSWHG-LIGG) in September 2018.

Data collection sheets were encrypted and stored on a password protected desktop computer in a locked office. Patient identifiers were anonymised and assigned unique identifying codes.

Conflicts of interest: None

Keywords: perinatal, palliative care, bereavement, pregnancy loss

Cite as: A retrospective review of the Perinatal Palliative Care Programme at Cork University Maternity Hospital (CUMH). C. Healy, A.M. Verling, R. Cotter, K. O’Donoghue. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.

*Presenting author
Supporting parents’ decision-making for autopsy consent

Fran Boyle

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Parents whose baby is stillborn face critical decisions at a time of intense grief. Among the most difficult is whether to consent to autopsy examination. Multiple barriers to perinatal autopsy consent have been identified and parents’ decisions reflect the often complex interplay of parent-, clinician- and system-level influences. Clinicians have a critical role in assisting parents to navigate decision-making but may be poorly equipped for this role. Detailed understanding of decision-making processes from both parent and clinician perspectives is needed to develop effective parent-centred decision support. A subset of data collected in an online survey completed in 2015 for The Lancet Ending Preventable Stillbirths Series was qualitatively analysed. The dataset comprised open-ended responses to items about experiences of the stillbirth autopsy consent process from 454 mothers and 638 clinicians from Australia and New Zealand. Mothers had a strong need for answers coupled with a strong desire to protect their baby. Four “decision drivers” were confirmed: preparedness for the decision; parental responsibility; possible consequences; and role of health professionals. Also highlighted was the “aftermath” of the decision: receiving the results; and decisional regret or uncertainty. Clinicians’ responses added further insights about the importance of addressing parents’ fears, respectful care of the baby, and system-level influences. A wide range of factors have potential to influence parent decisions for or against consenting to an autopsy. Creating supportive decision-making environments rests on understanding the significance of the decision to parents and the possible consequences of the decision made. Sensitive discussions with parents are required to explore their concerns and the issues most important to them.

Ethics statement: N/A

Conflicts of interest: None

Keywords: autopsy, post-mortem examination, decision-making, bereavement, stillbirth

Cite as: Supporting parents’ decision-making for autopsy consent. Fran Boyle. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 4.1 Classification, investigation and audit of perinatal death (interaction with parents) - Invited speaker

Parents engagement in the perinatal mortality review process (PARENTS Study)

Dr. Christy Burden

University of Bristol and North Bristol Trust, United Kingdom

Evidence suggests that bereaved parents had been until recently unaware that after a perinatal loss a formal review takes place, and many would welcome the opportunity to participate meaningfully in this process. Maternity units and staff had been apprehensive as to how it could and should be done. Our objective was to develop, pilot and evaluate a process to investigate whether that parental involvement in the Perinatal Mortality Review Process - PNMR was feasible, and if it would have potential to drive improvements in patient safety, and promote an open culture within healthcare. Design: Mixed-methods studies in two UK maternity units (Bristol and Manchester). Development process: Five pre-implementation focus groups were conducted with clinical staff including midwives, obstetricians, neonatologists and nursing staff. A three-round modified Delphi technique was used to reach a consensus on principles of parental involvement in the PNMR. This included a national consensus meeting workshop with stakeholders in bereavement care, and a two-stage anonymous online questionnaire. A six-month pilot of parental involvement in the PNMR followed the consensus meeting agreed principles. A focus group was undertaken with bereaved parents and healthcare professionals post implementation to investigate their perceptions of being involved in the process. Parental engagement in the PNMR is feasible and useful for parents and staff alike, including to inform discussions of causation. All UK hospitals should to give parents the option to engage with the review of their baby's death.

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, perinatal mortality review process, parents

Cite as: Parents engagement in the perinatal mortality review process (PARENTS Study). Christy Burden. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 4.1 Classification, investigation and audit of perinatal death (interaction with parents) - oral abstract communication

Maternity Healthcare chaplains and perinatal post mortem support and understanding in the United Kingdom and Ireland

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1) Background: Postmortem (PM) examination remains the gold standard in the investigation of perinatal death. Perinatal PM rates have been reducing in recent years following organ retention scandals. It is unknown what influences (if any) healthcare chaplains or religious teaching/ views have in the decision-making processes of bereaved parents as they consent to PM. Objectives: This study explores the role of healthcare chaplains in the support and decision-making of parents as part of the perinatal PM consideration process and whether religious views or teaching have a bearing on PM consent. 2) Methods: An online survey was conducted with maternity healthcare chaplains working in Ireland and the United Kingdom. Participants were contacted through professional chaplaincy organisations and networks. The data were analysed using Microsoft Excel. Free text was analysed manually. 3) Results: There were 46 respondents (n=25 UK, n=21 Ireland) with the majority representing Christian denominations (n=45), non-religious (n=2) and Islam (n=1). The majority of participants (n=42) provided care for bereaved parents following stillbirth/ neonatal death. Only a minority (n=18) had never been asked about PM by bereaved parents. However, while just over half (n=24) knew who conducted PMs in their trust/hospital, most (n= 27) did not feel adequately informed about PM to be able to offer support to parents when asked. No participants identified any religious objection to the practice of perinatal PM. 4) Conclusions: This study highlights the potentially supportive role healthcare chaplains can have in supporting parents in their decision-making surrounding perinatal PM as well as clarifying misconceptions concerning religious practice as it pertains to PM. This study identifies the need for greater training and integrated bereavement care where healthcare chaplains can play a role in the support of postmortem as ‘gold-standard’ investigative care following perinatal death.

Ethics statement: Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref No: ECM4(a) 07/03/18).
Informed consent was obtained as required entry to proceed with the online study.

Conflicts of interest: None

Keywords: perinatal postmortem, postmortem consent, chaplaincy, spiritual care,


*Presenting author
Session: Breakout 4.1 Classification, investigation and audit of perinatal death (interaction with parents) - oral abstract communication

Parents experience of the Coronial process following perinatal death

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(1) National Perinatal Epidemiology Centre, University College Cork, Ireland, (2) Pregnancy Loss Research Group, INFANT and University College Cork, Ireland, (3) School of Public Health, University College Cork, Ireland

1) Background: Of the 470 perinatal deaths in Ireland per annum, 10% will be referred to the Coroner for investigation. This may require a post-mortem examination and does not require parental consent to be proceed. In some circumstances, the investigation may be followed by an inquest. The objective of this study is to explore the experiences of parents who went through the Coronial process and to identify any support needs. 2) Methods: An interpretative phenomenological analysis was utilised as this allows for close examination of parents’ experiences. Purposive sampling was used to recruit nine parents who experienced perinatal death and whose case was referred to the Coroner. 3) Results: Almost all parents had heard of the Coroner but had never previously associated Coroners with perinatal deaths. Parents stated that they were informed their case was being referred to the Coroner. Parents were ill-prepared for the administrative procedures and bureaucratic governance of the Coroner’s Office. Although many of the parents knew these are legal proceedings, without recommendations from third parties, parents did not know to seek legal counsel and/or representation. Parents reported that the process was often adversarial and failed to meet their expectations. For most parents it took approximately two years to complete the Coronial investigation which negatively impacted parents’ health, relationships and reproductive decision-making. Parents had hoped that the inquest would provide them with the facts as parents were highly skeptical of internal hospital reviews. Interviews with parents revealed that their preference would have been for an external review however the Coroner’s investigation was the closest alternative. 4) Conclusions: Our findings illustrate the need for improved communication around investigations and reviews. In order to improve transparency and to meet parental needs, parents should be given the opportunity to be involved in stages of hospital reviews.

Ethics statement: Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref: ECM 4 (f) 07/02/17)

Conflicts of interest: None

Keywords: perinatal death, reviews, investigations, parents, qualitative


*Presenting author
**Session:** Breakout 4.2 Care provision following detection of life limiting fetal anomalies - Invited speaker

**Impacto psicológico del embarazo con diagnóstico de anomalías congénitas graves (Psychological impact of a diagnosis of severe congenital anomalies during pregnancy)**

Dr. Cecilia Mota González

*Instituto Nacional de Perinatología and Universidad Nacional Autónoma de México, Mexico*

Para la mayoría de las parejas el embarazo es un acontecimiento significativo, que plantea una serie de cambios en sus vidas, por lo que la posibilidad de que su futuro hijo padezca algún defecto congénito que limite su calidad de vida o incluso comprometa su vida, genera en los padres un desajuste emocional. Los defectos congénitos son una de las 10 principales causas de mortalidad infantil en México. En general ocasionan 3,372 muertes al año, esto representa el 10% de las muertes infantiles. Ante el diagnóstico de un embarazo con defecto congénito, es frecuente que aparezcan en las madres reacciones de incredulidad y negación del problema, seguido de la tristeza y desilusión por la imposibilidad de ver concretados sus proyectos alrededor de la maternidad/paternidad. Los sentimientos de culpa aparecen en la mayoría de ellos como resultado de la percepción de que son completamente responsables del bienestar del bebé; así mismo experimentan miedo ante la posibilidad del fallecimiento de su hijo. En muchos casos los padres deben de tomar la decisión de continuar o interrumpir su embarazo, por lo que es necesario brindarles acompañamiento emocional y apoyo psicológico. La intervención psicológica brindada a estas parejas puede dividirse en tres momentos: 1) Ante la comunicación del diagnóstico por parte del equipo médico, 2) en el transcurso del embarazo y/o ante la disyuntiva de tomar una decisión con respecto a su terminación cuando las anomalías son incompatibles con la vida, y 3) Una vez que el embarazo ha concluido y los padres se enfrentan ya sea a la muerte de su bebé o a su estancia en las Unidades de Cuidados Intensivos Neonatales. En cualquiera de los casos los padres desarrollan un proceso de duelo por la pérdida de las expectativas de gestar y parir un hijo sano y/o por la muerte de este, y es de suma importancia el trabajo de los aspectos emocionales para un mejor afrontamiento de la situación.

**Ethics statement:** N/A

**Conflicts of interest:** None

**Keywords:** embarazo de alto riesgo, anomalías congénitas, duelo perinatal.

**Cite as:** Impacto psicológico del embarazo con diagnóstico de anomalías congénitas graves. Cecilia Mota González. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 4.2 Care provision following detection of life limiting fetal anomalies - Invited speaker

Patient focused care following the detection of life limiting fetal anomalies at Hospital Sureste Madrid

Dr. Laureano Folgar

Hospital de Sureste, Madrid, Spain

Second trimester abortion of a desired baby because detection of life limiting foetal anomalies is very hard experience for the family. An integrated approach at the maternity centre with psychological support in our experience have better clinical results and also psychological. In our centre we offer to all pregnant who decided to abort after a diagnostic of malformation, the possibility to make the abortion at the hospital with the obstetric group that was following her pregnancy. Most common option in Spain, are normally send the pregnant to an outpatient abortion clinic without follow up of the process. Also, all these women have a visit with our perinatology psychiatrist to look the following actions, if it is necessary or required. In our experience this approach have a great impact in clinical results. No women have to be re-entered at the hospital for some intervention more. Before this policy, readmission was nearly 10%. The possibility to be treated by the same personal reduce the anxiety before the procedure who could be important to avoid posttraumatic stress disorder. All pregnant we offered, decide to stay at the hospital instead of go to an abortion clinic. In most cases at the interview before the hospital discharge, they remember the situation not so bad, mostly because the warm reception of the hospital personnel, what it is more than we expect in such situation.

The early psychiatric interview is the key to prevent anormal grief and later mental disorder. We could do preventives action in case we detect risk for abnormal grief and also, offer the women the opportunity to contact with us whenever they want, even if we do not detect risk at the first meeting. In few words, we consider that a multidisciplinary approach in a know place with know personnel have a lot of advantages to women how had a second trimester abortion of a desired pregnancy. In this way we consider that it mast be the standard of care.

Ethics statement: N/A

Conflicts of interest: None

Keywords: foetal malformations, abortion, grief, multidisciplinary interventions

Cite as: Patient focused care following the detection of life limiting fetal anomalies at Hospital Sureste Madrid. Laureano Folgar. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
The double grief: perinatal loss after diagnosis of birth defect

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1) Background: The impact of prenatal loss has been recognized and explored by professionals in the last 50 years, but little is known about the role of diagnosis of birth defects on parents’ grieving process. 2) Methods: Here we report preliminary results of a sub-analysis of the “Memory box survey”, conducted online among women affected by prenatal loss, who were referred to CiaoLapo charity (Italy) between 2007 and 2017. Quantitative and qualitative analysis were performed. 3) Results: The sample was comprised of 2357 women, recruited in all Italian regions (figure 1), who experienced a prenatal loss on average, 2.5 y before the interview (SD 3.2), with mean age of 32.6 years (4.9), and gestational age at loss of 25.0 weeks (10.8). Gestational weeks at loss were trimodally distributed: 8, 22, and 39. Birth defects were reported in 8.3% (195/2357) of cases, description of the specific defect was reported in 43% (84/195) of birth defect cases reported. Women who reported a birth defect were significantly more likely to have undergone an abortion (58.2% vs. 13.4%; χ²=244, p<0.001). Most women were very critical regarding care received, although women whose baby was stillborn due to a birth defect were less dissatisfied of professionals’ communication skills than other women (2.1 [0.2] vs. 1.7 [0.1]; p=0.03). No differences were observed in the Perinatal Grief Scale between women with or without a birth defect, while significant differences were reported in Despair subscale between women who aborted (for any reason) and those who did not (17.1 [7.6] vs. 15.9 [7.5]; p=0.02). When analysis was restricted to diagnosis of foetal issues, no difference was present between women who aborted and women who carried on the pregnancy. 4) Conclusions: Data from the present study also show that when a foetal malformation is diagnosed, the choice of aborting or continuing the pregnancy do not directly influence the levels of maternal grief.

Ethics statement: According to Italian regulation, for this type of studies the approval by the Ethics Committee is not required (GU n. 76 March 31, 2008); data were collected in keeping with General Data Protection Regulation of European Union (GDPR, EU 2016/679) and written informed consent was obtained from all participants.

Conflicts of interest: None

Keywords: perinatal loss, birth defects, abortion, grief


*Presenting author
Session: Breakout 4.2 Care provision following detection of life limiting fetal anomalies - oral abstract communication

Have no regrets: parents' experiences and developmental tasks in pregnancy with a lethal fetal diagnosis

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(1) St. Louis University, United States, (2) University of Rochester Medical Center, U.S.

1) Background: Lethal fetal diagnoses are made in 2% of all pregnancies. The pregnancy experience is certainly changed for the parents who choose to continue the pregnancy with a known fetal diagnosis but little is known about how the psychological and developmental processes are altered. 2) Methods: This longitudinal phenomenological study of 16 mothers and 14 fathers/partners sought to learn the experiences and developmental needs of parents who continue their pregnancy despite the lethal diagnosis. The study was guided by Merleau-Ponty's philosophic view of embodiment. Interviews (N=90) were conducted with mothers and fathers over time, from mid-pregnancy until 2 to 3 months post birth. Data analysis was iterative, through a minimum of two cycles of coding, theme identification, within- and cross-case analysis, and the writing of results. 3) Results: Despite individual differences, parents were quite consistent in sharing that their overall goal was to “Have no regrets” when all was said and done. Five stages of pregnancy were identified: Pre-diagnosis, Learning Diagnosis, Living with Diagnosis, Birth & Death, and Post Death. Developmental tasks of pregnancy that emerged were 1) Navigating Relationships, 2) Comprehending Implication of the Condition, 3) Revising Goals of Pregnancy, 4) Making the Most of Time with Baby, 5) Preparing for Birth and Inevitable Death, 6) Advocating for Baby with Integrity, and 7) Adjusting to Life in Absence of Baby. Prognostic certainty was found to be highly influential in parents' progression through developmental tasks. 4) Conclusions: The framework of parents' pregnancy experiences with lethal fetal diagnosis that emerged can serve as a useful guide for providers who care for families, especially in perinatal palliative care. Providing patient-centered care that is matched to the stage and developmental tasks of these families may lead to improved care and greater parent satisfaction.

Ethics statement: Institutional Review Board approval was obtained from all institutions. Informed consent was obtained from each participant through review of consent form, continual checking in with participants to insure continued desire to participate. Participants in any distress were spoken to calmly, with a change of topics away from emotional ones before interview was ended. IRB Number 12-0123 at University of North Carolina Greensboro.

Conflicts of interest: None

Keywords: phenomenology, longitudinal, prenatal diagnosis, pregnancy, developmental task


*Presenting author
Session: Breakout 4.3 Woman-centred birth planning and management following intrauterine death or cases of perinatal palliative care - Invited speaker

Medical decision-making and sensitive care in labor and delivery after diagnosis of intrauterine death

Dr. Katherine Gold

University of Michigan and International Stillbirth Alliance, United States

Labor and delivery in the setting of stillbirth require sensitive care to address unique medical and emotional needs of families. Multiple decisions surrounding labor and delivery arise after the diagnosis of an intrauterine demise. Decisions include how long to wait prior to induction or labor and whether to recommend vaginal or cesarean delivery. Options for induction and pain management may differ somewhat from usual delivery and clinicians should be aware of the impact of sedation on patient experience. Stillbirth deliveries are associated with specific medical risks which are less common in full-term, live-birth deliveries and must be anticipated for safety purposes. In addition, medical decision-making should be collaborative with the family when possible and based on research about what is helpful and harmful for families. The emotional aspects of grief and bereavement permeate the labor process and clinicians must be attentive to cues. Finally, caring for a bereaved family and delivering a stillborn infant impacts both experienced clinicians and new trainees and it is important to acknowledge this impact. Labor and delivery after the diagnosis of an intrauterine fetal demise involves some unique medical risks, and decisions about care should consider both evidence-based research and parental preference.

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, IUFD, labor and delivery, medical complications, bereavement

Cite as: Medical decision-making and sensitive care in labor and delivery after diagnosis of intrauterine death. Katherine Gold. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Session: Breakout 4.3 Woman-centred birth planning and management following intrauterine death or cases of perinatal palliative care - Invited speaker

Experiences of labour following diagnosis of intrauterine death

Paloma Martínez-Serrano

Unidad Docente de Matronas de la Comunidad de Madrid; Research Group in Nursing and Health Care and Puerta de Hierro-Segovia de Arana Health Research Institute, Madrid Spain

Intrauterine death has a devastating impact on parents. Experience of labour and the relationship with health professionals has a significant influence on mourning process. Greater knowledge of parents’ experience allow quality care to be planned with the aim of facilitating the initation and subsequent evolution of healthy mourning. Our research team performed a narrative review of the literature. Due to the fact that there is poor evidence in our environment, a qualitative research about the experiences of mothers and fathers following diagnosis of intrauterine death was conducted. Our findings on feelings and experiences described by parents in Spain are similar to those found in other countries. However, despite the growing interest in caring these parents, and the important initiatives carried out, the adequacy of care is still deficient in our environment. Four main categories emerged from in-depth interviews about parent’s experiences: denial of grief, ambivalence, guilt, going through and overcoming the loss. The parents stated a lack of recognition of their loss and their parenthood. Although the midwife was the highest valued professional, they referred to insufficiencies related to the care received, the management of information, communication and accompaniment on the part of healthcare professionals. This produced a negative experience which complicated the process of mourning and overcoming the loss. It is necessary to promote social recognition of these losses and train healthcare professionals in the accompaniment of this type of mourning. In this aspect, relevant issues are to acquire communication skills and develop a care model focussed in decision-making. Processes, such as the diagnosis, labour management, subsequent follow-up of the mourning and future pregnancies, should be standardized in order to avoid cares that not facilitating the initiation and evolution of healthy mourning.

Ethics statement: N/A

Conflicts of interest: None

Keywords: stillbirth, bereavement, parents, nursing care, midwifery.

Cite as: Experiences of labour following diagnosis of intrauterine death. Paloma Martínez-Serrano. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Obstetric violence during reproductive loss and perinatal bereavement care

Dr. Karina Romo

Innovia Foundation, Mexico

For more than a decade, the term Obstetric Violence has been used to describe a form of violence against women during maternal and perinatal healthcare. This form of violence manifests itself through acts and omissions that threaten women's physical and psychological integrity, including abuse, disrespect, over-medicalization and pathologization of physiological processes, as well as reducing women's capacity to make free informed choices in the course of their medical care. Despite growing interest in the topic, Obstetric Violence has scarcely been studied in the specific context of perinatal death and reproductive loss. Even though any form of obstetric violence is inadmissible, in these particular cases it aggravates an already traumatic, (perhaps devastating) experience. In this talk, I will address the origins and conceptual model of Obstetric Violence. Departing from three key themes: access to healthcare, evidence-based practice, and 'bedside manners' I will elaborate on the ways in which obstetric violence is exerted in the particular case of perinatal death. Drawing on women's personal accounts, I will delve into the impact of this form of abuse on women's lived experiences. Making Obstetric Violence more visible is the first step towards encouraging further research and crafting strategies to eradicate these abusive practices, and to ensure women's access to the respectful, compassionate care that they need at a time of extreme vulnerability.

Ethics statement: N/A

Conflicts of interest: None

Keywords: obstetric violence, pregnancy loss, perinatal bereavement care

Session: Breakout 4.4 Puerperal care (lactation suppression, milk donation) - Invited speaker

Breast milk donation following perinatal bereavement in Spain: challenges and barriers.

Dr. Nadia Raquel García Lara

Hospital Universitario 12 de Octubre and Asociación Española de Bancos de Leche Humana, Spain

Milk leakage and breast engorgement is a painful reminder of the loss after a perinatal loss. Many mothers may need lactation guidance after losing their child. Previous experience with milk donors following a perinatal loss show an important positive impact in their grief process. Bereaved mothers are an emerging subgroup of donors to milk Banks in United States and United Kingdom. In Spain, Human Milk Bank experience is short. We will go through Spanish Milk Banks experience with milk donors after a perinatal loss. The awareness of potential benefits of breastmilk donation after a perinatal loss has recently taken to The Spanish Human Milk Bank Association to develop a consensus guideline regarding this issue. Both milk donation following a stillbirth or in case the infant dead was after birth are encouraged. Firstly, this guide aims to help mothers with her options in lactation during bereavement (to do nothing about her lactation, to suppress their milk supply, who wishes to express her milk and/or who is interested in milk donation). In case of a mother is interested in milk donation we guide and support her in this process.

Ethics statement: N/A

Conflicts of interest: None

Keywords: lactation, breast milk donation, perinatal loss, human milk bank, Spain

Session: Breakout 4.4 Puerperal care (lactation suppression, milk donation) - Invited speaker

Lola’s journey: lactogenesis management after a perinatal loss, the development of Proyecto Lola

J. Vázquez-Dodero Fontes* (1), F. Vera-Constán (2,3), A. Rivas Molina (2)

(1) Proyecto Lola, (2) Asociación de Psicología Perinatal Murcia, (3) University of Murcia, (3) Asociación de Psicología Perinatal Murcia, Spain

Women who had a perinatal loss also need to manage their lactogenesis II (milk secretion). The Asociación Psicología Perinatal de Murcia has lead the creation of Project LOLA: breast milk donation after a perinatal loss. The main aim of the project is to support women to be able to make their own decisions, not just to follow hospital’s guidelines without any questioning. This project starts with a personal experience of one mother. After she decided not to follow the recommended treatment for lactation suppression (i.e. cabergoline), together with the “Asociación de Psicología Perinatal Murcia” she look into how to donate her breast milk. Thanks to the Hospital Santa Lucía in Cartagena, that cooperates with the Hospital Virgen de las Nieves in Granada, she was finally able to donate her breastmilk and Project LOLA was born. The main goal of Project LOLA is to boost knowledge about the variety of options that a woman can choose in lactation management. Target population it is not just women in general but also health professionals. Lactation management options include the medical treatment for lactation suppression, donation to milk banks, and any other ritual to overcome their own personal grief. Project LOLA is still growing. To spread the information about it, we have created resources such as a Facebook page to share experiences, information brochures, seminar talks, and a documentary about the experience (trailer already available in YouTube). Furthermore, we also work to crate more awareness amongst milk banks about the needs of donor mothers. Having good information to make personal decisions about lactation after a perinatal loss has psychological and physiological benefits for women. Lactation suppression following their own decisions may help the grief progression in a more natural and personal way: farewell of the lost baby, adaptation to the idea of “mother of a deceased baby”, physiological recuperation, altruism.

Ethics statement: No ethics approval required.

Conflicts of interest: None

Keywords: lactogenesis, breast milk donation, grief, perinatal

Cite as: Lola’s journey: lactogenesis management after a perinatal loss, the development of Proyecto Lola. J. Vázquez-Dodero Fontes, F. Vera-Constán, A. Rivas Molina. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.

*Presenting author
Lactation after loss: supporting women’s decision-making following perinatal death

Joanne Dickens

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Perinatal death (defined here as stillbirths and neonatal deaths) affected nearly 6 out of every 1000 births in the UK in 2016. These tragic outcomes have profound, enduring effects on women and their families that extend to broad aspects of their psychological and psycho-social wellbeing. Offering sensitive and compassionate clinical and bereavement care is the innate focus of the caring healthcare professional following perinatal loss. However, support and the facilitation of informed choice around the subject of lactation following loss is an area that may be disregarded or shied away from, resulting in physical effects for bereaved women such as breast engorgement, pain and mastitis and the additional psychological distress of dealing with such symptoms alongside the grief for their baby. The lack of advice and support offered to bereaved lactating mothers may be attributed to a healthcare professional’s lack of confidence and the scarcity of guidance and publications regarding lactation considerations following perinatal death. Professionals are likely to benefit from training and research in order to increase their knowledge and understanding of the physiology of lactation during pregnancy and involution following loss; as well as the implications of this for different types of perinatal death. An understanding of the range of individual and enduring emotional responses to grief and lactation may also be valuable; informing the facilitation of personalised lactation choices such as non-pharmacological and pharmacological methods of suppression alongside options such as expression either for donation or personal and comfort reasons. Bereaved mothers need sufficient and sensitive information and support for choices regarding lactation following the death of their baby to reduce the additional burden of distress caused where this is lacking. Further research, guidance and training for healthcare professionals is warranted.

Ethics statement: N/A

Conflicts of interest: None

Keywords: perinatal death, lactation, bereavement, grief, informed choice

POSTER PRESENTATIONS
RISK FACTORS
Analysis of the causes of fetal death in a high risk population in the National Institute of Perinatology, Mexico City


(1) Genetics and Genomics; (2) Pathology; (3) Immunobiochemical; (4) Obstetrics; (5) Clinical investigation; (6) General Director.
Instituto Nacional de Perinatología, Mexico City.

1) Background: The National Institute of Perinatology (INPer) is a third-level hospital in Mexico City which attends high risk pregnancies. The number of fetal deaths during 2016, 2017 and 2018 was 3.2%, 2.7% and 1.9%, respectively. The purpose of this study was to determine the causes of fetal death using the ICD-PM classification system from 22 weeks of gestation in a period from January 2016 to October 2018.

2) Methods: All stillbirths were examined by a pathologist and a medical geneticist. Stillbirth was defined as a fetal death occurring after 22 weeks of gestation. A complete maternal clinical history was performed. At birth, gestational age, birth weight and length, presence of congenital anomalies, macroscopic and microscopic findings in the placenta, autopsy, and cytogenetics studies were recorded.

3) Results: During the study period, 297 babies presented with fetal death of which 55.2% were antepartum and 44.8% intrapartum. Antepartum deaths presented more frequently at two gestational ages: 24 to 27 weeks and from 32 to 36 weeks. The majority of antepartum deaths were A1M5: Congenital abnormalities with no maternal condition and A3M4: Antepartum hypoxia and maternal medical and surgical conditions. 78.7% of intrapartum deaths presented from 22 to 27 weeks of gestation. The most common causes were I3M1: Acute intrapartum event and complications of placenta, cord and membranes and I3M2: Acute intrapartum event and maternal complications of pregnancy.

4) Conclusions: Fetal and maternal diseases are the most common cause of antepartum death. Intrapartum deaths are most commonly due to prematurity because of obstetrical complications of pregnancy.

Ethics statement: All patients gave their consent to participate in the study.

Conflicts of interest: None


Keywords: fetal death, analysis of causes

Prevalence of thrombophilia in patients with a stillbirth

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Obstetrics and Gynecology Service, Hospital Universitario “12 de Octubre”


2) Methods: Descriptive study. Main variable: Prevalence of thrombophilia in patients with fetal loss >16 GW Secondary variables: demographic data (BMI, age), smoking status, obstetric history (OH), anatomopathological (AP) findings of fetus and placenta, other pregnancy outcomes related to thrombophilia.

3) Results: Prevalence of thrombophilia: 13.16% (n=32). Most frequent thrombophilia: Protein S deficiency (4.93%, n=12). Mean BMI: 26 (19-41, CI 95%), Mean age: 35 y.o.(29-41, CI 95%). Smoking status: 21.9% (n=7) were smokers. OH: previous stillbirth (3.12%, n=1), recurrent miscarriages (3.12%, n=1). AP findings: placental infarction (31.25%, n=10), umbilical cord thrombosis (6.25%, n=2). Other pregnancy outcomes: RCIU (9.4%, n=3), abruptio placentae (6.25%, n=2).

4) Conclusions: The most common thrombophilia in our patients is protein S deficiency, which also has a higher than expected prevalence. We found no differences in the prevalence of the rest of thrombophilias when compared to general population. In those cases where thrombophilia was identified, it was difficult to establish whether it was a determining factor for stillbirth. Some AP findings like placental infarction or umbilical cord thrombosis, in the absence of other potential underlying causes, may support that thrombophilia played a major role. Our data does not support the need to investigate, in a systematic manner, the presence of thrombophilia in patients with unexplained stillbirth. However, we do consider studying those patients with AP findings which could suggest the presence of a thrombophilia. There is still the need for larger, well designed studies, in order to clarify if there are any subgroups of patients which may benefit from diagnosis and treatment of a potential underlying thrombophilia.

Ethics statement: Patient data has been collected from database used during patient consultations of our perinatal mortality outpatient clinic. This data is stored and only the main authors have the right to access to personal data to ensure subject safety. No personal data has been used to write this retrospective descriptive study, therefore no ethical approval (further than Heads of Service) has been required. The authors declare no conflict of interest.

Conflicts of interest: None


Keywords: thrombophilia, stillbirth, prevalence, causal relation

Study of the determinants of stillbirth at the Sélingué Reference Health Center from January 1st, 2015 to December 31st, 2017

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(1) Directorate General of Health and Public Hygiene; (2) National Institute of Training in Health Sciences; (3) Reference Health Center of Commune I; (4) Department of Obstetrics and Gynecology at the University Hospital Center Point G; (5) Sélingué Reference Health Center; (6) Pediatric Department of the Gabriel TOURE University Hospital Center; (7) Department of Teaching and Research in Public Health London School of Hygiene & Tropical Medicine.

1) Background: Stillbirth is a major public health problem in the African regions south of the Sahara and in Mali. About 2.6 million newborn babies were still counted in 2015 worldwide, about 7,200 stillbirths a day. According to the data of the Local Health Information System over a period from 2008 to 2016 the health district of Sélingué had the highest rate of stillbirth in the Sikasso region (51.7 per 1000 births). This prompted us to conduct this study whose general objective was to study the determinants of stillbirth among parturients at the Sélingué Reference Health Center (CSRéf) from January 1st, 2015 to December 31st, 2017. 2) Methods: This was a retrospective case-control study involving 440 files, including 110 cases and 330 controls. Data entry was done on Epi7, analysis on SPSS version 20 and writing on the Word. 3) Results: Bivariate analysis showed a statistically significant association between stillbirth and the following factors: primiparity [OR = 2.30 95% CI (1.16, 4.51), p = 0.01], transport by motorcycle [OR = 1.95, 95% CI (1.15, 3.31), p = 0.013], admission modes by other evacuation [OR = 3.35, 95% CI = (1.68, 6.65), p = 0.001] and self-reference [OR = 6.18 95% CI (3.07, 12.41), p = 0.000], prenatal consultation CPN [OR = 2.75 95% CI (1.69, 4.46), p = 0.000] and cord prolapse [OR = 12.86, 95% CI (2.7, 61.5), p = 0.001] and cord prolapse [OR = 12.86, 95% CI (2.7, 61.5), p = 0.001]. Multivariate analysis used as risk factors for stillbirth the non-achievement of ANC [OR = 3.05 95% CI (1.77, 5.26), p = 0.000], non-evacuation by ambulance [OR = 6.59 95% CI (2.96, 14.66), p = 0.000], those that are not self-referred [OR = 6.12 95% CI (2.19, 12.90), p = 0.000]. Ambulance evacuation was a protective factor [OR = 0.25 95% CI (0.18, 0.53), p = 0.000]. Finally cord prolapse [OR = 13.01 95% CI (2.41, 70.22), p = 0.003]. 4) Conclusions: These results once again demonstrate the importance of prevention with a focus on strengthening NPC and improving evacuation conditions.

Ethics statement:

Conflicts of interest: None


Keywords: stillbirth, stillbirth, determinants, OR

Investigation of lifestyle and social determinants associated with stillbirth in South Australia

A. Bowman (1-4), T. Sullivan (1-3), M. Makrides (1-4), V. Flenady (2,5), P. Middleton (1-4)

(1) South Australian Health and Medical Research Institute; (2) Stillbirth Centre of Research Excellence; (3) University of Adelaide; (4) Targeted Nutrition for Mother and Child Centre of Research Excellence; (5) Mater Research

1) Background: Stillbirth is a tragedy that affects six families a day in Australia and although many high income countries around the world have reduced their stillbirth rates, in Australia they have remained unchanged for two decades. In 2016, Australia recorded its highest rate of maternal obesity during pregnancy, and the inequality and disparity between social groups within communities is also at its peak. In South Australia (SA) this variety of factors is reviewed at a state-wide level to establish prevalence and geographical location of factors.

2) Methods: All births to women in South Australia were included in the study, for the period 1998 to 2016. The primary outcome of interest, stillbirth, is defined as a birth with no signs of life ≥20 weeks GA or ≥400g birthweight. The primary outcome was association between lifestyle, environmental and social determinant factors and stillbirth risk. 3) Results: We examined 363,959 births in South Australia during the study period. Included in this data are 362,184 livebirths and 1,775 stillbirths. We examined the association between multiple lifestyle and environmental factors and stillbirths examining the relative distribution as well as association through multivariable logistic regression. Stillbirths were seen to have a peak density at maternal age 28, but were also seen to have distribution peaks at ages 18-21 years and >35 years. Smokers during pregnancy were shown to experience nearly twice the stillbirth rates compared to women who don’t smoke, or who quit smoking before their first antenatal visit.

4) Conclusions: The results of this research provide findings about risk factors and their role in stillbirth specific to South Australia. In high income countries, such as Australia, where stillbirth rates have stagnated, and ongoing preventable stillbirths occur, this research forms the foundation for further investigation into causal relationships of combined lifestyle, environment and social determinants factors and stillbirth.

Ethics statement: Ethics has been approved by the Department of Health and Aging HREC and the Aboriginal human research ethics committee.

Conflicts of interest: None


Keywords: stillbirth risk, antenatal, obstetrics, lifestyle, environment, geographic risk

Lifestyle, environmental and sociodemographic factors: the impact on stillbirth risk

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(1) South Australian Health and Medical Research Institute; (2) Stillbirth Centre of Research Excellence; (3) University of Adelaide; (4) Targeted Nutrition for Mother and Child Centre of Research Excellence; (5) Mater Research

1) Background: The stillbirth rate in Australia has remained stagnant at 7.4/1000 births for over two decades. Stillbirth causes far-reaching devastation and grief for families, communities, health carers, and has extensive economic impacts. We aim to expand on a 2011 systematic review of stillbirth risk by identifying and updating evidence on lifestyle and environmental risk factors while including evidence on social determinants of stillbirth in high-income countries.

2) Methods: Databases were searched for studies examining risk factors of interest published between 1998-2018. Population/institutional cohort and case control studies were selected for inclusion. Reviews were hand-searched for studies of interest. Identified studies were screened by 2 reviewers and quality assessed using the RTI tool of assessment for observational studies.

3) Results: Of 65,784 search results, 412 studies were included with 32 factors of interest were identified. Results demonstrate high awareness and publication of factors such as maternal age, smoking and maternal ethnicity, yet many publications differed in their exposure measure method, as well as their stillbirth definitions. A meta-analysis for smoking as a dichotomous value included 74,975,484 pregnancies in 38 studies, the aOR was found to be 1.48 (1.36-1.60), but with high heterogeneity subgroup analysis is warranted due to large difference in populations and clinical settings.

4) Conclusions: The results of this research provide understanding of the combined impact that lifestyle and social determinants have on stillbirth risk in high income countries. Although a universal definition of stillbirth has been advised previously, there continues to be large variation in definitions used causing high heterogeneity between studies as mentioned in the 2011 Lancet systematic review. The variation between population characteristics and clinical settings could explain this result in comparing data from multiple high income countries. Results of this research will form the evidence base for tailoring antenatal care bundles to decrease stillbirth risk.

Ethics statement: Ethics approval was not sought for the conduct of this systematic review and meta-analysis

Conflicts of interest: None


Keywords: stillbirth risk, systematic review, antenatal, obstetrics, lifestyle, environment

A systematic review and meta-analysis of risk factors for and outcomes associated with reduced fetal movements in pregnancy

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1) Background: A systematic review was conducted to synthesis the evidence on risk factors for and outcomes associated with RFM in pregnancy to determine significant associations and where possible to inform practice change.

2) Methods: PubMed, EMBASE, CINAHL, Maternity and Infant Care, PsycINFO, and Science Citation Index (23rd March 2018) with no filters was searched. Non-randomised studies reporting on pregnant women with at least one episode of RFM ≥ 24 weeks gestation were included. For comparator analyses, data for women without RFM were also included. Studies were independently screened, selected and data extracted by two review authors. Risk of bias was assessed using the Quality in Prognosis Studies (QUIPS) tool. 3) Results: 34 studies met the inclusion criteria. 13 risk factors were identified, 5 were found to be predictive of RFM in pregnancy: ethnicity (OR 2.59, 95%CI 2.40-2.80, 2 studies, 5365 participants, I²=0%), anterior placenta (OR 1.31, 95%CI 1.11-1.55, 3 studies, 6852 participants, I²=0%), smoking (OR 1.18, 95%CI 1.02-1.35, 5 studies, 29557 participants, I²=4%), oligohydramnios (OR 4.04, 95%CI 3.29-4.97, 3 studies, 39407 participants, I²=0%) and polyhydramnios (OR 2.01, 95% CI 1.44-2.81, 4 studies, 39487 participants, I²=28%). RFM was found to be associated with stillbirth (OR 5.23, 95%CI 2.49-10.98, 15 studies, 95,829, I=81%) and small for gestational age (SGA) (OR 1.82, 95% CI 1.61-2.05, 12 studies, 37,251 participants, I=41%). Women with RFM in pregnancy were also more likely to have induction of labour, instrumental birth and emergency caesarean section. 4) Conclusions: Early identification by healthcare professionals of modifiable and non-modifiable risk factors, can contribute to improvements in clinical management and care of women with reduced or absent movements during pregnancy, possibly leading to prevention and reduction of adverse pregnancy, birth, fetal and neonatal outcomes.

Ethics statement: No ethics approval required.

Conflicts of interest: None


Keywords: reduced fetal movements, risk factors, perinatal outcomes, systematic review

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Does fetal autopsy contribute to indication of fetal death in Sao Paulo, Brazil?

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1) Background: Sao Paulo City is the richest area in Brazil, with 12.1 million inhabitants. Antepartum fetal deaths are predominant (90%). Many hospitals consider these deaths as potential ill-defined causes of death and refer them to autopsy at the Death Verification Service (DVS). The objective of this study is to evaluate the causes of Death Certificates (DC) filled out by hospitals and DVS.

2) Methods: It was employed the data from fetal deaths of 22 weeks and more recorded in the Mortality Information System issued by hospitals and DVS, from 2008 to 2015. The 10th International Classification of Diseases and Related Health Problems were used (ICD-10).

3) Results: The fetal mortality rate was 8.8 per thousand births in this period and 10,606 fetal deaths were studied, of which 86.8% were certified by DVS and 13.2% by hospitals. The main underlying cause of death issued by hospitals was Fetus Affected by Maternal Hypertensive Disorders (P000) (17.3%), followed by Fetus Affected by Other and Unspecified Morphological and Functional Abnormalities of Placenta (P022) (12.6%) and the third Fetus Affected by Other Forms of Placental Separation and Hemorrhage (P021) (11.8%). The DC issued by DVS the main underlying cause was Fetal Death of Unspecified Cause (P95) (45.6%), followed by Intrauterine Hypoxia, Unspecified (P209) (23.8%) and Intrauterine Hypoxia First Noted before Onset of Labour (P200) (17.1%). This result is paradoxical, since the main underlying causes of DC issued by DVS after autopsy are nonspecific (69%), contrary to what was observed in hospitals. This is due to two factors: a) the placenta is not sent with the fetus for autopsy, b) no information on the prenatal and delivery care is sent to DVS, making it difficult to indicate the basic cause of death.

4) Conclusions: The autopsy did not contribute to a better indication of the basic cause of fetal death. It is necessary to invest in information flow management framework to improve the indication of causes of death.

Ethics statement: The study does not require the approval of the Committee on Ethics in Research with Human Beings because it is a public information obtained through the computerized department of the Brazilian National Health System (DATASUS) at the electronic address http://datasus.saude.gov.br/

Conflicts of interest: None


Keywords: fetal mortality, stillbirth, cause of death, delivery of health care

Modifiable risk factors for stillbirth: a literature review

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1) Background: Stillbirth is defined in Ireland as an infant born weighing 500 grammes and/or at 24 weeks gestation who shows no signs of life. Having a stillborn baby has a wide range of individual and societal consequences. The aim of this work was to review the literature on risk factors that have a behavioural component. 2) Methods: To conduct this review, the most relevant studies in the research area of risk factors for stillbirth were selected. The first step was an exploratory literature review including all risk factors, once this work was completed, a focused literature review on modifiable risk factors was conducted. 3) Results: Evidence from this literature review found that supports that maternal modifiable behaviours have an impact on the risk of stillbirth. Attendance at antenatal care visits allows healthcare practitioners to monitor pregnancies, detect potential risk factors and diagnose pregnancy complications. The findings from this literature review suggest that smoking and illicit drug use may have the highest impact (OR 1.44 95%CI 1.20 to 1.73 and OR 1.94 95%CI 1.16 to 3.27 respectively) yet there is consensus in the literature that more clinical trials are needed to establish the safety of medical drug use during pregnancy. Maternal weight also needs to be taken into consideration when planning a pregnancy since it is not only an independent risk factor, but it can also lead to other risks such as gestational hypertension or diabetes. With regard to maternal sleeping habits, avoiding left-side sleeping might be a simple measure to reduce stillbirth risk (aOR left side 1.00, right side 2.54 95%CI 1.04 – 3.01, back 2.54, 95%CI 1.28 – 4.19), being possibly the most easily modifiable behaviour included in this review. 4) Conclusions: All these behaviours can be addressed through antenatal interventions. More research is needed to establish interventions targeting these behaviours as preventive measures to reduce the risk of adverse outcomes such as stillbirth.

Ethics statement: No ethics approval required.

Conflicts of interest: None

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Keywords: stillbirth, risk factors, health behavior

Risk factors for antepartum and intrapartum stillbirth at 20-23 weeks gestation


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1) Background: Half of stillbirths (20+ weeks gestation) in Western Australia (WA) occur at 20-23 weeks. However, there is a lack of research identifying risk factors. We sought to identify factors that predict antepartum and intrapartum stillbirth at 20-23 weeks using the broad range of linked data available from the WA Data Linkage System. 2) Methods: In this population-based cohort study of singleton births, we analysed de-identified linked data from core health datasets. Data on intrapartum stillbirths were available for 2005-2015 and antepartum stillbirths for 2011-2015. Intrapartum stillbirths were classified as occurring after spontaneous labour onset with intact membranes (SPON), spontaneous rupture of membranes prior to labour (PROM), or medically indicated (MI) where labour was induced or caesarean section occurred prior to labour or PROM (the SPON and PROM groups excluded, and the MI group included, cases with birth defects and/or medical terminations). Logistic regression was used to calculate the odds (OR) of antepartum and intrapartum (SPON, PROM, MI) stillbirth associated with each risk factor in comparison with SPON term livebirths (the preferred outcome). 3) Results: Complete sets of data were available for 623 singleton stillbirths including 112 (18%) antepartum, 81 (13%) SPON, 77 (12%) PROM, and 353 (57%) MI (including 310 medical terminations). While univariate and multivariate analyses identified common risk factors (e.g., extremely small for gestational age baby, threatened miscarriage) across stillbirth types, there appeared to be differences. For example, living in the most disadvantaged socio-economic quintile was a significant risk factor for antepartum (OR=2.0, 95% CI=1.1,3.7) and PROM (OR=2.4, 95% CI=1.0,5.6) stillbirth but not for SPON or MI stillbirth. 4) Conclusions: Research into the factors that predict stillbirth at 20-23 weeks is of great importance to bereaved parents and can help guide prevention efforts.

Ethics statement: This research was granted ethics approval by the Western Australian Department of Health Human Research Ethics Committee (#2011/64) and the Western Australian Aboriginal Health Ethics Committee (#613). These ethical approvals support a waiver of consent on the basis that the study: (1) utilises routinely collected information from existing administrative datasets (and, accordingly, does not include active participants), and (2) only has access to de-identified data, which are stored, analysed and disseminated according to strict protocols.

Conflicts of interest: None


Keywords: stillbirth, risk factors, prevention

Umbilical cord characteristics and their association with adverse pregnancy outcomes: a systematic review and meta-analysis

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1) Background: Current data on the role of umbilical cord complications are conflicting, estimates of the proportion of stillbirths due to cord accidents range from 3.4 to 10.1%. Various abnormalities including true knots, cord entanglements, and abnormal coiling of the cord may be associated with stillbirth. We have undertaken a systematic review to determine which cord abnormalities are associated with stillbirth, and identify sources of variation between studies.

2) Methods: Literature searches were performed in MEDLINE, EMBASE, CINAHL, and Google Scholar. Studies were included if they reported singleton pregnancies after 20 weeks’ gestation with no congenital abnormalities. Cohort or cross-sectional studies were included if they reported the frequency of umbilical cord characteristics or cord abnormalities and their relationship to stillbirth.

3) Results: 271 full text papers were identified after screening according to our inclusion and exclusion criteria. Of these, 23 contained usable data on the relation between cord abnormalities and stillbirth. Nuchal cords were present in 21% of deliveries and there was no evidence of an association with stillbirth when data were pooled (odds ratio (OR) 1.36, 95% confidence interval (CI) 0.72, 2.58, 42,866 pregnancies from 13 studies). Comparing multiple loops of nuchal cord (present in 4% of births) to single or no loops gave an OR of 2.36 (95% CI 0.99, 5.62, 6 studies). We were not able to look at the effect of tight or loose nuchal loops. The likelihood of stillbirth with a true cord knot found after birth was significantly higher than in those without (OR 3.96, 95% CI 1.85, 8.47, 911,814 pregnancies from 7 studies). Stillbirth was also increased in hypercoiled umbilical cords compared to normal (OR 4.62, 95% CI 2.44, 8.75, 2346 pregnancies from 3 studies).

4) Conclusions: Stillbirth is associated with cords with true knots and hypercoiled cords at delivery, the incidence of stillbirth is higher with multiple nuchal loops.

Ethics statement: Ethics approval not required

Conflicts of interest: None


Keywords: cord accidents, nuchal cord, stillbirth, umbilical cord

Adolescent pregnancy in Mexico and stillbirths 1997-2017

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1) Background: Adolescent pregnancy (AP) occurs in women aged 10 to 19 years old. Each year, around 21 million AP occurs. It is linked to adverse outcomes for the baby and is the leading cause of death among 15 to 19 year-old girls globally(1). Near 95% of AP occur in the developing world(2). Mexico is ranked first in AP among the member countries of the Organization for Economic Co-operation and Development (OECD)(3). From 2010-2017 the average of births of adolescent mothers accounted 18.74% of total births(4). In 2016 the adolescent fertility rate (births per 1,000 women ages 15-19) was 61.4(5). Stillbirths and deaths in the first week of life are 50% higher among babies born to mothers younger than 20 years than among babies born to mothers 20–29 years old(6). Stillbirth is defined by the International classification of diseases (ICD) as death prior to the complete expulsion or extraction from its mother of a product of conception with a birthweight ≥500g or ≥22 completed weeks of gestation or body length ≥25cm(7). The objective was to determine the number of stillbirths in adolescent pregnancies in Mexico from 1997-2017. 2) Methods: A descriptive and retrospective study was conducted with the data base from the National Institute of Statistics and Geography from 1997-2017. The variables described were maternal age, weeks of gestation and the years. The results of the quantitative variables were expressed as rates. 3) Results: In a 10 year period 383,096 stillbirths were registered in Mexico, 61,795 (16.13%) were from AP. The number of stillbirths decreased 35.18% from 1997 (22,476) to 2017 (14,567). The stillbirths from AP decreased 27.15% from 1997 (3,539) to 2017 (2,578). The rate of stillbirths of AP has increased from 15.75% in 1997 to 17.7% in 2017. 4) Conclusions: The rate of stillbirths of AP has increased due to a great reduction in total stillbirths but a lower one in stillbirths from AP. In order to reduce stillbirths, Mexican health and social programs must continue and reinforced focusing on the prevention of adolescent pregnancies.

Ethics statement: Ethics approval not required

Conflicts of interest: None


Keywords: adolescent pregnancy, stillbirth, Mexico

Using the 3-delays framework to prevent stillbirth: a mixed-methods study in Tanzania and Zambia

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1) Background: The Lancet Stillbirth Series highlighted the need for further research in LMICs to ensure that women and newborns receive appropriate care. However, effective intervention studies are likely to be multifaceted and challenging. The three-delays model has been proposed as a framework for understanding the complexities related to inadequate intrapartum care. Although predominantly used when researching maternal mortality, this model has the potential to support preventative interventions for stillbirth. Aim: To gain understanding of the complexities surrounding delays in effective intrapartum care in Tanzania and Zambia and to use this knowledge to develop and implement appropriate interventions to reduce stillbirths. 2) Methods: This study, guided by pragmatism, took place in rural and urban facilities in Tanzania and Zambia. A convergent parallel design was adopted, including data collected by, a retrospective case note review (n=2000), in-depth interviews (n=166) and non-participant observations (n=36). Quantitative data was analysed using descriptive statistics and multiple logistic regression. Qualitative analysis followed grounded theory principles. 3) Results: In the study period, included facilities reported stillbirth rates of 163/1000 in Tanzania and 102/1000 in Zambia. Defined delays (OR 1.69, 95%CI 1.06 to 2.76) and intrapartum transfer (OR 3.55, 95%CI 2.14 to 5.91) were identified as important joint predictors of stillbirth. The qualitative data offered multiple reasons for the 3 delays, including traditional beliefs, cultural constraints, lack of resources, seasonality, community constraints, fear of revealing HIV status and disrespectful care. 4) Conclusions: In Sub-Saharan Africa stillbirth rates are unacceptably high, prevention is reliant on women receiving timely care. Using the 3-delays model is a useful way of exploring modifiable factors and intervention trigger points when designing further research and planning future care strategies.

Ethics statement: Ethical approval for this study was obtained from University of Manchester (UREC 2018-4446-6653), The Catholic University of Health Sciences, Tanzania (CREC/287/2018) and the Independent Research Board (IRB), Zambia (2018-Jun-029). For the qualitative element parent participants were identified and approached via clinical teams, for consent for contact by the research team. Following, verbal and written explanations and time to consider, written (or thumb print) consent was obtained. Interviews were conducted at a venue of participants choice with pseudonyms used to protect identity. A study-specific distress policy was adhered to at all times. All data were managed securely and adhered to GDP regulations. Funding: NIHR Global Health Group for the Prevention and Management of Stillbirth in Sub Saharan Africa.

Conflicts of interest: None


Keywords: stillbirth, mixed-method, 3-delays, Africa

Fetal deaths: challenges for knowledge and intervention


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1) Background: Fetal mortality is still insufficiently known, valued and studied, especially through approaches that integrate the biological, epidemiological and social dimensions. Sao Paulo is a city with 12 million inhabitants. The fetal mortality is increasing since 2012. The aim of this multidisciplinary study is to understand the multiple risk factors of fetal death.

2) Methods: We are carrying out a prospective case control study with 415 cases (stillbirths, ≥22 weeks of gestation) and 415 controls (randomly selected live births) in hospitals of São Paulo. Mothers will be interviewed to obtain information on socioeconomic, clinical and obstetrical history, psychosocial characteristics, health care access and pregnancy conditions. Information on prenatal care card mother’s hospital records will be abstracted. Administrators of hospitals and managers of antenatal care program will be interviewed. To mothers of fetal deaths it will be applied the Perinatal Grief Scale. Placenta, umbilical cord mother’s blood will be collected for investigation of serum and tissue markers of angiogenesis. This material will also be analyzed to identify infectious diseases and exposure to air pollutants. Non-invasive autopsy will be conducted, by imaging and histopathology guided by image as well as traditional autopsy.

3) Results: Analysis will identify environmental, clinical and epidemiological risk factors for stillbirth, and investigate their interrelationships and estimate the individual contributions to fetal mortality in this setting. Innovative statistical approaches for mapping the multicausal etiology of fetal deaths will be employed such as causal models and generalized spatial structural equation models with Bayesian inference.

4) Conclusions: This proposal aims to articulate the epidemiological and clinical frontiers and search for new knowledge to fill important gaps in our understanding of fetal mortality which will allow the design of effective prevention strategies.

Ethics statement: This project was approved by The São Paulo Research Foundation, FAPESP title: Fetal deaths: challenges for knowledge and intervention, responsible researcher: Nelson da Cruz Gouveia CAAE: 97966918.6.0000.0065 Institution: University of Sao Paulo Medical School

Conflicts of interest: None


Keywords: fetal deaths, stillbirths, live births, non-invasive autopsy

Analysis of the causes of fetal death in Brazil, 2002 to 2017

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1) Background: Brazil had a population of 207.7 million inhabitants in 2017, the Mortality Information System (MIS), register all deaths, including fetal deaths of 22nd week of gestation and over. The stillbirths represent 2/3 of perinatal mortality and 90.8% of these were antepartum. This study aimed to investigate the trend of causes of fetal death in Brazil, between 2002 and 2017.

2) Methods: It was used the informations of MIS. The Fetal Mortality Rate (FMR) was calculated by the cause of death per thousand births, using the 10th International Classification of Diseases and Related Health Problems (ICD-10). The Time trends were assessed according to gestational age (>37 and ≥37 weeks) and exponential regression in Excel®.

3) Results: The FMR declined 0.9% per year, from 12.1 (37,417 deaths) in 2002 to 10.4 (30,574) for a thousand births in 2017. The decline in FMR was higher in preterm gestations (5% per year) than that among those with ≥37 weeks (0.8% per year), and this group represented 75% of fetal deaths in 2017. The FMR due to other disorders originating in the perinatal period (P96) presented a fall of 11% per year and the unspecified causes (P95) declined 8.8% per year in pregnancies ≥37 weeks. These causes of fetal death also showed decline trend in gestations of ≥37 weeks, but with lower decline and there was an increase of maternal factors and complications of pregnancy (P00-P01) in this group.

4) Conclusions: There was an increase in access to prenatal care in the period, contributing to the reduction of fetal mortality. The investigation of fetal deaths may have contributed to a better specification of the causes of death and to the reduction of non-specified mortality rates, but a large proportion of fetal deaths still remain with a non specified cause of death. This is probably due to lack of integration of the information from prenatal care and hospitals in which the delivery occurs.

Ethics statement: The study does not require the approval of the Committee on Ethics in Research with Human Beings because it is a public information obtained through the computerized department of the Brazilian National Health System (DATASUS) at the electronic address http://datasus.saude.gov.br/

Conflicts of interest: None


Keywords: fetal mortality, stillbirth, cause of death, delivery of health care

Fetal mortality from congenital syphilis in Brazil, 2002 to 2017

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(1) PhD student in Public Health; (2) Dept. Epidemiology, University of Sao Paulo (USP)

1) Background: The Mortality Information System (MIS) register all deaths, including fetal deaths occurring from the 22 or more weeks of gestation in Brazil. There has been a trend of decline in fetal mortality in the country. Although the diagnosis and treatment of syphilis and HIV in prenatal care is routine, there has been an increase in cases of Congenital Syphilis (CS). The goal of this study was to analyze the trend of the mortality rate by congenital syphilis in fetal deaths between 2002 and 2017 in Brazil. 2) Methods: It was calculated the Fetal Mortality Rate (FMR) for congenital syphilis (A50) as the basic cause of death per thousand births. The temporal trend was assessed by gestational age (>37 and ≥37 weeks) using the exponential regression analysis in Excel®. 3) Results: In the period from 2002 to 2017, there was an increase in the absolute number and the FMR by CS of 70 (0.02 deaths per thousand birth) to 509 (0.17), indicating a significant growth of 16% per year. The deaths by CS (90%) were concentrated in the gestation group with >37 weeks. Although adequate prenatal coverage in the country has grown 2.6% per year, reaching 67% of live births in 2016 with 7 or more visits, CS mortality has increased. 4) Conclusions: The data showed a large increase of CS deaths. The increased access to prenatal care was insufficient to prevent CS deaths. The prenatal routine is to perform at least two tests for syphilis infection and when confirmed positive the treatment should also be offered to pregnant women and their sexual partners the results can be related to failures in diagnosis or treatment of pregnant women. The monitoring and evaluation of all pregnant women diagnosed are important strategies that can support the elimination of CS.

Ethics statement: The study does not require the approval of the Committee on Ethics in Research with Human Beings because it is a public information obtained through the computerized department of the Brazilian National Health System (DATASUS) at the electronic address http://datasus.saude.gov.br/

Conflicts of interest: None


Keywords: syphilis congenital, fetal mortality, stillbirth, cause of death

Understanding cause of stillbirth amongst high risk groups of mothers in England: A multi-dimensional approach

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1) Background: In 2017, the English Government announced the commitment to halve the rate of stillbirths by 2025. To achieve this target, effective public health interventions aimed at reducing inequalities need to be based on a more detailed understanding of the differences in cause of death experienced by mothers from high risk groups. Differences in cause-specific stillbirth rates will be compared between groups of mothers using a multi-dimensional approach.

2) Methods: Data on all singleton births (gestation 24+0 to 42+6 weeks) between January 2015 and December 2017 for mothers resident in England were obtained from MBRRACE-UK. Cause specific stillbirth rates are compared between groups of mothers defined on the basis of their age, ethnicity and socioeconomic deprivation.

3) Results: There were 6,943 stillbirths (3.8 per 1000 total births). Unexplained antepartum stillbirths were the most common cause of stillbirth (33.6%). 8.5% of stillbirths were caused by congenital anomalies, ranging from 6.8% in mothers living in areas with less deprivation to 14.5% in ethnic minorities living in most deprived areas. Placental causes of stillbirth were highest in younger mothers with most deprived income and education (36.6%) and lowest in less deprived older mothers (24.6%).

4) Conclusions: Examining national cause specific stillbirth allows the identification of groups of mothers and causes that can form the focus for future intervention strategies aimed at reducing mortality. Ethnic minority mothers living in most deprived areas have the highest rates of stillbirth, and higher numbers of congenital anomalies than other mothers.

Ethics statement: MBRRACE-UK has S251 approval in England to collect data about stillbirths and neonatal deaths and use denominator data about all births without consent. For this analysis, conducted as part of the MBRRACE-UK programme, anonymised data were used.

Conflicts of interest: None


Keywords: stillbirth, neonatal mortality, cause of death

Intervals after stillbirth, neonatal death and spontaneous abortion and the risk of adverse outcomes in the next pregnancy in rural Bangladesh


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1) Background: Studies have revealed associations between preceding short and long birth-to-birth and birth-to-pregnancy intervals and poor pregnancy outcomes. Most studies have examined intervals that began with a live birth. Using data from Sylhet Bangladesh, we examined the effect of inter-outcome intervals (IOI) starting with a non-live pregnancy outcome on subsequent pregnancy outcomes.

2) Methods: We used pregnancy histories of 33,495 married women aged 15-49 years, with 64,897 pregnancy outcomes between 2000 and 2006. We examined the effects of the preceding outcome and the IOI length on the risk of stillbirth, neonatal death, and spontaneous abortion using multinomial logistic regression models.

3) Results: IOIs of 27-50 months and live births were baseline comparators. Stillbirths followed by IOIs >=14 months (> five month inter-pregnancy interval [IPI]) had increased risk for spontaneous abortion with adjusted relative risk ratio (aRRR) and 95% confidence interval of 2.53 (1.19, 5.36). Stillbirths followed by IOIs 7-14 months had aRRR 2.00 (1.39, 2.88) for stillbirths. Neonatal deaths followed by IOIs >=6 months had aRRR 28.2 (8.59, 92.63) for spontaneous abortion. Neonatal deaths followed by 7-14 and 15-26 months (> 17 month inter-pregnancy interval) had aRRRs 3.08 (1.82, 5.22) and 2.32 (1.38, 3.91), respectively, for stillbirths, and 2.81 (2.06, 3.84) and 1.70 (1.24, 3.84), respectively, for neonatal deaths. Spontaneous abortions and IOIs >=6 months and 7-14 months had, respectively, aRRRs 23.21 (10.34, 52.13) and 1.80 (0.98, 3.33) for spontaneous abortion.

4) Conclusions: In rural northeast Bangladesh, short intervals after stillbirth, neonatal death, and spontaneous abortion were associated with a high risk of a similar outcome in the next pregnancy. Two studies from similar settings have found benefits of waiting six months after adverse pregnancy outcomes before conceiving again, suggesting that incorporating this advice into programs should be considered.

Ethics statement: The Projahnmo trial was registered with ClinicalTrials.gov NCT00198705. The study was approved by the Johns Hopkins Bloomberg School of Public Health committee on human research and the Ethical Review Committee of the International Centre for Diarrheal Disease Research, Bangladesh (ICDDR,B). Verbal informed consent was obtained from all participating women.

Conflicts of interest: None


Keywords: pregnancy spacing, stillbirth, neonatal death, spontaneous abortion

Unexplained stillbirth: can risk factors be identified?

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1) Background: Stillbirth (SB) that remains unexplained despite investigation is a challenging target for prevention. Thus, we sought to identify characteristics and risk factors for unexplained SB. 2) Methods: Secondary analysis of a large, multi-center case-control study of SB and representative live births (LB). After excluding fetal anomalies and multiple gestations, we included 411 SB cases with complete evaluation including fetal autopsy, placental pathology and standardized history and laboratory evaluation, as well as 1953 LB. Each SB was assessed using the Initial Causes of Fetal Death (INCIDE) classification system. SBs with no probable or possible cause of death (unexplained) were compared to SBS with a possible or probable cause of death identified (explained), as well as to LB using univariable and multivariable regression. Weighting was used to account for over sampling of preterm births and non-Hispanic blacks in the LB population. 3) Results: Of the 411 SB included, 109 (26.5%) had no probable or possible cause of death and comprised the unexplained group. Unexplained SB were evenly distributed across gestational age groups from 20 through 42 weeks with 16-22% of the population in each group, while explained SBs were skewed toward the 20-23 week gestational age group (35%, p = 0.02). In multivariable analysis, compared to patients with LB, those with an unexplained SB were more likely to be younger and have a low BMI (>18.5). There were no differences in traditional risk factors for SB between unexplained SB and LB (Table 1). In multivariable analysis, women with unexplained SB were younger and less likely to be non-Hispanic black compared to those with explained SB (Table 2). 4) Conclusions: Women with unexplained SB had similar characteristics to those with LB and had few of the common risk factors for stillbirth overall. Prevention strategies should target the general population since traditional risk factors do not identify most cases of unexplained SB.

Ethics statement: All participants gave written informed consent as part of the original study and the study was approved by the institutional review boards of each clinical site and the data coordinating and analysis center.

Conflicts of interest: None

View with full poster: www.isa2019madrid.com/unexplained-stillbirth-can-risk-factors-be-identified

Keywords: unexplained stillbirth, risk factors

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Umbilical cord abnormalities and stillbirth

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1) Background: Umbilical cord abnormalities are commonly cited as a cause of stillbirth (SB) but details regarding these SBs are rare. Our objective was to characterize SB associated with umbilical cord abnormality using rigorous criteria based on pathologic findings and to examine associated risk factors. 2) Methods: The Stillbirth Collaborative Research Network conducted a prospective, population-based, case-control study of SB and live births from 2006-2008. This analysis includes the 512 SB who had complete fetal and placental evaluations and underwent cause of death analysis using the INCODE (Obstet Gynecol 2010, 16:254) classification system. Umbilical cord abnormality was defined as cord entrapment (defined as nuchal, body, shoulder cord accompanied by evidence of cord occlusion and/or fetal hypoxia by pathologic exam), knots/torsions/strictures with thrombi or other obstruction and evidence of fetal hypoxia by pathologic exam, cord prolapse and vasa previa. We compared demographic and prenatal factors between women with SB attributable to umbilical cord abnormality with those due to other causes as well as control live born. 3) Results: Of 512 stillbirths with complete analysis by INCODE, 53 (10.4%) were attributed to umbilical cord abnormality. 27 (5.2%) had cord entrapment, 23 (4.4%) knots/torsions/stricture, and 5 (0.9%) had cord prolapse. No cases of vasa previa were present. Characteristics were similar between groups except cotinine at delivery, which was more common in the Non-umbilical cord abnormality SBs (Table). SB due to umbilical cord abnormality were most common prior to 24 weeks (26.4%) and during the late preterm period (24.5%). Intrapartum stillbirth was less common in umbilical cord abnormality SBs. 4) Conclusions: Umbilical cord abnormality is an important cause of SB, accounting for over 10% of cases, even using robust pathologic criteria. It is difficult to identify cases at risk using clinical criteria. Further investigation should focus on prediction and prevention of SB associated with umbilical cord abnormality.

Ethics statement: All participants gave written informed consent as part of the original study and the study was approved by the institutional review boards of each clinical site and the data coordinating and analysis center.

Conflicts of interest: None

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Keywords: umbilical cord, stillbirth, abnormalities

Association of race-ethnicity and placental lesions in stillbirth cases

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1) Background: There is racial and ethnic disparity in stillbirth but mechanisms are uncertain. Our objective was to compare placental lesions between race/ethnicity groups, stratifying by stillbirths and live births.

2) Methods: Secondary analysis utilizing Stillbirth Collaborative Research Network data, collected in a prospective case-control fashion from five geographic catchment areas in the United States. Pathologic placental findings in singleton, non-anomalous stillbirths and live births were compared between race/ethnicity groups, stratifying on gestational age. Multivariable logistic regression was used to account for maternal age, education, insurance and income with non-Hispanic white as the referent group.

3) Results: Placental pathology results from 456 stillbirths and 1160 live births were analyzed. In term pregnancies, non-Hispanic black women were more likely to have terminal villous immaturity or hypoplasia in live births (aOR 3.72 (95% CI 1.56-8.89)). Non-Hispanic black women with a live birth at term were also more likely to have placental evidence of maternal inflammation with chorioamnionitis (aOR 2.61 (95% CI 1.29-5.26)). In non-Hispanic black women with preterm stillbirths, both maternal and fetal inflammatory lesions were more common (aOR 5.51 (95% CI 2.60-11.70) and aOR 4.18 (95% CI 1.42-12.32) respectively). At term, Hispanic women with stillbirths were more likely to have parenchymal infarction (aOR 3.72 (95% CI 1.12-12.37). Developmental umbilical cord abnormalities (aOR 2.69 (95% CI 1.06-6.83) and fetal vascular thrombi (aOR 2.46 (95% CI 1.11-5.41) were more common in term live births in Hispanic women. Among preterm stillbirths in Hispanics, maternal inflammation was more likely (aOR 2.14 (95% CI 1.05-4.35). Terminal villous immaturity/hypoplasia (aOR 52.24 (95% CI 1.69-1618.87) and fetal vascular thrombi (aOR 15.99 (95% CI 2.67-95.73) were more prevalent in Hispanic preterm live births. We had too few women of other race/ethnicity to comment on placental lesions.

4) Conclusions: Inflammatory and circulatory placental lesions are more common among non-Hispanic black and Hispanic women in both live births and stillbirths. These data suggest targeting inflammation and placental function may help reduce disparity in stillbirth.

Ethics statement: All participants gave written informed consent as part of the original study and the study was approved by the institutional review boards of each clinical site and the data coordinating and analysis center.

Conflicts of interest: None


Keywords: placental pathology, stillbirth, race-ethnicity

Are Placental histopathological (HPE) findings tell tales of Outcomes in Preterm Neonates?

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1) Background: Preterm placental HPE provides clues to the underlying cause of premature birth and may potentially be tell-tales of outcomes. The study evaluates the association of HPE of preterm placenta with early neonatal outcomes. 2) Methods: Placenta of liveborn preterms from 22 to 36 weeks were subjected to blinded expert HPE. Outcomes of these preterms were observed up to 15 days for mortality and common neonatal morbidities. Chi square and logistic regression used for analysis. 3) Results: A cohort of 520 live preterm births studied with mean birth weight (BW) 1871±521 grams, mean gestational age (GA) 34.2±2.2 wks with 55.8%(290) being growth retarded. 89.3% (464) survived beyond 15 days. HPE was unremarkable in 63.2%(329). Some pathology (ANY) seen in 36.7%(191) included Histological chorioamnionitis/funisitis (HCA), Funisitis (F), Maternal vascular lesions (HMVM), Fetal vascular lesions (HFVM), other inflammatory lesions (HINFL) in 125(24.0%), 16 (1.5%), 85(16.4%), 3(0.6%), 17(3.3 %) respectively. BW was significantly lesser with HCA (p=0.04) or HFVM (p=0.01) whereas GA with HCA(p=0.00), F(p=0.00), HFVM (p=0.01) or ANY(p= 0.02). Neonatal outcomes, Hyaline membrane disease (HMD), hypoglycaemia, jaundice and polycythemia were not significantly associated with any HPE findings. There was an increased odds of , Mortality with HCA(2.4,1.3-4.4), ANY(19,11-3.2) and HFVM(p=0.04), early onset sepsis(EOS) with HCA(4.3,2.1-9.1), F(8,12.3-28.5), HFVM( 12,11.0-142.3) and ANY (3.3,1.6-6.8), Non-HMD respiratory distress with HCA(19,2.0-3.1), F(5,5,2.0-15.4), HMVM(19,11-3.2), HINFL(3,0,1.1-8.2) and ANY(2.0,1.3-3.0), patent ductus arteriosus (PDA) with HCA (3.7,1.3-10.8) and F(7.7,14-41.4), severe perinatal asphyxia (PA) with F(3.1, 1.0-25.7). Though not significant, HMVM was associated with IUGR. 4) Conclusions: Lower BW or GA, neonatal mortality and early morbidities (EOS,Non-HMD,PDA and PA) are significantly associated with specific HPE findings. This may reflect an important causal association requiring further study.

Ethics statement: The study was granted ethical clearance by institutional ethical committee (F.No/11/IEC/MAMC/2016/4). Enrollment into study was after obtaining written informed consent from parents of neonates.

Conflicts of interest: None

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Keywords: preterm, placenta, preterm placenta, placental histopathology, preterm outcomes

Prenatal-onset Group B Strep (POGBS) disease as a cause of perinatal morbidity and mortality

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1) Group B Strep International; (2) LA Best Babies Network

1) Background: Intrauterine infection is increasingly recognized as a possibly preventable cause of stillbirth (SB). The objective of this review/analysis is to justify recognition of prenatal-onset group B strep (POGBS) sepsis, distinct from early-onset (EO) and late-onset (LO) infections from group B strep (GBS) and other microorganisms. 2) Methods: Logic model analysis: A) Conduct an expert systematic review and analysis of group B strep disease knowledge in order to justify recognition of POGBS sepsis, distinct from EO and LO infections from GBS and other microorganisms, B) To correlate patient experiences, we conducted a quasi-experimental “internet commons” inquiry of parent contacts who had suffered GBS SB, C) Computer-based national data bases were utilized to assess knowledge of GBS infectious disease. 3) Results: Much is known about GBS disease. Despite this knowledge, preventative regimes remain inconsistently applied, and in the best of circumstances are incompletely (85–90%) successful in reducing early-onset GBS infection and do not address late-onset or prenatal-onset GBS infections. 4) Conclusions: A) There is sufficient knowledge supporting the Centers for Disease Control & Prevention (CDC) use of the term “prenatal-onset GBS disease” as a distinct entity. B) Our limited, uncontrolled investigation supports clinical notions that a) GBS loss or SB occurs in a bimodal gestational time distribution with the preponderance of cases occurring near term (POGBS), and b) that mothers do not reliably demonstrate fever or “textbook” findings of potentially lethal intrauterine infection.

Ethics statement: No patients were involved. No institutional consent required/obtained.

Conflicts of interest: None


Keywords: prenatal-onset, sepsis, pregnancy, stillbirth

Ending preventable stillbirths: introducing a scorecard to measure progress against global targets

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Each year an estimated 2.6 million babies are stillborn. Progress to reduce this large burden has been slow. The Lancet’s 2016 Ending Preventable Stillbirths series’ Call to Action summarized what is required to end preventable stillbirths and ensure quality post-bereavement care, but as yet there is no regular tracking of progress. We developed a Global Scorecard to fill this gap. The Scorecard measures progress against the Call to Action’s three components: 2030 mortality targets, universal health care coverage (UHC) targets, and global and national milestones for improving care and outcomes for all mothers and babies (as specified by the Every Newborn Action Plan, ENAP), including those affected by stillbirth. For each target, we aimed to identify at least one indicator currently being tracked at the global level; the current Scorecard includes 17 indicators and is populated with the most up-to-date global data: a) Mortality: 31% of high-burden countries have set national stillbirth targets; no tracking of sub-national stillbirth rates; b) UHC: global standards set for antepartum and intrapartum care, but no tracking of quality, essential for stillbirth prevention. c) Milestones: ENAP milestones being tracked; work begun on global consensus on bereavement care, but no tracking of national bereavement care or stigma reduction. Existing monitoring mechanisms are inadequate to monitor progress against the Call to Action. Next steps include further refinement of the Scorecard with key stakeholders and creation of country-specific and high-income region versions. Despite shortcomings of existing data, the Scorecard suggests some progress is being made, but improvements in funding and accountability mechanisms are needed to achieve the goal of ending preventable stillbirths.

Ethics statement: The Projahmmo trial was registered with ClinicalTrials.gov NCT00198705. The study was approved by the Johns Hopkins Bloomberg School of Public Health committee on human research and the Ethical Review Committee of the International Centre for Diarrheal Disease Research, Bangladesh (ICDDR,B). Verbal informed consent was obtained from all participating women.

Conflicts of interest: None


Keywords: stillbirth, antenatal care, maternal health, newborn health, bereavement, stigma

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Investigation of the outcomes of pregnancies complicated by increased fetal movements: a prospective cohort study


(1) The University of Manchester Maternal and Fetal Health Research Centre, UK; (2) Liverpool Women's Hospital, UK.

1) Background: Whilst the significance of reduced fetal movements is well established in maternity care, retrospective studies suggest that a single episode of significantly increased fetal movements (IFMs) may also be associated with late stillbirth. To date there have been no prospective studies examining the association between IFMs and adverse pregnancy outcomes. This study aimed to report the outcome of pregnancies associated with a maternal perception of IFMs, as well as determining which factors were associated with an increased risk of adverse pregnancy outcome in this cohort.

2) Methods: Women reporting IFMs after 28 weeks' gestation were recruited from St Mary's Hospital, Manchester and Liverpool Women's Hospital, UK between 01.09.17-31.12.18. Demographic and clinical information was obtained and an ultrasound scan was performed to assess fetal biometry, liquor volume and umbilical artery Doppler. Maternal and fetal outcome data was collected post-delivery. Adverse outcome was defined as: stillbirth, birthweight >3rd centile, 5 minute Apgar score ≤7, umbilical arterial pH ≤7.05, and admission to neonatal intensive care. 3) Results: 63 women with IFMs participated. 7 (11.1%) of pregnancies ended in adverse outcome (birthweight >3rd centile 2 (3.2%), pH≤7.05 1 (1.6%), NICU admission 4 (6.4%). Adverse outcome was associated with an increasing maternal age (Odds Ratio (OR) 1.15, 95% CI 0.98-1.35, p=0.07) as was increasing gravidity (OR 1.30, 95% CI 1.02-1.65, p=0.03) and previous pregnancy loss >24 weeks’ (OR 2.26, 95% CI 1.19-4.30, p=0.01). There was no relationship with other clinical or sonographic measurements and adverse outcome in this population. 4) Conclusions: In this prospective study IFM was not associated with a high frequency of adverse outcomes. Currently available investigations were not able to differentiate pregnancies ending in adverse outcome. Further work is required to determine the strength of association between IFMs and adverse pregnancy outcome.

Ethics statement: Data was collected as part of the INVEST (Investigation of the Outcome of Pregnancies Complicated by Increased Fetal Movements) study (ethics reference: 17/NW/0229). Written informed consent was provided by all participants.

Conflicts of interest: None


Keywords: fetal movements, adverse pregnancy outcome, risk factors

Frequency of intra uterine fetal deaths in Zonal Hospital of Puerto Madryn ( Argentine) during the period 2014-2018

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1) Background: The Zonal Hospital "Dr. Andrés R. Isola", serves an estimated population of 100,000 habitants. About 700 births occur in the hospital each year. The objective of this presentation is to determine the frequency of Intra Uterine Fetal Deaths (IUFD) in hospital births during the years 2014, 2015, 2016, 2017 and 2018. 2) Methods: Retrospective, cross-sectional, observational and descriptive design. The documentation consulted is compiled in the Births-Book, and in the Monthly Obstetric Summary. The data analyzed in both documents are: gestational age, birth weight in grams, condition at birth, end of pregnancy, previous pregnancies, sex, congenital anomalies, maternal pathologies and stillbirth autopsy. In this series, the IUFD refers to all losses of 22 or more weeks of gestation. 3) Results: The occurrence of 30 IUFD was observed from January 2014 to December 2018, out of a total of 3062 live births. The Fetal Mortality Rate was 5.9 (2014), 6.1 (2015) 22.1 (2016), 5.3 (2017) and 10.2 (2018).The mean gestational age was 33.3 weeks. The average weight was 2118 grams. The mean maternal age was 26.5 years, multigravidae (2.3 previous pregnancies), way of ending pregnancy was cesarean section 60% and vaginal delivery 40%. With respect to the sex of IUFD: female sex 43.4%, male sex 50% and undetermined 6.6%. Congenital anomalies (CA) were observed in 4 dead fetuses (13.3%). They correspond to Potter sequence, trisomy 18 phenotype, unclassified CA. The maternal pathologies associated were: placental detachment normoincerta 23.3%, pregnancy-induced hypertension 13.3%, chorioamnionitis 6.6%, gestational diabetes 6.6%, syphilis 6.6%, cholestasis 3.3% and risk of preterm birth with cerclage 3.3%. The stillbirth autopsy was performed in 7 cases (23%). 4) Conclusions: The frequency of IUFD in our series demonstrates an increase in cases during the years 2016 and 2018. It is inferred the need for early detection of maternal risk factors, to avoid IUFD.

Ethics statement: The ethical approval for the study was granted by the Bioethics Committee of the Zonal Hospital of Trelew (Reference: 11/03/2019).

Conflicts of interest: None


Keywords: stillbirth, frequency, maternal pathologies, argentina

Decreased fetal movements: maternal and clinical responses

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(1) Centre of Research Excellence in Stillbirth, Mater Research Institute – The University of Queensland, Brisbane, Australia; (2) Safer Care Victoria, Australia; (3) Royal Prince Alfred Newborn Care, Sydney, Australia; (4) Centenary Hospital for Women and Children, ACT Health, Australia; (5) Mater Education, Mater Health Services, Brisbane, Australia

1) Background: Undetected fetal growth restriction (FGR) is a major contributor to stillbirth and other adverse pregnancy outcomes. Current antenatal detection of FGR is suboptimal, and practice surrounding this is variable. Improving the detection and care of pregnancies with FGR is an important strategy to reduce adverse outcome and is relevant to all maternity care providers.

2) Methods: A four and a half face-to-face workshop has been developed to provide education to clinicians to improve the detection and management of FGR. Evaluation of participant knowledge and confidence of 11 learning objectives was undertaken using a paper based or on-line survey administered immediately before and after the workshop.

3) Results: 585 participants have attended the 20 workshops held to date. Pre-workshop evaluation surveys were completed by 449 participants, including 387 midwives, 60 doctors and 2 nurse educators. Post-workshop evaluation surveys were completed by 327 participants, including 281 midwives, 44 doctors and 2 nurse educators. A high level of satisfaction was reported for all aspects of the workshop including quality of facilitators, learning resources, relevant content and presentation. The FGR education program appears to be beneficial in improving clinician knowledge and confidence in the detection and management of FGR across all learning objectives (see figure 1). Overall, 37% of participants reported being confident or extremely confident in best practice for the detection and clinical management of FGR prior to the program and this increased to 88% post-workshop. 92% of participants indicated they would change some aspect of their clinical practice following the workshop format.

4) Conclusions: The FGR education program appears to be beneficial in improving clinician knowledge and confidence in the detection and management of FGR. Participants reported a high level of satisfaction for all aspects of the workshop including quality of facilitators, learning resources, relevant content and presentation format.

Ethics statement: The fetal growth restriction program is a quality assurance activity and therefore ethics approval was not sought.

Conflicts of interest: None


Keywords: stillbirth, prevention, best clinical practice, decreased fetal movements

CARE EXPERIENCES
First “Pregnancy and Infant Loss Remembrance Day” in PSSJD

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In Parc Sanitari Sant Joan de Deu (PSSJD) we work on a multidisciplinary committee for perinatal and infant loss since 2015, with gynecologists, midwives, maternity nurses, pediatricians, psychologists, and pathologists. We aim to gradually change the professional view around a perinatal loss, so improve the care we offer to families who have lost their baby. Our first action was to standardize the care we provide and design our own guide for professionals. The cases review we conduct on a monthly basis and the positive response of the families we attend gave us an ambitious prospective. Perinatal Loss is still a taboo in our society, one of our hospital objectives is to open this reality to the society in general. Our project is a remembrance day, together with the international Remembrance Day for perinatal loss, which offers a meeting, a space, a recognition to all these families who have been through the death of their baby, patients, professionals, people in all. Numerous societies, in Spain and abroad, celebrate remembrance days, with positive outcomes from all perspectives, but the difference is the health professional view, a hospital which makes a statement towards these “invisible” losses. A brainstorming technique was performed between all professionals involved in the care of these families, to design from the dissemination campaign, through the activities, even the footprint we would like this day to impact on the hospital day-to-day. The Remembrance Day will be a day to recognize, remember, and raise awareness of families, health professionals and the wider community in general.

Ethics statement: Ethics approval not required.

Conflicts of interest: None


Keywords: remembrance day, pregnancy and infant loss, professionals

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Drivers of sedative administration in hospitals following intrauterine death

P.R. Cassidy (1,2)

(1) PhD student, Universidad Complutense de Madrid; (2) Researcher, Umamanita (Stillbirth charity), Spain

1) Background: Routine sedative administration (SA) in Spanish hospitals following intrauterine death has been previously reported (48% of cases). The objectives were to establish the primary drivers of SA and possible contextual predictors.

2) Methods: A cross-sectional descriptive design with an online questionnaire, including cases of stillbirth or TOPFA within 5 years prior to participation in the study. 796 women were asked if they had been “sedated or tranquilized (not analgesics, epidural anesthetic or sleeping pills)” during the hospital stay as well as the main reason for SA. CHAID (decision tree analysis) was used to test for statistically significant (p>0.05) relationships between SA and contextual predictors.

3) Results: In the SA sub-group (48%), 32.5% stated that they “asked for something to calm me”, 50.3% that healthcare professionals (HPs) “told me to take something to calm me” and 17.1% that HPs “gave me sedatives without consulting me”. The CHAID analysis found no significant differences between sedative and non-sedative groups based on socio-demographic or pregnancy variables, but did find significant relationships with structural care variables, though with small effect sizes: Nodes 1 & 2) women who saw a mental health professional (59.2% vs. 45.3%, p=0.002), Nodes 3 & 4) women in private rooms (49.1% vs. 34.2%, p=0.003), Nodes 5 & 6) women unaccompanied during the birth (59.1% vs. 45.3%, p=0.021) and Nodes 7 & 8) women who were alone when they receive the diagnosis (50.0% vs. 26.6%, p=0.010).

4) Conclusions: HPs are the primary drivers of SA, although a significant proportion of women asked for sedatives, which may relate to wide cultural trends and discourses and be a form of taking control in a stressful situation. Statistically significant associations between SA and unaccompanied women (during diagnosis, accommodation, birth) may suggest that SA is associated with structural weaknesses related to staffing or that SA has a symbolic care value for poorly trained HPs.

Ethics statement: The author’s institution (Universidad Complutense de Madrid) did not require ethics approval for non-clinical studies. Consent was given through informed participation in the online survey.

Conflicts of interest: None


Keywords: sedatives, stillbirth, TOPFA, bereavement care

Cite as: Drivers of sedative administration in hospitals following intrauterine death. P.R. Cassidy. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Nursing interventions that help relieve grief

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1) Background: The psychological suffering experienced by parents following perinatal loss is extremely hard to endure. We as professionals must reach out to and support parents as from the very moment of death to help them go through their period of mourning in a healthy way. The aim of this project was to discern what interventions on the part of the nursing profession may contribute to alleviating perinatal grief. 2) Methods: The project consisted of a cross-sectional study of a sample of 17 patients who had experienced perinatal loss and had been attended to at the General University Hospital of Catalonia from 2017 to February 2019. Telephone calls were made in accordance with the guidelines of a questionnaire. 3) Results: The most satisfactory interventions on the part of the nursing profession at the initial moment of perinatal loss proved to be the first support visit (76.47%), holding the baby (64.7%) and photos and footprints (29.41%). Interventions in the mourning process consisted of individual therapy (5.88%) and group therapy (11.76%). After experiencing perinatal loss, 35.29% of mothers became pregnant again. 4) Conclusions: The initial support visit serves to guide parents in a state of emotional shock. On the other hand, an appropriate farewell and possession of physical objects related with the baby contribute to a healthy process of mourning. The individual and group therapy samples were small, consequently the results are not significant. Lastly, the act of undergoing a healthy mourning process may be regarded as a means to reducing parents’ doubts as to whether or not to have another child.

Ethics statement: The author declares that the anonymity of the parents who constituted the sample and responded to the survey has been scrupulously respected. The telephone calls were made in strict accordance with regular mourning follow-up practice at this hospital institution. Consent was given by telephone during the course of these calls.

Conflicts of interest: None

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Keywords: perinatal loss, mourning process, interventions, nursing

Cite as: Nursing interventions that help relieve grief. T. Cerezo Martínez, X. Serra i Llanas, M. Fe Viso Cano. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Communicating bad news

S. Broderick (1), R. Cochrane (2)

(1) Retired Women’s Health Counsellor; (2) Consultant Obstetrician, University Hospital Lewisham, London, UK

If you are the one who has to tell a woman and her partner that there is a problem with their pregnancy, you become part of their life’s experience. They might remember you; you will become one part of a sad and complicated journey as they learn to live with their new reality. No one wants to create even more distress for the couple, but if you communicate poorly you will be remembered for the wrong reasons. With experience and effort we can learn to do this difficult work well. Communicating bad news makes some professionals fearful. Sometimes this fear interferes with their ability to do it well. Having to tell the bad news is not about you: it is about the parents, and the impact the news will have on them. This news will change their lives forever. Your ego needs to get out of the way. This task requires humility on your part. You need to understand and accept that no matter how well you impart the news, some people will be dissatisfied or angry with you. Why is this work difficult? Are we afraid of people’s reactions? Do we have expectations about how they will react? Are we more comfortable with reactions we recognise? People react in different ways: you may be criticised for gently leading up to the bad news, and then criticised the next time for coming straight out with it. Do we feel helpless? Feeling helpless does not mean that we cannot be helpful. We can be kind, and sympathetic. We can be a resource. We may become someone patients feel they can trust to care for them during the journey of this pregnancy and perhaps through a future one. Imparting bad and sad news is a challenge. By understanding our fears about this task – feeling helpless, or responsible, and not wanting to be the one who has to do it – will not enable you to make the bad news better, but it will give you a way into becoming more able to communicate as well as you can.

Ethics statement: Ethics approval not sought, as this content describes our professional experience.

Conflicts of interest: None

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Keywords: communication fears helpless understanding

Cite as: Communicating bad news. S. Broderick, R. Cochrane. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
A case report: MURIEL

C. García Terol (1), Anna and Rafel (2), B. Carreras Marcos (3)

(1) Midwife, Head of Maternity Services Parc Sanitari Sant Joan de Deu, Hospital, Catalonia, Spain (2) Muriel’s parents; (3) Psychologist EAPS, Parc Sanitari Sant Joan de Deu Hospital, Catalonia, Spain

Incorporate the patient experience in Quality improvement is highly recommended across the world health systems, in perinatal loss cases going back to the hospital to share their views with the health professionals sometimes is too hard for the family. Also the Health system tends to separate the family follow-up from the Health professionals who care for them in the first place, psychologist to help them in the grieving process versus midwives and gynecologists which give the bad news. Therefore it is very complicated to incorporate the “receiver” views on the “sender” way of doing. Anna & Rafel lost Muriel at a 33 weeks’ pregnancy. They came to the A&E Department because of a very bad headache, and the diagnosis of pre-eclampsia, placenta abruption and stillbirth were devastating. The Parc Sanitari Sant Joan de Deu (PSSJD) Maternity Unit designed a Professional Clinical Guide for Perinatal Loss on May 2017, on good practices are recommended, including the way professionals should give the bad news, but also the information needed to discuss a birth plan with the parents, the creation of memories following birth, as well as the psychological support available during or after the hospital stay. This report aims to describe the experience of Anna & Rafel, Muriel’s parents, about the care they received from PSSJD health professionals. Unfortunately the care given to families who go through a perinatal loss is not regulated nor standardized across hospitals in Spain. Health professionals should accomplished with bioethics principles, being one of them “Primum non nocere”, first do no harm. Families receive so different type of care depending on which hospital they randomly arrive and are cared for. The little or next to nothing attention they get sometimes, nor helps them in their loss, but can even harm their grieving process.

Ethics statement: Both Anna and Rafel have given full consent to the corresponding author to share their views about Muriel’s loss.

Conflicts of interest: None

View with full poster: www.isa2019madrid.com/a-case-report-muriel

Keywords: stillbirth, parents, patient experience

Cite as: A case report: MURIEL. C. García Terol, Anna and Rafel, B. Carreras Marcos. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
The perceptions of families whose babies died in the perinatal period about participating in a therapeutic photographic project

N. Grau Andrés (1), A. Fité (2), J. Plana Soria (3), M. Robles (4), V. Violant Holz (5)

(1) Psychologist and Photographer, creator of the Stillbirth Project; (2) Co-founder of Dol d'Estels and medical specialist in public health; (3) Midwife, Hospital de la Santa Creu i Sant Pau, Barcelona; (4) Nurse Specialist in Grief. Assistencial Supervisor of Servei de Suport al Dol de Ponent; (5) Associate Professor, Department of Didactics and Educational Organization, Faculty of Education, University of Barcelona.

1) Background: Despite being recommended for its benefits to the grief process, photographing of stillborn babies and neonates is not fully established in Spanish hospitals, meaning many families don't have any images of their children. The Stillbirth Project was set up to work with families to create symbolic images of loss (photographs containing important objects along with family members). The project requires parents to actively collaborate with a photographer in the production of the final images. The purpose of this study was to investigate the perceptions of the parents who have participated (n=180). 2) Methods: An anonymous online structured survey of closed-ended questions was administrated to all the participating families. 3) Results: 59 families responded (32%), all of which were mothers. Of these, 62.7% of the families did not have any previous photographs of their babies. 30.5% participated more than one year after the death of their child, 28.8% within six months and 13.6% within one month. 80% thought that they had participated at the right time in the grief process and 12% that they should have done so earlier. 89.8% affirm that participating had made it easier to talk more about their infants. All respondents stated that participating in the production of the “Stillbirth Project” photographs had helped them (rating of 4 or 5 out of 5) in the process of grieving. 4) Conclusions: The therapeutic function of creating or producing artistic images is well established as being a beneficial therapy for narrative and reconstruction processes in grief. Although the response rate is low, which may imply a selection bias, the Stillbirth Project appears to provide valuable support to families who seek help in the grief process through the creation of symbolic images in the form of photographs.

Ethics statement: Families have been informed that the participation is voluntary, that sending the answer through the link provided to them means that they agree to the cession of information rights and that they agreed to the cession by signing an informed consent and in any case they will be identifiable individuals.

Conflicts of interest: None


Keywords: grief, perinatal, bereavement, stillbirth, photography, memories

Cite as: The perceptions of families whose babies died in the perinatal period about participating in a therapeutic photographic project. N. Grau Andrés, A. Fité, J. Plana Soria, M. Robles, V. Violant Holz. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
The meaning of seeing and holding – an anthropological perspective on being with a stillborn baby

M. Lindh Jørgensen, D. Hvidtjørn

Unit for Perinatal Loss, Aarhus University Hospital, Denmark

1) Background: For a number of years there has been an ongoing debate about whether seeing and holding your dead baby after stillbirth is beneficial or harmful for the parents’ emotional health, but since Kingdon’s review in 2015 convincing scientific evidence supports the idea of parents being together with their dead children and achieving from the interaction. Bereaved parents are most often young, unprepared for and often inexperienced with death, grief and traumatic loss, hence they are completely reliant on a supportive and compassionate staff. Concluding that parents benefit from seeing and holding their stillborn baby and that hospital staff should support and encourage parental contact with the dead child, the aim of this study was to enlighten how this encounter between the grieving parents and their child’s dead body seems to be so advantageous and also why so many people seem to be so alarmed about it.

2) Methods: Mixed methods, combining a theoretical anthropological approach and an empirical epidemiological assessment, using original research data from the Danish “Life after the Loss” cohort.

3) Results: In the survey “Life after the Loss” the participants were asked if they saw or held their dead child and for how long: minutes, hours or days. Close to 100% saw and held the baby, no differences between men and women, and 60 % spent days with the child. When asked about who else saw the child 75% reported that their parents saw the child and 25% reported that their friends had seen the child.

4) Conclusions: Danish parents engage in contact with their stillborn child to a very high degree, including sharing the experience with family. Seeing and holding your dead baby has several purposes, including the use of ritualization to assist the transition into parenthood and allow the parents to benefit from the state of liminality.

Ethics statement: The study was approved by The Danish National Data Protection Agency (no. 18/15684, 7 October 2014).

Conflicts of interest: None

View with full poster: www.isa2019madrid.com/how-seeing-and-holding-your-stillborn-baby-is-beneficial

Keywords: stillbirth, seeing and holding, ritualization

A grounded-theory study on the impact of disrespectful maternal and newborn care on stillbirth experiences, in Zambia and Tanzania

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(1) Division of Nursing Midwifery and Social Work, The University of Manchester, Manchester, UK; (2) The Catholic University of Health Sciences, Mwanza, Tanzania; (3) Ministry of Health, Lusaka, Zambia

1) Background: Most stillbirths occur in low income countries. In Tanzania and Zambia the rates are 22.5 and 20.9 per 1000 live births, respectively. Despite the huge burden of stillbirth in these countries, health care facilities do not have programmes in place to support those affected. The limited available evidence suggests that, following a stillbirth, women do not receive the respect they deserve. We, therefore, mapped our data onto the 12 respectful care principles, identified by Shakibazadeh, to gain insight into the important elements of respectful care and to identify areas for improvement. Aim: To explore the intrapartum views and experiences of women, partners, health providers and stakeholders on stillbirth care.

2) Methods: A Straussian Grounded Theory approach was adopted using in-depth interviews (n=166) and non-participant observations (n=32). Data collection took place in 6 facilities (3 in Zambia and 3 in Tanzania), representing primary, secondary and tertiary levels of care. Purposive and theoretical sampling was used, the sample size being determined by data saturation. Following consent, interviews were audio-recorded, transcribed verbatim and translated (and back-translated) from local language into English. Data analysis followed grounded theory principles of constant comparison and included open, axial and selective coding. Ethical approval was received from the partner universities, Ministries of Health and health facilities involved.

3) Results: Although positive examples of care were reported, participants’ narratives were dominated by examples of disrespectful intrapartum care. A failing in all of the 12 respectful care domains was evident. Despite having the trauma of losing their baby, women were refused care until they gave health care workers payment, were publicly scolded when they asked questions, were left not knowing why their baby had died, and placed in inappropriate environments next to women with live babies. Partners were generally unsupported and health providers were ill-equipped to provide women with optimum care.

4) Conclusions: Existing systems and processes are not meeting the needs of women following stillbirth. Disrespectful care impacts on physical wellbeing, adds to women’s psychological burden and influences their future health care decision-making. Whilst health providers are aware of disrespectful care they need support to practice differently in order to provide women with timely, effective and respectful care.

Ethics statement: Ethical approval for this study was obtained from University of Manchester (UREC 2018-4446-6653), The Catholic University of Health Sciences, Tanzania (CREC/287/2018) and the Independent Research Board (IRB), Zambia (2018-Jun-029). For the qualitative element parent participants were identified and approached via clinical teams, for consent for contact by the research team. Following, verbal and written explanations and time to consider, written (or thumb print) consent was obtained. Interviews were conducted at a venue of participants choice with pseudonyms used to protect identity. A study-specific distress policy was adhered to at all times. All data were managed securely and adhered to GDP regulations. Funding: NIHR Global Health Group for the Prevention and Management of Stillbirth in Sub Saharan Africa

Conflicts of interest: None


Keywords: stillbirth, qualitative, grounded theory, respectful care

What can we learn from the ways people use metaphor to talk about pregnancy loss?

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(1) University of Birmingham; (2) University of Bristol; (3) Coventry University; (4) University of Alberta; (5 University of Cambridge

1) Background: It is estimated that approximately 1 in 5 known pregnancies end in miscarriage, 1 in every 200 births is a stillbirth, and 2,000 terminations for reasons of foetal anomaly are performed in the UK each year. Often unexpected and unexplained, pregnancy loss engenders complex emotions that are difficult to articulate. A powerful way of exploring such experiences is to consider how bereaved parents use metaphor to communicate and make sense of what are extremely challenging situations and feelings. Metaphor is a device by which a concept, experience or object is described in terms of another, for example people may talk about women’s careers hitting a ‘glass ceiling.’ While traditionally seen purely as a literary or creative device, contemporary researchers of metaphor consider it to be a fundamental element of human language and thought, an important device by which we understand and express our feelings and lived situations. Metaphor is therefore a particularly useful mechanism for working through experiences that are not widely shared as it frequently involves the use of something that is familiar, tangible or common to describe something that is unfamiliar.

2) Methods: We interviewed 35 bereaved parents about heir experiences of pregnancy loss, then identified and analysed the metaphors they used to describe their experiences.

3) Results: Metaphors used to express the situations and decisions they encounter are numerous and sometimes highly idiosyncratic, but often revolve around a range of key themes, such as movement, space or the body. For example, individuals may describe the process of undergoing a termination as a ‘rollercoaster,’ or understand one’s sense-of-self following a stillbirth as needing to be ‘rebuilt.’

4) Conclusions: By examining how metaphor allows individuals to articulate these unfamiliar experiences, our research has highlighted a number of concerns regarding our understanding of the grieving process, how people respond to their grief, and ultimately their recovery.

Ethics statement: This project received ethical approval from the University of Birmingham and was funded by the ESRC.

Conflicts of interest: None


Keywords: pregnancy loss, bereavement, grief, metaphor

Parents' and health workers' experiences of care and support after stillbirth in Kenya and Uganda: A phenomenological study

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(1) Division of Nursing, Midwifery and Social Work, The University of Manchester, UK (2) School of Nursing Sciences, University of Nairobi, Kenya (3) College of Health, Makerere University, Kampala, Uganda

1) Background: Ensuring compassionate care and support for parents experiencing stillbirth is key to ameliorating adverse outcomes for families and society. Quality of care and support from health workers has been demonstrated to be inconsistent across high income settings. There is a dearth of research exploring the response of health systems in low/middle income countries, including Sub Saharan Africa, which bear a disproportionate burden of stillbirths. Here, we explored the views and experiences of parents and health workers of care and support after stillbirth in urban and rural settings in Kenya and Uganda.

2) Methods: Following consent, one to one interviews were conducted with women (N=75) and male partners (N=51) who had experienced the stillbirth of their baby (up to 1 year). Health workers (N=53, midwives, nurses and doctors), who provided care after stillbirth, in the same sites, also participated. Interviews were audio-recorded, transcribed and analysed using Van Manen’s reflexive approach.

3) Results: Recurrent themes in participants’ narratives revealed barriers and facilitators to the provision of quality care after stillbirth. Parents reported insensitive staff communication and behaviour and deficits in information provision. Facility policies such as inflexible visiting and requirements for partners/relatives to confirm identity before transfer of the baby to the mortuary compounded parents’ distress. Health workers described significant personal impacts, an increasing blame culture surrounding poor outcomes and a lack of education and preparation for caring for bereaved parents.

4) Conclusions: This study has contributed to understanding the response of the health system to bereaved parents in Kenya and Uganda, identifying potential service improvements. The results will be used to develop interventions to improve bereavement care e.g. educational packages, which will be tested in future trials.

Ethics statement: Approval for this study was obtained from University of Manchester (UREC2017-0233-4462), University of Nairobi/Kenyatta National Hospital (P240/05/2017) and Makerere University SHSREC/UNCST (SS 4666). Parent participants were identified and approached via clinical teams, for consent for contact by the research team. Following, verbal and written explanations and time to consider, written consent was obtained. Interviews were conducted at a venue of participants choice with pseudonyms used to protect identity. A study-specific distress policy was adhered to at all times

Conflicts of interest: None


Keywords: bereavement care, parents experiences, professional experiences, lmic

Breaking bad news during prenatal ultrasound screening

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1) Background: Breaking bad news during pregnancy is a difficult matter for health practitioners and only a few studies tell us which specific communication skills they need. This study reviewed current literature and suggests a guideline on how to break bad news during prenatal ultrasound screening. 2) Methods: We reviewed all studies published between 1990 and 2017, written in English, and indexed in Medline, PsycNET and Google Scholar databases. We included all studies on: (1) breaking bad news during ultrasound, (2) communication during screenings and examinations, and (3) patient-centred care. Studies concerning the father’s exclusive point of view and studies with no ob/gyn bibliographic background were excluded. We suggested a guideline based on the SPIKES (Setting, Perception, Invitation/Information, Knowledge, Empathy, Summarize/Strategize) protocol that breaks down the communication process in three moments: “before”, “during” and “after” the diagnostic exam. 3) Results: This narrative review shows how the communication modality affects patients’ well-being and their grieving process. The emerging concept of “Grieving multiple losses” is an important one: parents who receive a life-threatening foetal diagnosis grieve both the loss of a healthy baby and their prospect of future parenting. Patients often feel alone and stigmatized by relatives and friends, so they look for support from health care practitioners, who need to know parents’ needs to better break bad news without grounding their knowledge on stereotypes. Based on this review, we created a step-by-step guideline that provides easy to follow recommendations and “dos and don’ts”, tailored to prenatal ultrasound screenings. 4) Conclusions: Starting from results of our literature review, we created a new communication guideline for healthcare providers. Further research could validate its use in a clinical setting.

Ethics statement: No subject was enrolled in this study, approval from the ethics committee was not required.

Conflicts of interest: None


Keywords: communication skills, prenatal care, breaking bad news, prenatal screening

Healthcare for perinatal grief within the Healthcare Follow-up Programme for Puerperal Care in the Health Area of Lanzarote, Spain

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Stillbirth is a devastating experience for parents. In our environment, pregnant women receive continuous care for the correct control of pregnancy, delivery and postpartum. In the case of gestational or perinatal loss, this care is interrupted, not attending to the physical, emotional and psycho-social needs. This lack of continuity of care in addition to not being respectful with the process and not detecting risk, can cause a deep sense of abandonment in women and contribute to the complication of mourning. Since June 2018, the Puerperal Domiciliary Care Program aims to promote the proper evolution of the puerperium by favoring health and early detection of risk for the mother and / or the newborn. To guarantee continuity of care and improve accessibility, two actions were implemented: - Creation of a medical referral computer application for specific cases, which allows filtering by inclusion criteria, in which perinatal death is included since February 2019. - Implementation of telephone consultation with the midwife through 012. A protocol has been designed to follow up miscarriages and late fetal losses. This will involve the multidisciplinary team including: follow ups from community midwives, obstetric review and mental health referral criteria. This will be within a framework providing high standards of care and improve the way in which miscarriages and fetal demise handled in an individual and personal manner. The aim of this project is to improve the grieving process of women and families affected.

Ethics statement: No ethics approval required

Conflicts of interest: None


Keywords: stillbirth, puerperium, home care, midwife, continuity of care

Mater Mothers Perinatal Loss Service

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(1) Pastoral Care Practitioner, Mater Mothers Hospital; (2) Perinatal Loss Coordinator, Mater Mothers Hospital

1) Background: The Mater Mothers’ Hospital is one of Australia’s largest tertiary providers, delivering over 10,000 live babies every year. It is also the home of one of the most successful Perinatal Loss services in Australia. The purpose of this study is twofold: (1) to critically evaluate the exclusive Perinatal Loss Service and the care experiences of families who have experienced a loss (2) to provide an overview of a holistic approach model of care and its benefits. It aims to primarily care for the human spirit by addressing the physical, emotional, social and spiritual needs. Perinatal Loss does not discriminate against race, culture or age and with this knowledge, the service equips all families, through evidenced based care, to manage their grief and loss.

2) Methods: A quality assurance questionnaire covering topics such as: memory creation, spiritual needs/rituals, education and critical care, provided during time in hospital, is sent to families within three months of their loss.

3) Results: The findings indicate the Mater Mothers Perinatal Loss service is exceptional in the way in which bereaved families are cared for. 95% surveyed were extremely satisfied 90% found memory creation and rituals performed were meaningful in their grieving and healing.

4) Conclusions: The implications of this study proves that the tools used benefits the families as they journey forward and heal after their loss. Given the nature of the traumatic experience that these families have endured, as well as the widely differing needs of a culturally, linguistically and socio-economically diverse population, there are challenges. Some of these include the low response rates to the survey, as well as varying individual needs relating to marginalised populations.

Ethics statement: The Mater Mother’s Perinatal Loss service sought the advice and support of the Mater Research HREC Committee. Participation in the study was voluntary and questionnaire responses were provided anonymously.

Conflicts of interest: None


Keywords: bereavement care, spiritual care, perinatal loss

Perinatal loss: the emotional impact of the death of one of the twins on the family and professional team in a NICU

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This is the story of a family that showed us the strength of love and the courage of a premature birth of their twins on different days and the death of one of them. This is also the story of all those professionals who accompanied them in bidding farewell to one of their sons and in the daily struggle for the survival of the other twin. This family began their paternity in the NICU with the birth of their twins. Pau was born at 25.6 gestational weeks (GW) while Héctor remained intrauterus for a further 11 days having been born with 26.6 GW. Vanesa and Rafa were aware of the risks due to extreme prematurity but nothing predicted the death of the second twin, who initially presented a better prognosis. Héctor died at 47 days of age due to an uncommon complication while Pau was still struggling to survive. After facing grief due to the extreme prematurity of their children, Vanesa and Rafa lived the hardest moment of their lives: whilst mourning the death of their son, they had to remain strong in order to continue supporting Pau in the same NICU where they said goodbye to Héctor. Héctor’s death had an emotional impact on the entire team as, despite their loss, we had to continue supporting the parents, caring for and celebrating each of Pau’s tiny victories. The special circumstances presented by this case, illustrates the emotional impact on both parents and those professionals who accompanied them during these difficult 6 months. It was both a challenge and an honor to have been by their side. The relationship that we built with them has shown us the tremendous love shared by this family. The trust and faith that Vanesa and Rafa have placed in our team was crucial to overcome the many struggles that we faced together.

Ethics statement: Informed consent was provided by the family.

Conflicts of interest: None


Keywords: emotional impact, perinatal loss, premature twins, emotional impact, perinatal loss

Cite as: Perinatal loss: the emotional impact of the death of one of the twins on the family and professional team in a NICU. J. Puig, S. Dias. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Perinatal loss ¿Do we know how to communicate bad news?

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(1) Midwifery, Motril Hospital; (2) Midwifery, Andalusian Service Health

1) Background: Bereavement is a series of normal and healthy responses in a person when a loss occurs. This research focuses on the information received from the obstetric team and more specifically their skills to communicate this kind of news. The relationship with parents is based on sensitivity, empathy, respect and understanding, as well as adequate verbal and nonverbal communication. There are phrases that are used to break the silence, although they seem comforting, they may only manage to minimize or invalidate the parents’ pain. The objective of this study is to identify and classify the expressions/comments made by health professionals in a situation of perinatal loss.


3) Results: The care received by a couple who has suffered a perinatal loss and the health professionals performance has a huge impact on the development of a healthy grieving. The way the bad news were given and received is a risk factor for the development of a complicated bereavement. Below are shown in the table 1 sentences/expresions that validate the loss and those that should be avoided.

4) Conclusions: Professionals who are part of the scenarios where perinatal losses occur should be aware that their communications skills can promote the development of a healthy grief with a series of humanized care intended on the one hand, to recognize and validate the loss, legitimizing the reactions and feelings of loss of couples and, on the other hand, to promote the empowerment of parents through a common space in which they participate more actively and make their own decisions in an informed manner.

Ethics statement: No ethics approval required.

Conflicts of interest: None


Keywords: perinatal bereavement perinatal loss stillbirth care bereavement

Cite as: Perinatal loss ¿Do we know how to communicate bad news? M.T. Rivas, R.B. Arrabal, R. Sáez. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Stigma toward families of small, severely ill or stillborn babies and their mothers in Ghana: the experiences of postpartum women in Ghana

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(1) The Center for Learning and Child Development of Ghana; (2) Oakland University & (3) Johns Hopkins School of Public Health

1) Background: Small, ill and stillborn infants are subject to both medical and social vulnerability. This stigma has received little attention, especially in sub-Saharan Africa, where the burden of these conditions is highest. 2) Methods: We conducted a qualitative study to explore stigma related to baby’s size and appearance among 30 postpartum women who had given birth to small, severely ill or stillborn infants. Participants were recruited from two tertiary hospitals located in Accra, Ghana, and participated in semi-structured interviews. Mothers were asked about their understandings of the etiology and impact of birth size, health condition, or death, and the social experiences of having a small, severely ill or deceased newborn in the postnatal period. Data analysis was informed by interpretive phenomenology. 3) Results: Mothers’ evaluation of their babies’ smallness was based on their size, and not their weight. Stories indicated that babies’ identity was tainted because of their “undesirable” physical features and people’s unfamiliarity with their size or unique appearance. Participants’ narratives show that both caregivers and others characterized small or severely ill babies as being abnormal or looking “animal-like.” This devalued identity, mothers reported, was the basis for several negative stigmatizing behaviors toward them and their infants, which ranged from gossip to withdrawal of social support. Participants described ways in which mental distress from having a small or severely ill newborn manifested in their lack of self-care. Participants also described how having a stillbirth was a reason for withdrawal of social support and secrecy. 4) Conclusions: In Ghana, being born small or having a severe health condition is an attribute that invites stigma toward the mother-child dyad. Having a stillbirth also leads to shame, secrecy and withdrawal of social support. Beyond prevention of these adverse outcomes, the findings support a multi-pronged approach, including sensitization, counseling, and multi-disciplinary health care team to address this stigma and its consequences.

Ethics statement: Three ethical review boards approved this study. They were the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB No. 6651), the Ethical and Protocol Review Boards of the Ghana Health Services (ID: Ms-Et/M2-P4.1/2015-2016) and the University of Ghana Medical School (ID: GHS-ERC 16/09/15). All participants provided a written informed consent before the interview proceeded.

Conflicts of interest: None


Keywords: Ghana, postpartum, stigma, stillbirth, severe illness

Cite as: Stigma toward families of small, severely ill or stillborn babies and their mothers in Ghana: the experiences of postpartum women in Ghana. S. Kwame, E. Sacks. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Health workers’ experience of communicating the bad news to parents following a stillbirth at sub-national level in Uganda

E. Ssegujja (1,2), M. Andipartin (3)

(1) Makerere University School of Public Health, Kampala Uganda; (2) University of Western Cape, School of Public Health, South Africa; (3) University of Western Cape, Department of Psychology, South Africa

1) Background: Losing a loved one due to stillbirth is a heartbreaking experience to parents and devastating to a health worker. Delivering news is every pregnant woman’s worst nightmare and a daunting task to health workers more so in the absence of a structured protocol to aid in communication. It remains an everyday challenge in the fight against stillbirth and systematic documentation of experiences especially from resource-constrained setting is still missing. This paper explores the health workers’ experience in communicating stillbirth loss to the mothers from a relatively high stillbirth burden district in Uganda. 2) Methods: A cross-sectional descriptive study was conducted in a single district case in Uganda. Qualitative interviews were conducted from August to October 2018 on a purposively selected sample of 15 key informants using audio recorders and interviews transcribed verbatim. Content analysis technique using Atlas ti guided the analysis. 3) Results: Overall great feelings of vulnerability due to inadequate skills were noted among health workers. Doubts about key message to communicate, the cause and context hence guided the nature of communication and delivery of bad news. Cases due to facility-related causes differed to either a doctor or facility in-charge while direct disclosure by midwives was done for cases due to maternal and fetal conditions. Sequencing of disclosure events was common where some information was shared at discharge and later after discharge. When space allowed, mothers were isolated before disclosure while c-section cases, disclosure was withheld until recovery and thereafter led to an isolation room for emotional recovery before discharge. Reported difficulty to deliver bad news to compliant mothers was noted. 4) Conclusions: Health workers felt their competence to manage was challenged first by the loss but also by inadequacy in communication skills calling for interventions to bridge this gap.

Ethics statement: Ethical approval was from University of Western Cape Biomedical Research Ethics Committee (BM/17/9/1), Makerere University School of Social Sciences Research and Ethics Committee (MAKSS REC 12.17.110) and Ugandan National Council for Sciences and Technology (SS 4575). Permission from district authorities and individual written consent were obtained before interviews. Respondents’ safety was ensured by conducting the interviews in a secure and quiet location, giving assurance that data collection was purely for study purposes, anonymizing the data and keeping it on a password protected computer only accessed by the study team.

Conflicts of interest: None


Keywords: stillbirth, communication, parents, health workers

Cite as: Health workers’ experience of communicating the bad news to parents following a stillbirth at sub-national level in Uganda. E. Ssegujja, M. Andipartin. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Still Life – Engaging the public with stillbirth research through creative methods: A pilot project

K. Cresswell (1), S. Thomas (2,3), L. Stephens (2,3), M. Dilworth (2), A.E.P. Heazell (2,3), C. Sibley (2), M. Desforges (2)

(1) Public Programmes Team, Research and Innovation Division, Manchester University NHS Foundation Trust, Manchester UK; (2) Division of Developmental Biology and Medicine, Faculty of Biology, Medicine and Health, The University of Manchester; (3) Manchester University NHS Foundation Trust, Manchester UK

1) Background: The University of Manchester’s Maternal and Fetal Health Research Centre (MFHRC) is a specialist stillbirth research centre funded by Tommy’s, the largest UK baby research charity. Stillbirth remains a taboo subject for many, often leaving families affected by it socially isolated. It is therefore imperative to raise public awareness about stillbirth and the research taking place to prevent it. Members of the MFHRC ran a pilot project in 2018 to engage both women who had a stillbirth and the wider public with their research. 2) Methods: 3 women who had experienced stillbirth took part in 4 creative workshops. The workshops were developed by an artist alongside MFHRC researchers, midwives and a public engagement practitioner. The workshops helped the women express their experiences through art whilst providing a safe space for discussion about stillbirth and research. MFHRC researchers also took part in the workshops to facilitate the discussions on research. 30 pieces of art, poetry and sculpture were created and showcased at a public exhibition.

3) Results: Workshop participants reported reduced feelings of guilt and blame around their stillbirths due to a greater understanding of the causes: ‘It helped me to let go of some of the blame on myself – we learned so much about the placenta… there was no way I could have known or had any control over what was going on’ (Participant). Exhibition attendees felt that they had a greater understanding of stillbirth and appreciation of the need for research in the area: ‘The exhibition really moved me. It really demonstrated how vital research is not least to help make sense of the loss.’ (Exhibition Attendee). 4) Conclusions: Creative public engagement techniques could be an effective way of discussing highly sensitive topics such as stillbirth. The resulting outputs may be incredibly powerful in raising public awareness of these issues and engaging people in research.

Ethics statement: Ethical approval was not required for this project as it was a public engagement project rather than a research study. The wellbeing of the women involved in this project was of high importance and as such steps were taken to ensure they had support during and after taking part in the workshops. A specialist midwife was present at all workshop sessions and participants were able to contact the specialist midwives after the sessions for further support if required. Consent was sought from the women to take part and to showcase any pieces created.

Conflicts of interest: None


Keywords: stillbirth, public engagement, research, creative, placenta, raising awareness,

A narrative inquiry into the experiences of indigenous women in Canada who have experienced perinatal loss

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(1) McEwan University and St. Stephen's College; (2) University of Alberta, Edmonton, Alberta, Canada

1) Background: This study is a narrative inquiry into the experiences of Indigenous women in western Canada who have experienced the death of their child during the perinatal period. It is difficult to accurately reflect the infant mortality rate for Indigenous women due to a lack of data collected, however, it is estimated that the rate is at least twice that of the national average and in some communities as high as three to four times the national or regional average. The objective of this research is to understand Indigenous women's experience, as well as to address how health care practices and bereavement programs can be improved. This research comes at a critical time when Indigenous communities are reclaiming, reviving and reintegrating culturally meaningful ways of attending to women.

2) Methods: In this narrative inquiry study, I engaged in conversations with four women over a period of two years (2015 to 2017). Narrative methods consisted of tape-recorded conversations, field texts and observations. Through a collaborative process of interpretation and analysis, interim and final research texts reflect the women’s experiences, as well as my relationship with them.

3) Results: Spending time together allowed the women to articulate their stories of loss. Making spaces for Indigenous women means creating spaces in which they can explore and represent life experiences, a risky and sometimes difficult process. Allowing women to tell their stories, humanized the process of loss and validated their emotions and feelings. The research in this way also became a journey marked by healing and recognition of the strength of Indigenous women and families.

4) Conclusions: Narrative inquiry is attentive to experience over time and in diverse places, beginning from, and unfolding through, relationships. It is important care providers position themselves as people alongside Indigenous women to actively listen, learn from, and inquiry into lived experiences of Indigenous women.

Ethics statement: Ethical approval was obtained from the Research Ethics Board at the University of Alberta, Edmonton, Alberta, Canada (Approval #: Pro00054203). Individual written consent was obtained by all participants, access to a counselling referral was offered to each participant.

Conflicts of interest: None


Keywords: indigenous women, Canada, perinatal loss, qualitative, narrative inquiry

Cite as: A narrative inquiry into the experiences of indigenous women in Canada who have experienced perinatal loss. R. Tootoosis, V. Caine. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
PREGNANCY AFTER LOSS
Group Psychotherapy intervention in perinatal loss looking for a new pregnancy: supporting families within the hospital environment

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Perinatal bereavement is a complex experience which has a deep impact on families’ psychological wellbeing. It remains very challenging for parents to process their feelings and thoughts regarding their babies, as society tends to deny the legitimacy of their loss. Ambiguous feelings often emerge in the process of “moving on” when such families are desiring a new baby, while they also struggle with the memory of the “lost child” and the place it occupies in their hearts, their minds and family history. We offer group psychotherapeutic intervention for families who lost their babies on the 3rd trimester of pregnancy, for families who suffered the loss of a newborn and who are desiring a new pregnancy. The group is coordinated by a Clinical Psychologist with psychologists/psychiatrists in-training participating as observers. Emerging issues are: Feelings of guilt when families are moving along in the process of bereavement, adjustment issues which manifest as lack of acceptance of their current situation, avoidance of young babies, fear of a new pregnancy and of not loving their future baby. The group allows the opportunity for parents to process their experiences with the Hospital staff. It also provides an opportunity to make suggestions regarding how a “more supportive approach” would better meet their specific needs. Mindfulness exercises are also used to address intense painful emotions as they emerge in the group. We believe that Group Psychotherapy is a particularly useful tool for assisting families in the context of perinatal loss. Specifically, when such families who have suffered the loss of a baby embark on a new pregnancy with added stressors due to unprocessed feelings regarding their previous loss. We consider that these families need a different level of care from health professionals, a group psychotherapeutic intervention which can become a “holding environment” and a safe space for these families.

Ethics statement: Ethics approval no required.

Conflicts of interest: None


Keywords: perinatal loss, families, group psychotherapy, new pregnancy, mindfulness

Cite as: Group Psychotherapy intervention in perinatal loss looking for a new pregnancy: supporting families within the hospital environment. L. Álvarez-Cienfuegos Cercas, Y. Beizama Bergara, L. Pina Camacho. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Planning the next pregnancy

S. Broderick (1), R. Cochrane (2)

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Care in a future pregnancy after the death of a baby needs to be sensitively planned. Some bereaved parents cannot contemplate another pregnancy, or another at the same hospital. A letter from a consultant obstetrician is required with details of her loss and a plan for future care, wherever that is. A small team of an obstetrician, a senior midwife and an experienced counsellor creates a sense of trust and a degree of safety. Parents are not confronted with staff who may not know their ‘story’. Women, their partners and their wider families will all be anxious: caring for them can be challenging but hugely worthwhile. Some women want to be seen weekly, some less often. It may take them time to trust that the plan will work, particularly if their previous experience of care was not good. Once a baby has died no parent can assume that they will have a live baby. Repeated pregnancies with a ‘good’ outcome do not equal confidence. A woman who had a term stillbirth in her first pregnancy because of a true knot in the cord was just as anxious in her third pregnancy, even though the second baby was fine. Parents may want to revisit the place where they gave birth. The last time they were there was when they were bereaved. Parents then have the opportunity to deal with feelings that might overwhelm them before the next birth. If the mode of delivery is different from the last, it is valuable to take parents through the process, including e.g. visiting the anaesthetic room and the theatre. Understanding what will happen will lessen their anxiety. Knowing in advance what to expect can be very helpful. Giving parents as much control as possible in an area where they have experienced having no control is vital in a future pregnancy. Having supportive advocates, knowing what to expect and believing that their feelings and concerns will be at the forefront of their experience will be empowering for them.

Ethics statement: Ethics approval not sought, as this content describes our professional experience.

Conflicts of interest: None

View with full poster: www.isa2019madrid.com/planning-the-next-pregnancy

Keywords: sensitive caring empowering plan

Cite as: Planning the next pregnancy. S. Broderick, R. Cochrane. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Impact of prior perinatal loss on subsequent pregnancies: a bibliographic review

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1) Background: Many believe that becoming pregnant again after a perinatal loss from miscarriage, stillbirth, or neonatal death will ease a parent's grief, wipe away the sad memories of loss, and make a woman smile again. However, pregnancy after perinatal loss is increasingly recognized as a psychologically stressful period of time. 2) Methods: A bibliographic review was made in the Pubmed online databases, on March of 2019. The keywords for the search were the following: pregnancy, perinatal loss, grief. 3) Results: Although parents had differing responses at the time of the loss, all described similar emotions during the current pregnancy which they attributed to the previous loss. These emotions included increased concern related to the outcome of the current pregnancy, a heightened sense of risk since the loss, a realization that something could go wrong with the current pregnancy, and a need for increased vigilance. Additionally, a relationship has been demonstrated between anxiety during pregnancy and developing prenatal attachment. The parents in these studies had many anxieties related to the outcome of subsequent pregnancies. Regardless of the timing of the loss or the investment in the previous pregnancy, a greater need to monitor the progress of the current pregnancy and a hesitancy to anticipate a positive outcome was reported. 4) Conclusions: Understanding how parents experience a subsequent pregnancy after perinatal loss can also assist nurses in addressing the specific needs of parents themselves during the next pregnancy. Teaching coping strategies to be used in subsequent pregnancies could help parents to acquire a greater sense of control during this stressful experience for his family. If higher levels of anxiety can diminish prenatal attachment, this is an important clue for nurses in their care of families who have experienced a loss.

Ethics statement: No ethics approval required.

Conflicts of interest: None


Keywords: perinatal loss, subsequent pregnancies, grief, bibliographic review

Impact of pregnancy after loss “Rainbow Clinic” in a UK University Hospital, on continuity, unplanned attendances and cost; a mixed methods study

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Department of Obstetrics and Gynaecology, Norfolk and Norwich University Hospital, Norwich, Norfolk, United Kingdom.

1) Background: Norfolk and Norwich University Hospital in the East of England, United Kingdom has approximately 6000 babies delivered per annum and provides obstetric care via a number of themed clinics. A specialised Rainbow clinic was introduced to provide care for women and their families with pregnancy after loss. The Rainbow team consists of a Consultant Obstetrician and Specialist Bereavement Midwife who provide holistic care in a continuity model. This is a mixed methods study, qualitatively examining the early impact of Rainbow Clinic on continuity of obstetric care, numbers of both planned and unplanned admissions along with cost saving modelling.

2) Methods: Unmatched cohort data was analysed from hospital notes, handheld notes and the maternity IT system (Euroking). All women who have been referred to Rainbow Clinic and subsequently delivered were included in the Rainbow Cohort, the same number of women immediately preceding introduction of the Rainbow Clinic made up the Pre-Rainbow Cohort. A review of published data was performed to provide estimates for the cost saving modelling.

3) Results: There was a reduction in planned attendances in the Rainbow cohort 6.83 appointments versus 8.33 in pre-Rainbow cohort. There was a statistically significant reduction in the number unplanned attendances in the Rainbow cohort (2.33 attendances versus 8.16 in pre-Rainbow cohort). The authors also noted a reduction in number of different clinicians seen at planned appointments in post-Rainbow cohort (3.66 versus 5.6 in pre-Rainbow cohort) and an increase in number of times seen by the same clinician (4.16 versus 3.33 in pre-Rainbow cohort).

4) Conclusions: This cohort study demonstrates an association between continuity of carer in pregnancy after loss care and a reduction in unplanned attendances in the antenatal period. The authors have also demonstrated the potential financial savings associated with this model of care.

Ethics statement: Ethics approval was not sought.

Conflicts of interest: None


Keywords: pregnancy after loss, continuity of carer

Cite as: Impact of pregnancy after loss “Rainbow Clinic” in a UK University Hospital, on continuity, unplanned attendances and cost; a mixed methods study. B.G.C. Tomlinson, K.L. Kordtomeikel, A.B. Gibson. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Pregnancy After Stillbirth: An international qualitative analysis of the patient experience -- Research In Progress

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In Canada, about 3000 stillbirths occur per year, 3.5-5 per 1000 live births. Many of these families will conceive again shortly after this devastating loss, but these subsequent pregnancies are fraught with anxiety and worry for multiple reasons. There are few guidelines on how to best care for these patients, medically or psychologically. Prenatal care studies frequently leave out women who have had stillbirths. They are either excluded during recruitment, considered “confounding” during analysis, or it is simply not specified if women’s previous births were live or not. This is the gap we’re interested in. This study is a retrospective analysis of a cross-sectional survey. The data is secondary data from a large-scale multi-language, web-based survey of 2716 bereaved parents across 40 countries in six languages, as part of The Lancet Stillbirth Series Call to Action: Impact on Priorities in High-Income Countries. A subsection of this survey was answered by respondents who reported a subsequent pregnancy after their stillborn baby. In addition to quantitative questions, three open-ended questions were asked about perceptions of their care in that subsequent pregnancy and how that care could have been improved. A social constructivist framework will look to those written responses of patients to gain access to their experiences. Our epistemological assumption is that the reality of the patient experience is subjective, meaning it is constructed from the patients themselves, rather than verifying ideas we already hold. Inductive thematic analysis with an open coding framework and constant comparative method will give a robust insight into parents’ experiences and what would be considered high quality, excellent care. What are the most important aspects of patient-centred care in pregnancy after stillbirth, from the parent perspective? This is research in progress and results are expected by Spring 2020.

Ethics statement: This is a secondary data analysis -data is currently housed at the Mater Research Institute, University of Queensland. Original study received approval through the Mater Institute as: Project 22696: “Priorities to address stillbirth in high income countries”. We have received amendment approval to share the data with the primary author: Amendment to Project 22696. Reference: AM/MML/22696 (V2). -now applying for ethics approval through the University of Guelph, Ontario, Canada, for use of secondary data. -then data sharing agreement will be put in place between our institutions.

Conflicts of interest: None


Keywords: subsequent pregnancy after stillbirth, patient-centred care.

Information regarding the cause of stillbirth has a limited ability to predict the outcome of a subsequent pregnancy

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(1) Maternal and Fetal Health Research Centre, Faculty of Biology, Medicine and Health, University of Manchester, UK; (2) Division of Obstetrics, St Mary’s Hospital, Manchester Academic Health Sciences Centre, UK; (3) St Mary’s Hospital, Manchester University NHS Foundation Trust, Oxford Rd, Manchester, UK.

1) Background: Women who experience a stillbirth are 5 times more likely to experience a recurrent stillbirth, as well as having increased risk of other adverse outcomes. Origins of this increased risk are not well understood as few studies have examined cause of death in recurrent pregnancy loss. This study aimed to explore the relationship between the cause of index stillbirth and subsequent pregnancy outcome. 2) Methods: Retrospective cohort study, cases included if stillbirth was investigated, subsequent pregnancy care provided, and birth was in the same tertiary UK maternity unit. Stillbirth classified using the ReCoDe system. Data on maternal characteristics, findings of investigations at the time of death and the cause of death were extracted and logistic regression performed to determine whether these factors were independently associated with adverse outcome in subsequent pregnancy. 3) Results: In this cohort (n=213), there were 43 adverse outcomes (20.2%) including: one stillbirth, one neonatal death. Most common were preterm delivery (11.3%) and birthweight >10th centile (10.3%). Half of preterm deliveries were iatrogenic, where delivery expedited for abnormalities in fetal growth (42%) and antepartum haemorrhage (25%). There was no significant association between maternal characteristics and adverse outcome in subsequent pregnancy. Cause of stillbirth (p=0.96), gestation of stillbirth (p=0.18) and stillbirth placental weight >10th centile (p=0.13) were not associated with subsequent pregnancy outcome. Maternal vascular malperfusion evident on placental histology had increased risk of adverse outcome in subsequent pregnancy p>0.01 (OR 5.31 (95% CI 1.16, 24.35). 4) Conclusions: Women who have a history of stillbirth have increased risk of adverse outcome in subsequent pregnancies. However, maternal characteristics and classification of cause of stillbirth do not affect risk of adverse outcome. Therefore, increased surveillance is recommended in all pregnancies after stillbirth.

Ethics statement: This study was approved by South East Coast- Surrey research ethics committee (Ref 16/LO/1666)

Conflicts of interest: None


Keywords: stillbirth, recurrence, maternal vascular malperfusion, adverse outcome

Cite as: Information regarding the cause of stillbirth has a limited ability to predict the outcome of a subsequent pregnancy. N. Graham, G. Batra, A.E.P. Heazell. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Is stillbirth a risk factor for development of systemic lupus erythematosus in the UK?

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1) Background: Autoimmune Connective Tissue Diseases (CTDs), such as Systemic Lupus Erythematosus (SLE), have a female preponderance and are associated with an adverse pregnancy outcome (APO). This study assessed the prevalence of CTDs, antiphospholipid syndrome (APS) and autoimmune antiphospholipid antibodies (aPL), in women with an APO, compared to those who had an uncomplicated livebirth. 2) Methods: A national study was performed, using the Clinical Practice Research Datalink (CPRD) for the timeframe 01/01/2000-31/12/2013. Each case of APO was matched to 5 livebirths by primary care practice and maternal age. Women were followed serially for SLE diagnosis, CTD, APS or autoimmune antibodies. Poisson regression was performed to calculate relative risk ratios (RR) and 95% confidence intervals (CI) for the development of these conditions for APO vs. livebirth. 3) Results: CPRD identified 20,123 APOs, matched to 97,323 livebirths. 875,590 person-years follow-up was available. Mean follow-up was 7.45 years (SD 4.39). 1,850 new autoimmune diagnoses were recorded, with an SLE incidence of 0.05%. Stillbirth was associated with an increased risk of developing specific autoimmune conditions (RR 5.82 (95% CI 4.97-6.81)), as was miscarriage (RR 3.41 (95% CI 3.03-3.85)), fetal growth restriction (RR 2.69 (95% CI 1.50-4.83)) and placental abruption (RR 3.39 (95% CI 1.96-5.89)). For SLE specifically, the risk was greatest following stillbirth (RR 4.10 (95% CI 3.14-5.36)). For CTD, SLE and development of non-aPL antibodies, the risk was greatest within 4 years of APO, whereas aPL antibody and APS diagnosis were highest ≥ 5 years from APO. 4) Conclusions: APO is associated with an increased risk of subsequent development of maternal CTD, including SLE. This may result from an underlying immunological factor which predisposes women to both APO and subsequently CTD development or that APO initiates an autoimmune process which culminates in the development of clinically evident CTD.

Ethics statement: Ethical approval was granted by the Independent Scientific Advisory Committee (ISAC) (protocol 14_106R).

Conflicts of interest: None


Keywords: stillbirth epidemiology

Psycho-adaptive changes and mindful breastfeeding in the postpartum period after previous perinatal loss

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1) Background: Childbirth, which affects both the woman and her relatives, is one of the most important developmental transitions in a woman's life. This developmental transition stage brings physical, psychological, social, and spiritual changes in women's lives and affects new mothers' wellbeing. Because it is directly related to the mother's/baby's health, examining the readiness of mother to childbirth and helping her to be a mindful mother are important caring interventions, especially for women who had a perinatal loss in her previous pregnancy. Mindfulness practices become a resource for birthing, parenting, and living with awareness, kindness, connectedness, and care. 2) Methods: The aim of this study was to emphasize on mindfulness-based interventions in the motherhood process in women who had a perinatal loss in her previous pregnancy. This study employed a descriptive qualitative approach. Using the purposeful sampling method, 18 primiparous women who received postnatal care at the Antalya Education and Research Hospital between May-June 2017 were interviewed. A thematic analysis was conducted to derive themes from subthemes, which were derived from the contents of the interview. 3) Results: The women's experiences about psycho-adaptive changes were collected under eight main themes. These themes were respectively changed in values, change in personality, change in hand skills and time management, change in priorities, change in problem-solving skills, increase in self-esteem, change in social life, and change in relations. Some themes have sub-themes. 4) Conclusions: The findings of this study reveal that the mothers have experienced significant personal, behavioral, and life changes, have attained maternal identity and have adapted to their maternity roles.

Ethics statement: Ethical approval was obtained from the Ethical Committee of the Antalya Training and Research Hospital that follows international standards and the principles adopted by the World Medical Association Declaration of Helsinki (Approval No: 70/05)

Conflicts of interest: None


Keywords: psycho-adaptive changes, breastfeeding, motherhood

Cite as: Psycho-adaptive changes and mindful breastfeeding in the postpartum period after previous perinatal loss. O. Korukcu, K. Kabukcuoglu. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Helping families navigate the emotional tidal wave of subsequent pregnancy post perinatal loss

K. Ludski

CEO Red Nose Australia, Director Peace of Mind Counselling and Supervision

Pregnancy should be one of the happiest times of a family’s life. A time of excitement, planning, dreaming of a future with a beautiful and healthy baby. However, for families who have experienced perinatal loss their subsequent pregnancies are fraught with intense fear, anxiety and a whole gamut of mixed emotions. The associated struggle to hold both excitement at the prospect of a healthy baby and the grief attached to the previous loss is evident in many cases. There is also the perception, by those supporting the grieving family, whether that be family, friends or clinicians that a subsequent pregnancy signals the end of the grieving period and a re-engagement with ‘normal’ life. It is important that individuals supporting these families understand the impact of the previous loss and are resourced with strategies to provide support to help families navigate the emotional tidal wave of a subsequent pregnancy. This session will focus on strategies to best support families through a subsequent pregnancy through a lens of self-compassion, self-understanding and the integration of the Dual Process Model. This abstract represents the voices of the perinatally bereaved I have supported over the last 16 years. There are consistent themes that have emerged in regard to subsequent pregnancies post loss and the lack of real understanding by friends, family and clinicians of the intense emotions and anxiety that are experienced in a subsequent pregnancy. Clients feel they need to hide their true feelings and emotions at this challenging time and wear a mask of happiness.

Ethics statement: Ethics approval not required

Conflicts of interest: None


Keywords: perinatal loss, subsequent pregnancies, support

Cite as: Helping families navigate the emotional tidal wave of subsequent pregnancy post perinatal loss. K. Ludski. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Health guidelines for pregnancy after perinatal loss

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A new pregnancy, for those who have suffered miscarriage, stillbirth or the death of a baby at or after birth, is an especially sensitive and potentially vulnerable period, that often requires professional support tailored to the physiological and psychological needs of the mother-to-be. A new pregnancy after the loss of a baby may cause a high level of stress that should be dealt with all through the gestation period. The stories and experiences shared by the women that attend the Grieving Parents Support Group lead by the Asociación de Psicología Perinatal Murcia (APPM), highlight the need of healthcare professionals with specific training that can provide quality attention. From the knowledge of experience, we propose to create a Counseling Guide for Pregnancy after Perinatal Loss that collects required information to be able to plan the process of labor and delivery to avoid stressful situations. The objective of the guide is twofold: (a) to continue raising the awareness and visibility of perinatal grief, and (b) to offer quality healthcare able to cover all aspects of a human being. Once completed, the guide will be made available through primary health care centers and hospitals in Murcia, in paper and digital format (through QR codes). The APPM also has the support and collaboration of the association of midwives at the Hospital Clínico Universitario Virgen de la Arrixaca of Murcia. The specific needs of these kinds of pregnancies supported by healthcare professionals with specific training, awareness and empathy. The creation of this Guidelines implies a recognition of the situations suffered during perinatal grief, and the circumstances and symptomatology associated with the new pregnancy. In addition, the guide helps improve the training of medical personnel and enables the future mother to trust again in the public health service.

Ethics statement: No ethics approval required

Conflicts of interest: None


Keywords: miscarriage, stillbirth, pregnancy, neonatal, mourning, rainbow-baby, guidelines

Pregnancy after stillbirth: maternal and neonatal outcomes and health service utilisation

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(1) Cork University Maternity Hospital, Ireland; (2) University College Cork, Ireland; (3) School of Nursing and Midwifery, University College Cork, Ireland; (4) Pregnancy Loss Research Group, INFANT Centre, University College Cork, Ireland

1) Background: Pregnancy after stillbirth attracts increased antenatal surveillance and interventions. Maternal and neonatal outcomes, and health service utilisation in pregnancy after stillbirth within an Irish context was lacking. Objectives: The study’s purpose was to investigate the needs of women in pregnancy after loss, and to investigate maternal and neonatal outcomes. 2) Methods: A retrospective cohort study of all pregnancies after stillbirth from 2011-2017 was conducted. Data were collected from a single tertiary-referral university maternity teaching hospital with 8,000 births annually and a dedicated fetal medicine team. 3) Results: There were 222 stillbirths reported. 65.3% of women (145/222) had a pregnancy after loss, the majority of whom (131/145) had a livebirth. 19.3% of pregnancies (28/145) ended in miscarriage, but 57.1% (16/28) had a livebirth after miscarriage. Average inter-pregnancy interval was 1.3 years, with 20% (29/145) conceiving within the same year. The average number of antenatal hospital visits was twice that expected (9.2, range 0-27), and the average number of ultrasound scans was five times higher than expected (5, range 0-29). 63.4% of women had screening for gestational diabetes (83/131). 59.5% of births (78/131) were vaginal. 40.5% (53/131) were caesarean sections, 9.6% more than the national average. 48.1% of women (61/131) had an induction of labour, 21.7% more than national rates. Past obstetric history was the indication for induction of labour in 63.5% (40/61). There was a statistically significant increase in the rate of preterm deliveries in pregnancy after loss compared to the general obstetric population (22.9%, 30/131). 23.4% of babies (32/137) required admission to the neonatal unit, more than twice the national average. 4) Conclusions: Pregnancy after stillbirth requires increased surveillance and intervention compared to the general obstetric population. Increased health service utilisation places greater demands on hospital resources. We should be cognisant of additional supports required for women and their families in pregnancy after loss.

Ethics statement: Full ethical approval for this study was obtained from the Local Hospitals Ethics Committee and the Local Information Governance Group (LIGG). This was a retrospective cohort review of patient notes. Data access was approved by the LIGG and limited to the named authors. All data were anonymised and securely stored.

Conflicts of interest: None


Keywords: stillbirth, pregnancy after loss, outcomes

Cite as: Pregnancy after stillbirth: maternal and neonatal outcomes and health service utilisation. R. Roseingrave, M. Murphy, K. O’Donoghue. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
MORTALITY PREVENTION
Fetal movements in stillbirth prevention

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1) Background: Maternal perception of fetal movement is one of the first signs of fetal life and is regarded as a manifestation of fetal wellbeing. A significant reduction or sudden alteration in fetal movement is a potentially important clinical sign. It has been suggested that reduced or absent fetal movements may be a warning sign of impending fetal death. Raising awareness among pregnant women of the importance of detecting and reporting reduced fetal movement (RFM) and ensuring providers have protocols in place, based on best available evidence, to manage care for women who report RFM are one of the four lines of action proposed by the “Saving babies lives” guidance to prevent Stillbirth. At present timely delivery is the only strategy to prevent stillbirth in response to concerns about fetal wellbeing. The objective of this study is to review the latest evidence about fetal movements in stillbirth prevention.

2) Methods: Systematic review in database: Cuiden, PubMed, Cochrane, Medline and Google academic Search strategy: published in the last 5 years, free full text available, according to my search topic, English or Spanish. Key words: “fetal movements” (movimientos fetales) - “perinatal death” (muerte perinatal) – stillbirth (muerte fetal).

3) Results: RFM is only modestly associated with increased risk of stillbirth and whether RFM is a symptom of inevitable fetal death or whether it can be used as an alert to prompt action and improve outcome is unclear. Encouraging awareness of fetal movements it may be harmful. Stillbirths were not significantly reduced by this intervention and there was no effect on perinatal mortality. Current evidence regarding excessive fetal movements is sparse.

4) Conclusions: Information that women receive about the importance of fetal movements and what to do if there are changes is inconsistent and may not be evidence based. Awareness of reduced fetal movement (RFM) is promoted to reduce stillbirth, but the evidence to support the effect of RFM awareness is uncertain. It is important that midwives know the evidence in order to deliver consistent information to women in their care. There is no evidence that any formal definition of RFM is of greater value than the subjective maternal perception in the detection of fetal compromise. This study highlights the need for continued research, education and training in the identification, investigation and management of RFM. Further research is needed to clarify optimum management strategies to optimise maternal and fetal outcome.

Ethics statement: Ethical approval was not sought as it was not required for this study. The authors have stated explicitly that there are no conflicts of interest in connection with this article, neither external funding.

Conflicts of interest: None


Keywords: stillbirth, "perinatal care", "fetal movement"

Cervical length sonographic measurements among non-standardized physicians compared to standardized physicians for the detection of risk of preterm delivery in women of the opportune screening network in Guanajuato

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1) Background: WHO defined as preterm, babies which are born before 37 weeks of gestation, this has family, social impact. Combining sonographic cervical measurements and maternal history, risk for preterm birth can be predicted before 28 SDG with a sensitivity of 81%, and administer preventive treatment to avoid preterm birth or avoid unnecessary management. There are programs that trains and certifies medical staff to perform sonographic screenings, but in our region, the attachment to standard has not been determined. Objective: To measure the concordance between sonographic measurements of cervical length made by non-standardized physicians compared to standardized physicians in order to detect the risk of preterm delivery in pregnant patients.

2) Methods: A Cross-sectional non probabilistic comparison of concordance in sonographic cervical length of consecutive cases was conducted in 1145 women with pregnancy from the state of Guanajuato during the sonographic screening in the 1st trimester at the State Center for timely screening (CETO).

3) Results: A sample of 1145 patients with 91 losses, mean of maternal age 26.3 years, nutritional status with normal weight in 35.3%, over weight and obesity in 61.7%, history of abortion in 23.2% and 9.3% had preterm birth history, gestational age was averaged in 13 weeks, cervical length 33.2mm, Cohen’s Kappa test was performed to evaluate the concordance between seven trained and certified sonographers, the personel with the highest Kappa were those who had undergone a process of standardization, this is showed in table 2.

4) Conclusions: There was an improvement in the degree of inter observer agreement when the staff is subject to standardization processes.

Ethics statement: Approved by the research ethics committee of the Hospital de Especialidades Materno Infantil de León with folio 130-2018.

Conflicts of interest: None


Keywords: preterm delivery, standardization, sonographic measure, cervical length,

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Mortality risk amongst very low birth weight infants born in the Republic of Ireland, 2014-2016

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(1) Researcher Epidemiologist, National Perinatal Epidemiology Centre, University College Cork; (2) Researcher, National Perinatal Epidemiology Centre, University College Cork; (3) Consultant Neonatologist, National Maternity Hospital

1) Background: Globally, there are approximately six million deaths of children under 5 years of age each year, the leading cause of which is preterm birth complications. Very preterm infants are at especially high risk of mortality. The Vermont Oxford Network (VON) is a non-profit voluntary collaboration of health care professionals from nearly 1000 neonatal intensive care units around the world and it maintains a database of information regarding the care and outcomes of high-risk newborn infants. We aimed to use the VON data to assess whether very low birth weight (VLBW) infants born in Ireland in 2014-2016 had a higher than expected risk of death.

2) Methods: Since 2014, all 19 neonatal units in Ireland have contributed data to the VON database on VLBW infants, defined as an infant who is born alive and whose birth weight is between 401 and 1500 grams OR whose gestational age is between 22 weeks 0 days and 29 weeks 6 days (inclusive). VON colleagues use multivariable logistic regression models to quantify the risk of mortality associated with a range of infant characteristics. We used coefficients from these regression models to calculate standardized mortality ratios (SMRs).

3) Results: The VON database had data on 1,812 VLBW infants born in Ireland in 2014-2016, of which 1,765 were records from their hospital of birth. The mortality risk for these 1,765 infants was 1.17 times higher than expected, a statistically significant excess mortality (95% CI: 1.05, 1.29). Infants born at 22-23 weeks had a 23% higher mortality risk (SMR=1.23, 95% CI: 1.02, 1.44) that was almost wholly due to the infants not administered resuscitation. Infants born at 24-27 weeks in a tertiary unit did not experience higher than expected mortality (SMR=1.01, 95% CI: 0.80, 1.23) but those born in non-tertiary units had a 70% higher mortality risk (SMR=1.70, 95% CI: 1.25, 2.15).

4) Conclusions: These findings support the recommendations that resuscitation should be administered to all infants born at 23 weeks who present in favourable condition, i.e. without congenital anomaly, severely small for gestational age, severe hypoxia or severe infection. In line with the existing Model of Care for Neonatal Services in Ireland, infants born before reaching a gestational age of 28 weeks should be delivered at a tertiary neonatal unit.

Ethics statement: The current work was developed in the context of the National Clinical Audit of “Very Low Birth Weight Infants in the Republic of Ireland”. This audit collects data on the care and outcomes of newborn infants, aiming to review the care provided and recommend improvements to the quality and safety of care for newborn infants and their families. Neonatologists and paediatricians collect anonymised and confidential data on the care of these infants. No personal identifiers are obtained. In line with the Irish “Healthcare Audit Criteria and Guidance”, this does not require formal ethical approval.

Conflicts of interest: None


Keywords: neonatal care, very low birth weight infant mortality, birth outcomes

Bumps, Babies, Parents, Tips (Video) – health care messages for young parents

M.J. Evans

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1) Background: The stillbirth rate in the UK remains one of the highest within the high-income countries (4.2 per 1000 in Scotland). Young parents in particular may be misinformed about risk by peers and/or relatives. Communicating risk factors to prospective parents may reduce the rate. Objectives: We examined the understanding of pregnancy related health messages in a group about to deliver or who had delivered within the past 18 months. We then created a new targeted health care resource. 2) Methods: We invited young people who had engaged with the Lothian Family Nurse Practitioner Service (FNP) to attend workshops and share their experiences, sources and knowledge of “safer pregnancy” messages. Themes related to risk factors were extracted and “sound bites” created. Participants selected and recorded the messages. The animation was created using the recorded messages and images from the workshops. Participation was voluntary. 3) Results: 9 mums, 2 dads and 8 babies attended the workshops. Messages came from peers and family members. Myths identified by the group included “smoking results in small, easy to deliver babies” and “babies’ movements slow as they grow”. Health messages considered important related to smoking, drinking, babies’ movements, healthy eating and sleep position. They raised concerns regarding mental health issues and a fear of being judged which may lead to lack of engagement with health professionals in early pregnancy. All members of the group felt empowered by the process. 4) Conclusions: Participants drew attention to possible mental health issues, and all felt fear of being judged deters people from seeking advice in early pregnancy. This study demonstrates the need to listen to and be guided by an appropriate peer group when creating resources. The group felt that they would engage with a resource which used real people and real voices. Involvement with family nurse practitioners encouraged a healthy approach to pregnancy and care of infant.

Ethics statement: This project was submitted to the local ethics group (Edinburgh University) who deemed that ethical approval was not necessary. All participants were volunteers and gave consent for images to be used.

Conflicts of interest: None


Keywords: health care messages, risk factors, young parents, safer pregnancy

Preventing stillbirths and the role of the midwife during the preconception and antenatal period

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1) Background: Perinatal mortality rates are crucial indicators of public health wellbeing, as they reveal the effectiveness of healthcare strategies. There are unjustified variation rates in stillbirths in normally formed singleton pregnancies across Europe which indicates that decreasing the number of antenatal fetal deaths is possible.

2) Methods: A traditional narrative review of the literature available was undertaken to uncover research into the midwifery role which related to stillbirth prevention during the preconception and antenatal periods. The PEO strategy has been used due to its qualitative nature for this traditional literature review.

3) Results: The midwife's public health role and practice involvement is key in reducing stillbirths. Midwives need to understand and respond to women's and their family needs and wishes, because preconception and prenatal health are crucial periods to ensuring life-long health. The multi-faceted approach of low-cost, effective and evidence-based midwifery interventions, before and during pregnancy, includes personalised screening programs, obesity reduction, smoking/alcohol cessation, acknowledgement of reduced fetal movement, sleeping on one side from 28 weeks and correctly identifying fetal growth restriction.

4) Conclusions: After examining the literature, it is concluded that midwifery care impacts on the prevention and reduction of stillbirths. Midwives have a privileged position to educate, empower and support women to modify health habits by applying the best evidence-based practice whilst caring for them and their babies. However, in the UK and Spain, barriers have been identified such as a national shortage of midwives and lack of continuity of care. Both features are key to improving women's and babies' health by providing women-centred care and greater informed choice. From an international perspective, strong leadership is needed to target stillbirths. Reports, audits and clear evidence-based guidelines/protocols should be designed to promote healthy and safe pregnancies.

Ethics statement: No institutional consent required.

Conflicts of interest: None


Keywords: stillbirth, midwifery, prevention

Cite as: Preventing stillbirths and the role of the midwife during the preconception and antenatal period. E. Fernández García, M.J. Gutiérrez Martín, Y. del Campo Sanz, S. Varona Iglesias. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Protocol for implementing and evaluating a bundle of care to reduce stillbirths in Australia: The Safer Baby Bundle

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Action to address the neglected tragedy of stillbirth has begun. The Safe Baby Bundle (SBB) has been developed to address the priority evidence practice gaps in stillbirth prevention in Australia. Similar care bundles in the UK have shown a 20% reduction in stillbirth rates. The priorities included in the SBB are: 1) improved detection and management of impaired fetal growth; 2) increasing awareness and management of women with decreased fetal movements; 3) smoking cessation support; 4) provision of maternal safe sleeping advice; and 5) improved decision-making around timing of birth for women with risk factors. A survey of Australian maternity services and a series of workshops were conducted to inform the SBB. In partnership with three health departments in Australia, implementation of the SBB will commence in mid-2019. The overarching aim is to reduce stillbirth rates from 28 weeks’ gestation in Australia. Strategies to facilitate the uptake of the SBB will be based on organisational and health professional change, and helping women and their families to achieve positive outcomes. The first phase aims to reach public maternity hospitals totalling 175,200 births annually (>50% births in Australia). Phase 2 includes national roll out drawing on methods from the UK. Time series analyses will examine changes in stillbirth rates (and other adverse outcomes) comparing 15-years pre-implementation (2.6 million births) with the three-year post-implementation rate (525,600 births) using routinely collected data. Surveys will be undertaken pre and post implementation, evaluating women’s experience, clinician acceptability, and the impact on hospital resource use. Incremental cost-effectiveness of the SBB compared to standard care, will be evaluated. The SBB promotes collaboration between parents, researchers, service providers and policy makers to implement and evaluate the SSB to address the high stillbirth rates in Australia.

Ethics statement:

Conflicts of interest: None

View with full poster: N/A

Keywords: implementation, stillbirth, bundle of care, prevention

Improving the detection of fetal growth restriction: evaluation of user experience of an interactive educational program

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1) Background: Undetected fetal growth restriction (FGR) is a major contributor to stillbirth and other adverse pregnancy outcomes. Current antenatal detection of FGR is suboptimal, and practice surrounding this is variable. Improving the detection and care of pregnancies with FGR is an important strategy to reduce adverse outcome and is relevant to all maternity care providers. 

2) Methods: A four and a half face-to-face workshop has been developed to provide education to clinicians to improve the detection and management of FGR. Evaluation of participant knowledge and confidence of 11 learning objectives was undertaken using a paper based or on-line survey administered immediately before and after the workshop. 

3) Results: 585 participants have attended the 20 workshops held to date. Pre-workshop evaluation surveys were completed by 449 participants, including 387 midwives, 60 doctors and 2 nurse educators. Post-workshop evaluation surveys were completed by 327 participants, including 281 midwives, 44 doctors and 2 nurse educators. A high level of satisfaction was reported for all aspects of the workshop including quality of facilitators, learning resources, relevant content and presentation. The FGR education program appears to be beneficial in improving clinician knowledge and confidence in the detection and management of FGR across all learning objectives (see figure 1). Overall, 37% of participants reported being confident or extremely confident in best practice for the detection and clinical management of FGR prior to the program and this increased to 88% post-workshop. 92% of participants indicated they would change some aspect of their clinical practice following the workshop format.

4) Conclusions: The FGR education program appears to be beneficial in improving clinician knowledge and confidence in the detection and management of FGR. Participants reported a high level of satisfaction for all aspects of the workshop including quality of facilitators, learning resources, relevant content and presentation format.

Ethics statement: The fetal growth restriction program is a quality assurance activity and therefore ethics approval was not sought.

Conflicts of interest: None


Keywords: fetal growth restriction, education, stillbirth prevention

Australian women’s perceptions on sleeping position in late pregnancy

K. Warrilow (1,2), A. Gordon (2,3), R. Cronin (4), F. Boyle (5), D. Ellwood (6), P. Middleton (7), V. Flenady (8)

(1) Mater Research Institute, University of Queensland; (2) University of Sydney; (3) Royal Prince Alfred Hospital; (4) University of Auckland; (5) University of Queensland; (6) Griffith University; (7) South Australian Health and Medical Research Institute; (8) Mater Medical Research Institute, University of Queensland

1) Background: Stillbirth remains a major global public health burden. Recent research suggests that supine sleeping in the last trimester of pregnancy increases the risk of stillbirth. Public awareness campaigns to support side sleeping could provide women with advice on how to change this modifiable risk factor. The aim of this study was to determine current awareness and practices around sleep position in pregnant women in Australia to inform future public awareness campaigns. 2) Methods: A 27-question online survey was undertaken from November 2017 to January 2018. The survey was based upon sleep surveys previously undertaken in New Zealand (Cronin et al) and by Tommy’s pregnancy charity in the UK. It was disseminated via pregnancy websites and social media platforms to women ≥28 weeks gestation. 3) Results: 325 women responded to the survey, 13 (4%) reported sleeping supine or in a propped-up position in the past week. 286 (88%) women had read or heard about the importance of side sleeping in pregnancy. 131 (40.3%) stated that the most helpful information came from the internet with 1 in 2 specifically accessing pregnancy websites. 125 women (38.5%) had changed their sleeping position in the third trimester based upon advice they had received, with 98/125 (78%) saying it was not difficult or only a little difficult to change. 4) Conclusions: Australian women have a high awareness of side sleeping in pregnancy and are willing to change. A public awareness campaign would provide clear advice on a risk factor that women could change themselves, offering potential for stillbirth prevention.

Ethics statement: The survey was undertaken by the Centre of Research Excellence in Stillbirth based at the Mater Research Institute, University of Queensland in partnership with the University of Sydney and was approved by the Ethics Review Committee of Mater Misericordiae Ltd. Human Research Ethics Committee

Conflicts of interest: None

View with full poster: N/A

Keywords: stillbirth, prevention, sleep position

#MovementsMatter: Evaluation of a public awareness campaign in Victoria, Australia

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Pregnancy loss is the most common complication of pregnancy. The end of a pregnancy or the death of a baby through miscarriage, stillbirth, neonatal and infant death can have a devastating and long-lasting impact on the woman and her family. The Implementation Group for the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death in Ireland has found that the information available to bereaved parents and health care providers alike differs greatly from area to area. We found that, increasingly pregnant women are accessing information about pregnancy and childbirth from the internet. Supported by funding from the Irish Hospice Foundation, the website, “PREGNANCY AND INFANT LOSS IRELAND” is an initiative of the afore-mentioned Implementation Group. A multidisciplinary working group, with a parent representative, worked to develop the website in collaboration with a commercial design company. This group researched similar websites and looked at their content and intended use. The Parents Forum from the Standards Implementation programme were asked what they thought would be useful to bereaved parents when accessing such a website. It was agreed by all involved that the website should be a resource for bereaved parents and health care professionals to signpost them to information and support structures.

Then information was compiled and written by the Programme Manager in collaboration with the working group. The design company then designed and built the website around the information provided to them. The final design and content was shared with expert colleagues, at a National Bereavement Forum with their feedback considered. The website was publicly launched in April 2019. A website management group was set up to oversee the management of the website, to ensure content is up-to-date and to assess the need for further development of the website. A valuable resource for parents who experience pregnancy loss the website provides accurate and accessible information on a sensitive subject, shares the latest research on pregnancy loss, promotes emotional well-being, and offers details on how to access the appropriate support services.

**Ethics statement:** Ethical approval was not necessary for the development of the website.

**Conflicts of interest:** None


**Keywords:** fetal movements, stillbirth, public awareness, prevention, campaigns

**Cite as:** #MovementsMatter: Evaluation of a public awareness campaign in Victoria, Australia. R. Cotter, K. O'Donoghue. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Can Doula Birthing Support Reduce the Risk of Stillbirth? Setting a research agenda

J.A. McGregor (1,2), J.I. French (2), C. Carvalho (3), M. Perhach (1)

(1) Group B Strep International; (2) LA Best Babies Network; (3) Quebec Association of Doulas

1) Background: Information suggests that doula care during pregnancy may reduce risks of stillbirth (SB). Our objectives were to: A. Conduct a logic model review and analysis to examine the possibility of doula participation reducing the risk of intrapartum SB, B. Suggest research approaches for measuring the possible benefit of doula support for birthing vs. prenatal or preconception care, C. Review the established benefits of doula care for pregnancy adverse outcomes.

2) Methods: We conducted a logic model analysis. An electronic literature search was conducted using the search terms “doula” and “stillbirth.”

3) Results: Reviews prior to 2008 suggested multiple benefits of supportive birth attendants providing physical and emotional support for women in labor provided multiple benefits in observational and quasi-experimental studies. Further research reaffirmed these and other benefits employing trained professional doulas. These benefit include reduced necessity of primary cesarean section, shorter labors, reduced use of oxytocin and lower rates of low birth weight and NICU admission along with improved maternal satisfaction and breastfeeding rates.

4) Conclusions: Current reviews report improvements with doula participation in improved outcomes including more spontaneous births, shorter labors, fewer primary cesarean births and higher APGAR scores. ACOG and SMFA concluded that doula care reduced the risk of primary cesarean section. They concluded, “This resource is probably underutilized.” No studies were found describing adverse effects. Modern hospital care cannot provide the “constant supportive care” that professional doulas intend to provide. Doula birth support is documented to be associated with multiple maternal and neonatal benefits. No information was found regarding SB or fetal death outcomes. A research agenda including large epidemiology-informed studies should be designed and performed to evaluate the effects of doula participation in varied populations.

Ethics statement: No patients were involved. No institutional consent required/obtained.

Conflicts of interest: Charmaine Carvalho is the principal of Montreal Mothers Therapy

View with full poster: www.isa2019madrid.com/can-doula-birthing-support-reduce-the-risk-of-stillbirth-setting-a-research-agenda

Keywords: doula, pregnancy care, pregnancy benefits

Preconception care (PC) can reduce risks of stillbirth (SB)

J.A. McGregor (1,2), J.I. French (2), M. Perhach (1)

(1) Group B Strep International; (2) LA Best Babies Network

1) Background: Preventive strategies for SB and other adverse pregnancy adverse outcomes (AOs) are underappreciated. Our goals are to a) utilize a Logic Model analysis to identify and prioritize life course, lifestyles, and medical strategies to reduce risks of SB and b) discuss group B strep recommendations including testing and vaccine updates. 2) Methods: We employed electronic databases (PubMed, Medline, Google) to search information using “preconception care” and “stillbirth” or “fetal death” as search terms (1990-2018). 3) Results: A. Recommendations are authoritatively available (CDC-P, ACOG, AAFP, WHO, Cochrane and Gates/Aga Khan). B. The most applicable strategies for individual and family were suggested as: a) Age, >17 years, b) Interpregnancy interval >1½ year > 3 years, c) Avoidance of toxic substances/pollution, d) Maintenance of recommended BMI. C. The most effective medical strategies were judged to be: a) Pregnancy planning.spacing services, b) Nutritional and BMI counseling, c) Folate and omega-3 supplementation started preconception, d) Provision of genetic and vaccination services, e) Provision of evidence-based SB prevention services. D. Women and families require life course, lifestyle, and fertility knowledge and services including recommended nutrition, STI prevention, family planning and means to avoid toxicants and environmental hazards, as well as screening for ACEs and violence or abuse. 4) Conclusions: A. Recommendations for PC services are available and can reduce risks of SB. B. Because of generalized applicability, life course, lifestyles and evidence-based modeled strategies will likely be most effective for reducing SB in differing populations. C. Public health approaches can be effective in both rich and poor country settings. Family planning, screening for violence, nutrition, and general medical services are deemed most likely to reduce risks of SB, D. Specialized PC services should be implemented and measured for efficacy.

Ethics statement: No patients were involved. No institutional consent required/obtained.

Conflicts of interest: None


Keywords: preconception, stillbirth, recommendations, logic model

Prompting parent prenatal infection prevention using the mnemonic “HYGIENE”

J.A. McGregor (1,2), M. Perhach (1), A. Perhach (1)

(1) Group B Strep International; (2) LA Best Babies Network

1) Background: In developed countries, up to 24% of stillbirths have been attributed to infection. Infection is estimated to contribute to nearly half of stillbirths in developing countries. Prenatal infection can be caused by a wide variety of microorganisms, including bacteria, viruses, and parasites. Our goal is to help parents avoid prenatal infections.

2) Methods: A. We listed routes of prenatal infection. B. We listed microorganisms that can commonly cause prenatal infection. C. We identified behaviours that could help reduce the risk of prenatal infection.

3) Results: A) We created a mnemonic to remind parent of behavioral changes that can help avoid the many types of prenatal infections: H - Handwashing, Y - Yes to prenatal care, G - Good food prepared safely, I - Immunizations, E - Evade others’ bodily fluids, N - No to unnecessary invasive procedures, E - Environmental precautions. B) We share this mnemonic on a poster with a companion handout (suitable for providers to give their patients) detailing specific behavioral changes and the type of infection that the behavior could help prevent. C) This mnemonic has been subjectively welcomed by parents and perinatal healthcare providers.

4) Conclusions: Giving parents easily understood behaviors/habits to help avoid the risk of prenatal infection can be studied in future controlled trials with the goals of a) reducing infection/inflammation morbidity and mortality and b) determining if this a better prevention strategy than overwhelming parents with unexamined ways to prevent the multiple types of prenatal infection.

Ethics statement: No patients were involved. No institutional consent required/obtained.

Conflicts of interest: None


Keywords: pregnancy, mnemonic, infection prevention, perinatal

Cite as: Prompting parent prenatal infection prevention using the mnemonic “HYGIENE”. J.A. McGregor, M. Perhach, A. Perhach. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Knowing your audience: investigating stillbirth knowledge in Australia to inform the creation of a public education campaign

D. Pollock (1), C. Foord (2), B.M. Farrant (3), C. Shepherd (3), J. Warland (1)

(1) University of South Australia, Adelaide, Australia; (2) Still aware, Adelaide, Australia; (3) Telethon Kids Institute, University of Western Australia, Perth, Australia.

1) Background: Stillbirth is a significant public health issue that has mostly been an ignored and taboo topic. Recently, an Australian senate committee reported on the future of stillbirth research and education in Australia. One of the recommendations was to develop a public education campaign, and funds have been committed towards this. However, there is no information on the general knowledge of stillbirth in the Australian population, and thus it is not known what type of information is needed to run an effective stillbirth education campaign.

2) Methods: The online survey was open to any Australian over the age of 18. Questions on socio-demographics, general knowledge of pregnancy, fetal movements, incidence, risk factors, causes of stillbirth and what an effective campaign might look like were included.

3) Results: To date, 270 people have participated. Only 25.9% were able to correctly identify the incidence of stillbirth in Australia. Many participants believed that babies run out of room near the end of pregnancy (33.3%, with 21.6% unsure) and 26.5% (with 27.8% unsure) thought that it is normal for movements to slow down before labour. Over 62% wanted a public awareness campaign on stillbirth. Over 65% of participants stated they were comfortable in hearing from bereaved parents and 71% were comfortable having stillbirth discussed on either TV, posters or in public. However, 47.7% reported they would be uncomfortable seeing pictures of stillborn babies in those same mediums.

4) Conclusions: A public education campaign which includes the stories of bereaved parents is needed to increase Australia’s stillbirth knowledge.

Ethics statement: This study was approved on the 5/12/2016 by the University of South Australia Human Research Ethics Committee. Protocol number 0000036017. Participants were informed that participation is voluntary and they could stop the survey at any time. Services for mental health support were stated at the start and end of the survey.

Conflicts of interest: None


Keywords: advocacy, bereavement, stillbirth education, health promotion, education

Cite as: Knowing your audience: investigating stillbirth knowledge in Australia to inform the creation of a public education campaign. D. Pollock, C. Foord, B.M. Farrant, C. Shepherd, J. Warland. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Preventing stillbirth: how the Count the Kicks public health campaign is saving babies in the US

E. Price

Healthy Birth Day, Inc., Iowa, United States

Count the Kicks is an evidence-based stillbirth prevention campaign that has contributed to the state of Iowa’s near 29% reduction in stillbirth since its launch in 2008. We are on a mission to replicate this success in every state across the United States of America with a goal to save 6,000 babies every year. This will happen through changing the norms of third trimester conversations about stillbirth and stillbirth prevention to include the importance of monitoring fetal movement daily in the third trimester. The research on which Count the Kicks is based demonstrated a 33% reduction in stillbirth amongst all pregnant women during a 17-month intervention period of teaching moms how to monitor their babies’ movements and a 50% reduction in stillbirth among pregnant women reporting concerns of reduced fetal movement. With this knowledge, the nonprofit Healthy Birth Day, Inc. developed a campaign of mom-centric educational materials and tools that allow expectant women to quantify their babies’ movements. Count the Kicks allows moms to record real data of their own baby’s movements that can be shared with providers if they notice a change from what is normal for their baby. With this information, moms are saving their babies’ lives. During this presentation, we will describe the Count the Kicks campaign and demonstrate our free tools to help mothers monitor their babies’ movements. Visitors will have an increased knowledge of potential to prevent stillbirth through daily monitoring of fetal movement in the 3rd trimester of pregnancy, and the modern tools available to support expectant parents to monitor their babies’ movements, like our free Count the Kicks app which has been downloaded 86,000 times in 140 countries and is available in 10 languages. The app has already saved countless babies in the U.S., and has collected more than 60 “baby save stories”.

Ethics statement: Ethics approval not required.

Conflicts of interest: None


Keywords: stillbirth prevention

Cite as: Preventing stillbirth: how the Count the Kicks public health campaign is saving babies in the US. E. Price. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Understanding stillbirth prevention strategies at sub-national level in Uganda

E. Ssegujja (1,2), M. Andipartin (3)

(1) Makerere University School of Public Health, Kampala Uganda; (2) University of Western Cape, School of Public Health, South Africa; (3) University of Western Cape, Department of Psychology, South Africa

1) Background: The global response to stillbirth stemming from the 2011 Lancet stillbirth series “call to action” have had a lasting impact on prevention strategies in regions with the highest-burden. With decentralization of health services and a call to the integration of strategies have seen many of these strategies translated at a subnational level where implementation takes place. However, documentation of such experiences is still lacking. This paper illuminates the translation experiences of stillbirth prevention strategies in a single district case in Uganda. 2) Methods: A cross-sectional descriptive study was conducted in a single district case with relatively high stillbirth rates in Uganda. Qualitative interviews with a purposively selected sample of 15 key informants including health workers, facility and district managers were conducted. Data were audio-recorded and transcribed verbatim with the content analysis done using Atlas ti. 3) Results: A heightened vigilance towards stillbirth burden influenced the nature of the response by re-orienting service provision towards better management. Adapted strategies from MoH and implementing partners were merged to define the stillbirth prevention package. Key strategies were centered at the district like improved data capture, health worker training, regular perinatal review and geographical prioritization of high burden areas. Facility level strategies were proper documentation and review of management practices, operationalizing of referral system, increased vigilance during screening, management of high risk mothers by specialists at no extra cost. Community strategies aimed at creating demand for ANC services by linking mothers through VHT referral forms and availing a toll free line for easy communication. 4) Conclusions: Targeting the different levels helped focus strategies to different risk factors and implementation challenges highlighting the potential of these strategies to reduce stillbirth burden.

Ethics statement: Ethics approvals from University of Western Cape Biomedical Research Ethics Committee (BM/17/9/1), Makerere University School of Social Sciences Research and Ethics Committee (MAKSS REC 12.17.110) and Ugandan National Council for Sciences and Technology (SS 4575) were obtained. Permission from the district authorities and individual written consent were secured before interviews. Respondents’ safety was ensured by clarifying purpose of the study, conducting the interviews in a secure and quiet location, anonymizing data and keeping it on a password protected computer only accessed by the study team.

Conflicts of interest: None


Keywords: stillbirth, prevention strategies, sub-national level

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Pharmacological interventions for the prevention of foetal growth restriction: systematic review and network meta-analysis

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1) Background: Foetal growth restriction (FGR) includes different conditions in which a foetus fails to reach the own full growth, and accounts for 28-45% of non-anomalous stillbirths. The management of FGR is based on the prolongation of pregnancy long enough for foetal organs to mature, while preventing starvation. As no firm evidence exists to guide clinicians towards the most effective therapeutic intervention, we performed a systematic review and network meta-analysis of available literature.

2) Methods: We searched MEDLINE and Embase for clinical trials and observational studies performed on gestating women with clinically-diagnosed risk of FGR. All experimental interventions were included. Studied outcomes were birth of small for gestational age (SGA) babies, stillbirth or neonatal death, and pre-eclampsia.

3) Results: Systematic review and network meta-analysis are still undergoing. Final results will be presented in the communication. Here we report preliminary results. A total of 16772 records were identified, after 8-step screening 11 studies were included in the meta-analysis. Nine studies were randomised controlled trial, 2 were observational studies. Among the outcomes, seven studies evaluated pre-eclampsia, 6 SGA, 9 foetal or neonatal death. Quality assessment of the studies is still undergoing. With regard to pre-eclampsia, aspirin showed a protective effect with respect to placebo or no treatment (direct comparison OR 2.93 [1.40-6.12] – mixed comparison OR 4.21 [1.37-12.97]), and aspirin + LMWH was superior to placebo/no treatment (OR 4.18 [1.70-10.28]) and sildenafil (OR 5.03 [1.46-17.33]).

With regard to the outcomes SGA and stillbirth or neonatal death, no significant association was found.

4) Conclusions: Although data are still preliminary, aspirin alone or associated with LMWH seems to be significantly more effective than placebo or no treatment in preventing pre-eclampsia in women with FGR, while no significant preventive effect was found regarding birth of SGA or stillbirth/neonatal death.

Ethics statement: No subject was recruited for the research. Before starting the systematic review and network meta-analysis, the protocol was registered with PROSPERO (registration number CRD42019122831).

Conflicts of interest: None


Keywords: stillbirth, pre-eclampsia, foetal growth restriction, small for gestational age

Finding the first step: creating a stillbirth scorecard for the United States

L.J. Wimmer

Star Legacy Foundation

Stillbirth is a significant public health issue in the United States, accounting for 24,000 deaths every year. An estimated one-fourth of all stillbirths in high-income countries worldwide occur in the US. Unfortunately, the US lags significantly behind other high-resource nations in reducing stillbirth rates. Additionally, there are not any federally-funded or national professional organizations focused on stillbirth prevention opportunities. The lack of awareness, understanding of the issues, and evidence-based interventions impede progress. Star Legacy Foundation is a non-profit organization based in the United States and is dedicated to improvements in stillbirth prevention and care. In an effort to expand awareness and understanding of stillbirth issues in the United States, this organization created a national and state-based score card system that will help health professionals, policy makers, and advocates better understand the nature of this crisis and where efforts should begin to address it. Description of the development process along with criteria used for evaluation will provide insight into the status of stillbirth in the United States, both among the individual states and compared to international colleagues. The first steps to improvement include acknowledgement and understanding of the problem. This scorecard program aims to ensure key influencers within the United States have access to in-depth information as well as strategies for future research initiatives. When the United States is able to meet the current stillbirth rates and reduction rates as the top-performing countries, there will be a significant decrease in the number of stillbirths occurring in high-resources settings worldwide.

Ethics statement: Ethics approval not required.

Conflicts of interest: None


Keywords: stillbirth, stillbirth rate, stillbirth prevention, awareness, united states

CLASSIFICATION, INVESTIGATION AND AUDIT
Description of perinatal mortality data in a tertiary care hospital: are there any trends?


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1) Background: The objectives were to analyse perinatal deaths (PD) in our hospital and to study if there are any trends in our data. 2) Methods: Neonatal mortality (NM) can be classified into early (ENM) if it occurs 22 weeks of gestation) from 1985. The FD rate in our hospital since 2008, oscillates between 3.5 and 6.5 ‰, comparable to other developed countries. 3) Results: Antepartum mortality (APM) and ENM have decreased until 2000 and have remained stable since then. This decline is probably due to health care improvements. From a neonatal point of view, the use of antenatal corticosteroids for fetal maturation. From an obstetrics point of view, detection of placental related diseases like fetal growth restriction and prevention of prematurity. The increasing complexity of the patient (mother, fetus and newborn) might have been a counterbalance accounting for the stability in the last 18 years. Intrapartum mortality (IPM) and LNM have remained stable since 1985. IPM in our setting is usually due to cervical insufficiency, which is often seen in nulliparous women who are not high-risk population a priori, therefore barely preventable. LNM has been growing in comparison to ENM. The reason could be that some infant deaths that previously occurred before first week of life, have now been delayed. Finally, FD account for around 60% of all PD. We must focus on the importance of FD and the prevention of known risk factors (maternal pathology, placental related disorders and prematurity). 4) Conclusions: APM and ENM have experienced a reduction until 2000 and remained stable since then. IPM have remained stable since 1985. The proportion of LNM may be increasing in comparison to ENM. The proportion of FD is clearly higher than ND, so we must encourage practices focused on its prevention.

Ethics statement: Patient data has been collected from database used during patient consultations of our perinatal mortality outpatient clinic. This data is stored and only the main authors have the right to access to personal data to ensure subject safety. No personal data has been used to write this retrospective descriptive study, therefore no ethical approval (further than Heads of Service) has been required. The authors declare no conflict of interest

Conflicts of interest: None


Keywords: perinatal death, neonatal mortality, fetal mortality, trends

Perinatal mortality rates: description of the last thirty years in a tertiary care hospital

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1) Background: To describe perinatal mortality rates (PMR) at Hospital Universitario “12 de Octubre”, Madrid. 2) Methods: PMR are the best tool to monitor the quality of perinatal care. Perinatal deaths refer to a combination of fetal (FD) and neonatal deaths (ND), assuming common factors may be associated with them. There are several definitions used to describe perinatal death, which vary globally and are not always well defined. There is also a huge variability in registering FD worldwide. We have been recording our PMR since 1985, using the following definitions: Early PMR. FD >28 WG and ND ≤28 days of age. National PMR. FD >22 WG and ND ≤28 days of age. 3) Results: The absolute number of perinatal deaths in our hospital oscillates between 36 and 60 cases per year since 1985. Perinatal mortality has decreased until 2000, remaining stable afterwards. This reduction may respond to the introduction of antenatal corticosteroid therapy for fetal maturation. Early PMR has been around 4 to 6 ‰ since 2000, being consistent with data of other developed countries. This stability is probably due to the increasing complexity of the patient (mother, fetus and newborn), which emerges as a new challenge despite health care improvements. The comparison between the rest of PMR becomes more difficult because there is no data available. 4) Conclusions: PMR is an important tool to monitor the quality of perinatal care, but it may not be useful to improve clinical assistance. Instead, it urges to find other quality markers. During the last 10 years, we have implemented new protocols based in management of conditions like preeclampsia and fetal growth restriction, treatment and prevention of prematurity, perinatal infections and chorioamnionitis. Learning from the impact of these new clinical approaches in a high-risk population groups, may translate real changes despite the stability of PMR.

Ethics statement: Patient data has been collected from database used during patient consultations of our perinatal mortality outpatient clinic. This data is stored and only the main authors have the right to access to personal data to ensure subject safety. No personal data has been used to write this retrospective descriptive study, therefore no ethical approval (further than Heads of Service) has been required. The authors declare no conflict of interest.

Conflicts of interest: None


Keywords: perinatal mortality rate, perinatal care, quality marker

Parents' Voices at review: developing resources to support health professionals in engaging parents in the hospital review of their baby’s death

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There are around 5,470 perinatal deaths in the UK annually. The unexpected death of a baby around the time of birth is devastating for parents, their most pressing question being why their baby died. Local hospital perinatal mortality review forms part of standard National Health Service (NHS) care. It should provide families with as much information as possible about why their baby died. Hospital review is also a means to learn lessons, improve care and potentially prevent future deaths. Recent national reports have highlighted the paucity of perinatal mortality reviews in the UK, including the failure to engage parents in the hospital review process. This both impacts parents’ experience of care and presents a missed opportunity to learn lessons. The new national Perinatal Mortality Review Tool (PMRT) is designed to ensure robust and standardised review. A multi-disciplinary sub-group of the MBRRACE-UK/PMRT collaboration was formed in November 2018 to develop a pathway and resources to support parent engagement in the PMRT. The PMRT parent engagement subgroup benchmarked a pathway and resources against the Bristol PARENTS2 study and Health Quality Improvement Scotland’s ‘Being Open’ pilot. Several resources were developed, for national roll-out: a) A flow-chart for engaging parents; b) Sensitive worded letters for parents; c) Feedback forms for parents to comment on any aspect of their care; d) Guidance on writing a plain English summary of the review findings, free from jargon and insensitive language. These templates are available via the PMRT website: www.npeu.ox.ac.uk/pmrt. Parents have the greatest stake in understanding why their baby died. In lieu of clear explanations, many parents will blame themselves. There are clinical benefits from engaging them: their input improves the quality of reviews by giving further focus and information to the process. It may indeed save future lives.

Ethics statement: The PMRT is commissioned by the Healthcare Quality Improvement Partnership on behalf of the Department of Health (England), NHS Wales and the Health and Social Care Division of the Scottish Government. It does not require ethics committee approval as this is not a research activity. Personal identifiable data are collected without parental consent with approval under s251 of the NHS Health Act 206 in England and Wales (17/CAG/01) and with approval from the PBPP panel in Scotland (1718-0249/Kurinczuk).

Conflicts of interest: None


Keywords: parent engagement, sensitivity, resources, pathway, lesson-learning

BHRUT Hospital quality improvement initiative to improve bereavement care: strategies to review, re-evaluate, and reduce term intrauterine death

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1) Background: BHRUT supports RCOG Each Baby Counts Initiative to reduce stillbirths and severe brain injury by 50% by 2025. BHRUT Stillbirth rate is 3.62/1000, (<10% the UK average) [MBRRACE Report 2016]. AIM: BHRUT Quality Improvement Initiative to Improve Bereavement Care aim to: (a) Review Serious Incidents (SI) related to stillbirth/IUD using local proforma and national PMRT; (b) Re-evaluate the IUD Guideline; (c) Reduce Term IUD and Promote Service Delivery Improvement. 2) Methods: Retrospective review of all SI and RCA due to IUD 28 weeks - term between April 2017 - March 2018. This highlighted- (a) TEAM WORKING BHRUT has comprehensive and integrated multidisciplinary Maternity Governance Team, Midwifery Bereavement Team and Serious Incident Group that identify, investigate and improve bereavement care. (b) RCA & LOCAL SI INVESTIGATIONS – Consistency & Duty Of Candour. - Consistency: Almost all SI involving stillbirth/IUD cases are investigated by one dedicated Consultant to promote consistency; - Patient Involvement: Parents are reviewed in dedicated Consultant Debriefing Clinic. (c) PMRT: STANDARDIZED NATIONAL REVIEW 3) Results: BHRUT Maternity SI Annual Report April 2017/March 2018 showed– 17 Serious Incidents - 6 IUD - 6/17 (35%), including: 4 Term babies 38+4/40 – 41+3/40 weeks; 2 Preterm babies 34+2/40 and 29+6/40. 40 Stillbirth/IUD >24 weeks (exclude Fetal Abnormalities) –6/40 (15%) Stillbirth/IUD was SI. LESSONS LEARNT: -Missed Opportunities to - identify IUGR (n=4) confirmed on post-mortem; identify early & late onset IUGR, reduced growth velocity and previous IUGR so not referred for growth scan and fetal surveillance (CTG). 4) Conclusions: ACTION PLANS & RECOMMENDATIONS: (i) Introduced dedicated Debriefing Clinic for bereaved women/couple - patient communication; (ii) Ultrasonographers now empowered to order serial growth scans at 28/40, 32/40 & 36/40 if previous IUGR identified at booking; (iii) Rewrite IUD Guideline; (IV) Disseminate lessons learnt.

Ethics statement:

Conflicts of interest: None

View with full poster: N/A

Keywords: missed IUGR, review, fetal loss, stillbirth, case review

Sharing lessons learnt: review 48 IUD cases using PMRT at BHRUT (March 2018 - March 2019)

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1) **Background:** BHRUT delivers 8,500 women annually, with stillbirth rate < 10% below the UK average (3.62/1,000 versus 3.93/1,000) [MBRRACE Perinatal Mortality Report 2016]. OBJECTIVE - BHRUT introduced Perinatal Mortality Review Toolkit (March 2018) to standardise stillbirth case reviews. (a) Review Quality of Care provided; (b) Assess Grading of Care and decide whether different care might have resulted in different outcome; (c) Develop Action Plans for Service Improvements. 2) **Methods:** To assess fetal losses >22/40 weeks (March 2018-March 2019). 3) **Results:** - 48 cases reviewed showed - High Risk at Booking (n=33) (68.8%); Primigravida (n=16) and Multiparous (n=32); Booking - <12 weeks (n= 39) (81.3%); Ages 21yrs - 43yrs (<20yrs n=0; 20yrs-29yrs n=14; 30yrs-40yrs n=33 & >40yrs n=1); BMI < 30 (n=37); BMI 30-35 (n=5); BMI 36-40 (n=2); BMI >40 (n=2); Unknown (n=1); GRADING OF CARE - Grade A - No Issue (n=26) (54.2%); Grade B - Care made No difference to outcome (n=11) (22.9%); Grade C - Care might made difference to outcome (n=9) (18.8%); Grade D - Care most likely made difference to outcome (n=2) (4.2%). Serious Incidents (SI) requiring RCA Investigation (n=2) (4.2%). Problems Identified: (1) Antenatal Clinic Did Not Attend (DNA) Guideline followed but no appointment available - 3wks; (2) Missed IUGR: (a) Risk factors identified at booking (previous IUGR) but serial scans not done/done incorrect intervals/IUGR missed. (3) Reduced Fetal Movements Cases with no evidence of advising patient to seek help. (4) Women with Essential Hypertension had inadequate BP treatment in 1st trimester (2nd fetal loss). 4) **Conclusions:** SERVICE IMPROVEMENT: (a) Rewrite the Antenatal Clinic DNA Guideline followed but no appointment available - 3wks; (b) Missed IUGR: (a) Risk factors identified at booking (previous IUGR) but serial scans not done/done incorrect intervals/IUGR missed. (3) Reduced Fetal Movements Cases with no evidence of advising patient to seek help. (4) Women with Essential Hypertension had inadequate BP treatment in 1st trimester (2nd fetal loss). 4) **Conclusions:** SERVICE IMPROVEMENT: (a) Rewrite the Antenatal Clinic DNA Guideline; (b) Empower Ultrasonographers to order serial growth scans (28/40, 32/40 and 36/40) if previous IUGR identified at booking; (c) Introduce Reduced Fetal Movement (RFM) Education Campaign, RFM Posters in Antenatal Clinic; (d) Improvement Service Delivery for Women with Essential Hypertension.

Ethics statement:

**Conflicts of interest:** None

View with full poster: N/A

**Keywords:** missed IUGR, review, fetal loss, stillbirth, case review, share lessons

Perinatal pathology: current practice and hopes for the future

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1) Background: Post-mortem and placental examination provides valuable information regarding cause of death following stillbirth and neonatal deaths but what are the difficulties facing the specialty? Objectives: This study examined the current practice and challenges facing consultant perinatal pathologists.

2) Methods: Voluntary, anonymised online questionnaire-based study of consultant paediatric/perinatal pathologists (UK and Ireland).

3) Results: Thirty consultants responded (44% of total registered with EQA scheme). 6 (20%) gave an incorrect answer regarding the frequency of stillbirth. 23 (73%) had been working for 10 years or more. 23 worked in split posts: 17 (56%) paediatric and perinatal and 6 (20%) split with adult pathology. 9 (31%) felt that paediatric and perinatal pathology posts should be separate. Reasons for entering the specialty included availability of jobs (10), inspiring consultant (12) and personal interest (18). 20 (69%) had received negative comments. 15 (50%) felt that consultants should be involved in autopsy consent and 7 (24%) met parents to discuss the autopsy. In the last 5 years, 12 (40%) had never been asked to see the parents. 17 (58%) stated that clinicians never attended the autopsy though 15 (50%) felt that they should. 11 (38%) saw parents with clinicians to discuss the findings and ten (37%) would have liked to but had no time. 15 (52%) provided a “plain English” report on request. 29 (97%) felt pathologists should be involved in the review process with protected time for this. 15 (50%) were involved in bereavement training and 29 (96%) were happy to be contacted by a chaplain to discuss faith specific issues. 20 (69%) felt training in bereavement counselling and resilience was appropriate for those undertaking autopsies but only 4 (14%) had been offered training in bereavement and 5 (17%) in resilience. All surveyed would encourage trainees to follow their path. 18 had trainees in post.

4) Conclusions: The study outlined lack of time for trainees, parents and participation in perinatal mortality and morbidity reviews and a need for bereavement counselling and resilience training. Protected time is required in contracts to allow for extended roles. It is noteworthy that all would encourage trainees to enter the discipline despite having faced negative comments.

Ethics statement: Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref No: ECM4(a) 07/03/18)

Conflicts of interest: None


Keywords: stillbirth, neonatal death, coroner, procurator fiscal, perinatal pathology

Perinatal pathology and the coroner/fiscal systems: consultant views

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1) Background: During the past year (2018) it has been suggested that all stillbirths and neonatal deaths should be referred to the Coroner/Fiscal for investigation. Objectives: This study was designed to examine the views and current practice of consultant perinatal pathologists.

2) Methods: Voluntary, anonymised online questionnaire-based study of consultant paediatric/perinatal pathologists (UK and Ireland).

3) Results: Thirty consultants responded (44% of total registered with EQA scheme). Six consultants (20%) gave an incorrect answer regarding the frequency of stillbirth within the UK/Ireland Demographics: 73% had been working for 10 years or more and one had retired but continued locum work. Nineteen (63%) were trained in the UK/Ireland, five (17%) within the EU and 5 (17%) outside the EU. Coroners’/Fiscal Work: 18 (60%) felt that the Coroner/Fiscal should be notified of all intrapartum stillbirths, 15 (50%) early neonatal deaths, 16 (53%) late neonatal deaths and only 1 all cases of stillbirth. 15 (50%) felt the Coroner/Fiscal should investigate all intrapartum deaths and early neonatal deaths and 16 (53%) late neonatal deaths. 9 (30%) expressed the view that the decision to report to the coroner/fiscal should be done on a case by case basis rather than being mandated by type. 7 (23%) expressed dissatisfaction at the coronial system with one stating that the burden of the coronial work had caused them to leave their post. 3 (10%) felt that coronial/fiscal involvement was inappropriate in this type of work where issues were often of a medical nature and may contribute to delays in issuing the reports.

4) Conclusions: The study indicated that coronial/fiscal work was an area of controversy with the majority appearing to favour a flexible approach to cases rather than a mandated approach to investigate all cases. The concerns expressed included financing the system, insufficient consultant time, communication difficulties during the process and prolonged reporting times.

Ethics statement: Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref No: ECM4(a) 07/03/18)

Conflicts of interest: None


Keywords: perinatal pathology, trainees, recruitment

Perinatal pathology – hope for the future? The Trainees perspective

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1) Background: Post-mortem and placental examination provides valuable information in stillbirths and neonatal deaths but the number of perinatal pathologists is falling. Objectives: This study looks at barriers to recruitment. 2) Methods: Voluntary, anonymised online questionnaire-based study of trainee pathologists (UK and Ireland). 3) Results: Twenty nine trainees responded. 8 underestimated the stillbirth rate (1 in 1000), 4 overestimated it (1 at 1 in 50, 3 at 1 in 100). GI pathology was ranked the most important specialty by 14 (48%) and perinatal pathology most important by 2 (80% of cases and six in >20% of cases. 9 (31%) had encountered negative comments about the specialty from other trainees and/or relatives. 27(93%) felt that bereavement training should be offered to those entering the specialty. 19 had been involved in examining placentas, 12 felt clinicians were disinterested in findings. The main barriers were, small specialty (9), autopsy focus (8) and number of placentas (3). 16 (55%) had considered the specialty but commented that paediatric and perinatal should be split due to the distressing nature and lack of interest in autopsy. 4) Conclusions: Nearly half of trainees surveyed misquoted the stillbirth rate and the impact of post-mortem and placental examination on diagnosis. The main barriers to entering the specialty included “distressing” autopsy work, onerous placental work and few training centres. Negative comments were not a deterrent. The selection of GI as the most important specialty by the majority may reflect early exposure to the discipline. These issues could be resolved by early exposure to perinatal pathology and the development of novel, tailored training programmes with “top up” modules in specialist centres.

Ethics statement: Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref No: ECM4(a) 07/03/18)

Conflicts of interest: None


Keywords: perinatal pathology, bereavement, stillbirth, neonatal death

Unexplained stillbirths and stillbirths in women with diabetes are associated with increased placental inflammation and trophoblast area

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1) Background: Quantitative assessment of immunohistochemical staining of placental tissue has found that stillbirths associated with fetal growth restriction have a distinct phenotype which is also present in some “unexplained” stillbirths. We applied this method to describe placental morphology in women with diabetes (WwD) to compare placental morphology from pregnancies in non-diabetic women with live births (healthy control group), live births in WwD, non-anomalous stillbirths in WwD and unexplained stillbirths.

2) Methods: Matched Samples (n=10/group) were obtained and 5µm tissue sections cut from three areas of placenta and stained with haematoxylin and eosin to assess syncytial nuclear aggregates or immunoperoxidase staining using antibodies against CD31, Cytokeratin-7 (CK7), Ki67, CD163, CD45 and CD3. Tissue sections were imaged and staining quantified in whole slide analysis where possible or 10 regions of interest using QuPath and Histoquest software.

3) Results: Unexplained stillbirths and those in WwD had increased area of CK7 immunostaining compared to healthy controls (Median 1.94% and 1.80% vs 1.51%/villous area respectively, p<0.001). There was no difference in villous vascularity. Ki67 was decreased only in unexplained stillbirth compared to healthy controls (Median 2.93% vs. 4.08%/nuclei; p<0.05). Compared to healthy controls there were increased CD163+ macrophages in placentas from live births in WwD (Median 12.56% vs 4.88%/nuclei; p<0.05), which were further increased in unexplained stillbirths and stillbirths in WwD (Medians 11.67% and 15.15% respectively; p<0.001). There was no change in the proportion of CD45+ and CD3+ cells.

4) Conclusions: The isolated increased macrophages suggests sterile inflammation which cannot solely be attributed to post-mortem artefact as they are also increased in live births in WwD. Further studies are needed to identify causes of the observed phenotypes which may give mechanistic understanding in these cases of stillbirth.

Ethics statement: Because this research used human tissues for which that consent had previously been given for ethically approved research, approval was sought for and granted by the proportional review sub-committee of the West Midlands – South Birmingham Research Ethics Committee (16/WM/0372)

Conflicts of interest: None

View with full poster: N/A

Keywords: stillbirth, diabetes, placenta, inflammation

Analysis of Irish inquiry reports relating to pregnancy loss services (2005 – 2018)

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1) Background: External inquiries are carried out following specific adverse maternal events and aim to identify issues in the maternity care provided to pregnant women and make recommendations to improve standards of care. Published literature comparing external reports and assessing their impact on maternity services is limited.

2) Methods: From the national inquiries into the maternity services in Ireland, 10 publically-available health-service-commissioned inquiry reports published between 2005-2018 relating to pregnancy loss services, were analysed. Two clinicians reviewed these, separately, to examine the content and recommendations made in each report. Quantitative and qualitative data was collected using a specifically designed review tool. The findings and recommendations from each report were studied by descriptive thematic analysis outlining emerging themes and issues.

3) Results: The reports focused on maternity services in relation to pregnancy loss and/or clinical care provided around the time of the loss. The inquiry team was multi-disciplinary (MDT) and named in 5 reports (4-14 people). It was clearly stated that affected families and relevant clinical staff were involved in four inquiries, only one of these described supports to families during the inquiry process. Only 4 reports commented on good aspects of care provided; reports focusing mostly on unfavourable issues.

4) Conclusions: This was the first structured review of pregnancy-loss national inquiry reports in Ireland, outlining some of the main issues arising from them. Clinical staff and families should always be involved and supported during the inquiry process. Inquiries are important to highlight issues of concern; by standardising the process relevant implementable recommendation are more likely to be generated. Recommendations made in inquiry reports, can have a profound impact on maternity services if/when implemented adequately.

Ethics statement: Only publicly available reports were reviewed, therefore no ethics approval was required.

Conflicts of interest: None


Keywords: pregnancy loss reviews, national inquiry, engaging with staff, parental involvement

Perinatal mortality audits and reviews: current systems, challenges and the way forward

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1) Background: Perinatal deaths occur and are devastating for parents, families and all health care professionals involved. Perinatal mortality reviews (PMRs) take place to highlight good care, as well as identify contributory factors and analyse weaknesses in health care services. Failure to examine perinatal deaths for substandard care prevents learning and may lead to recurrence of events. 2) Methods: The different types of PMRs being done internationally were studied through a structured scientific literature review (1940 to 2018). This has been completed as part of a doctoral study in Ireland focusing on PMRs. 3) Results: Differences in definitions of stillbirths and neonatal deaths have, and continue to, impede international comparisons. While confidential enquiries (CE) give impartial expert assessment on anonymised information, unit-based multi-disciplinary team (MDT) meetings provide extensive information on perinatal deaths with local knowledge. Detailed, impartial, multidisciplinary examination (e.g. CE) is required for a profound understanding of the care provided to women with poor perinatal outcome. Involving bereaved parents in the PMR process is essential, however it is still mostly unexplored. 4) Conclusions: Reliable national perinatal mortality data facilitates international comparison and benchmarking. Ongoing development of specific electronic PMR tools will promote a regulated, systematic national process for PMRs. To accomplish informative local PMRs, clinical staff and bereaved families are now and should be regularly involved. Well-attended local MDT perinatal mortality meetings are an efficient way of circulating findings to staff and encourage progress. A standardized and structured approach to the process should be developed to facilitate sharing of experiences and challenges at national (or international) level. To achieve a reduction in the number of perinatal deaths, substandard care must be identified and progress made accordingly.

Ethics statement: Only publicly-available reports were analysed, therefore no ethics approval was required.

Conflicts of interest: None


Keywords: perinatal mortality review, confidential enquiry, bereaved parent involvement

Applying ICD-PM death classifications to existing South African Perinatal Problem Identification Programme (PPIP) data: what did we learn?


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1) Background: In order to progress towards ending preventable perinatal deaths worldwide, the classification and causes of deaths must be appropriate and comparable globally. The World Health Organization (WHO) application of the tenth edition of the International Classification of Diseases (ICD-10) to perinatal deaths (ICD Perinatal Mortality, ICD-PM) was recently developed to align with these needs. ICD-PM had not yet been applied to existing national perinatal mortality data collection systems. 

2) Methods: The ICD-PM, was applied to South Africa’s national perinatal mortality audit system (PPIP) for all perinatal deaths (>1000g and >=28 weeks gestation) between 1st October 2013 and 31st December 2016 (n=26,810). The specific objective objectives were: (1) to assess if ICD-PM can be applied to existing datasets, (2) to explore if the features of ICD-PM including maternal condition being included in perinatal deaths, the consideration of the mother-infant dyad as a single entity and information around the timing of deaths (antenatal, intrapartum, neonatal) are advantageous. 

3) Results: Most deaths were antepartum (n=15619, 58.2%), followed by neonatal (n=7466, 27.8%) and intrapartum (n=3725, 14.0%). Antepartum deaths were largely due to unspecified cause (A6, n=10542, 67.5%), other specified antepartum disorder (A4, n=2947, 18.9%) and disorders related to fetal growth (A5, n=1270, 8.1%). The main primary cause of intrapartum deaths were acute intrapartum events (I3, n=2476, 65.2%), other specified intrapartum disorder (I5, n=479, 12.9%), and intrapartum death of unspecified cause (I7, n=373, 10.0%). The main causes of death in the neonatal group were complications of intrapartum events (N4, n=2194, 29.3%) and low birthweight/prematurity (N9, n=1458, 28.5%). Maternal condition was identified in 58.8% (n=8891) of antepartum deaths, 89.0% (n=3314) of intrapartum deaths and 79.6% (n=5945) of neonatal deaths. 

4) Conclusions: ICD-PM increased the number of perinatal deaths due with a maternal condition, however this was mainly due to intrapartum asphyxia events and abruptio placentae/placenta praevia been classified as a maternal rather than perinatal condition in ICD-PM. This aspect must be explored further. Another main difference was that ICD-PM classified deaths as antepartum, intrapartum or neonatal as compared to PIPP classifications of fresh/macerated stillbirths or neonatal deaths in PPIP.

Ethics statement: Data were collected with the permission of the South African Department of Health. This analysis was approved by the technical task team who run the database and produce the reports from the South African Medical Research Council/University of Pretoria Maternal and Infant Health Care Strategies unit. This was a secondary analysis and all identifiers of the cases were removed. Ethics approval was given by the University of Western Australia Human Ethics Committee (RA/4/1/7955, 20 November 2015).

Conflicts of interest: None


Keywords: perinatal death coding, stillbirth, maternal condition

Degree of post-mortem investigation following perinatal loss

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1) Background: Perinatal death, defined as intraterine fetal death at ≥20 weeks gestation, plus neonatal deaths within the first 7 days of life, rates have remained stable in the United States over the last decade. The American College of Obstetricians and Gynecologists have published guidelines for the post-mortem evaluation of stillbirths, with autopsy recommended. However, autopsy rates continue to decline. Less invasive post-mortem imaging has been suggested, but it is unclear if this has been incorporated into practice. Additionally, it is not known what evaluation early neonatal deaths receive and if it differs from stillbirths. 2) Methods: We conducted a single center retrospective review of all perinatal deaths from 2011-2017. We sought to determine the frequency and degree of post-mortem investigation to include autopsy, imaging, laboratory, and genetic studies. 3) Results: Over a 7 year period there were 97 perinatal deaths, with 54 stillbirths (56%) and 43 neonatal deaths (44%). The majority of deaths occurred between 20-25 weeks (stillbirths, n=31, neonatal deaths, n=30). 91 cases had placental pathology completed (94%) and 29 deaths had autopsy performed (30%). Stillbirths were significantly more likely to receive autopsy (p=0.013) and post-mortem genetic testing (p=0.0004) when compared to neonatal deaths. Parvo virus (p=0.0001), anti-phospholipid antibody (p=0.003), and kleihauer-betke (p=0.005) testing were all more likely in stillbirth post-mortem investigation than neonatal deaths. Neonatal deaths were more likely to have a documented physical exam (p=0.002) and be seen by a neonatologist or pediatrician (p=0.0001). Nearly a third of all deaths had no evaluation beyond placental pathology. There was only one case utilizing less invasive post mortem imaging. 4) Conclusions: Investigation following perinatal death is more likely in stillbirths than neonatal deaths and there is very limited use of less invasive methods. Stillbirths were more likely than neonatal deaths to receive post-mortem investigation, yet all neonatal deaths were seen by a pediatrician or neonatologist. This suggests pediatricians and neonatologist may have room for improvement following perinatal death.

Ethics statement: This study was reviewed and approved by the local investigational review board. A case number was assigned (C.2018.143d). Appropriate measures were taken to ensure all protected health information was secure. All authors contributed to the project and meet the requirements for authorship.

Conflicts of interest: None


Keywords: stillbirth, perinatal death, autopsy, post-mortem exam, non-invasive autopsy

The incidence of fatal fetal anomalies associated with perinatal mortality in Ireland

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1) Background: Major congenital anomalies were responsible for 146 of the 374 perinatal deaths in Ireland. Little is known about what conditions are most responsible for perinatal mortality. While there is no universally-agreed definition in Ireland, the term fatal fetal anomaly (FFA) is used in law to describe a condition likely to lead to death of the fetus in utero or within 28 days of birth. The aim of this study was to identify what congenital anomalies are responsible for perinatal death and whether they are classified as a FFA.

2) Methods: Anonymised data pertaining to all perinatal deaths that occurred between January 2011 and December 2016, from all 19 maternity units in Ireland, were obtained from the National Perinatal Epidemiology Centre. Secondary data analysis was conducted using SPSS Version 23.

3) Results: Between 2011 and 2016 there were 3,048 perinatal deaths in Ireland, of which 59.3% (n=1807) were stillbirths and 40.7% (n=1241) were neonatal deaths. Congenital anomalies were present in one third of all perinatal deaths (34.4%, n=1049) and were more likely to be present for infants who died following birth than those who died in utero (46.2% v 26.6%, p>0.001). Of these 1,049 perinatal deaths, 28.5% (n=299) could be definitively classified as FFA with an additional 40.2% (n=422) lacking sufficient information to be classified. Stillbirths were more likely to have a congenital anomaly classified in line with commonly accepted definitions of FFA than neonatal deaths (33.5% v 24.3%, p>0.001).

4) Conclusions: Irish legislation now allows for termination of pregnancy for FFA. There is no agreed definition or classification of FFA, however this descriptive analysis from a national registry of perinatal deaths illustrates that 10% of deaths over a 6 year period can be attributed to FFA using the criteria set out in the Irish legislation. This knowledge is required to inform clinical practice and counselling of parents who receive a diagnosis of a fetal congenital anomaly.

Ethics statement: This study is secondary data analysis of anonymous data. Ethical approval was sought by the National Perinatal Epidemiological Centre, from the Clinical Research Ethics Committee of the Cork Teaching Hospitals, prior to collecting same.

Conflicts of interest: None


Keywords: congenital anomaly, prevalence, perinatal death, maternity care

Comparing apples and oranges: a retrospective linked data study assessing the concordance between hospital discharge data, electronic health records and register books for diagnosis of inpatient admissions of miscarriage

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1) Background: Despite the high occurrence of miscarriage, there is a limited research assessing the validity of the outcome of a diagnosis of miscarriage at hospital settings. The aim of this study was to determine agreement between the Hospital Inpatient-Enquiry (HIPE) system, the electronic health records (EHR) and register books for the diagnosis of miscarriage. 2) Methods: Retrospective chart review comparing agreement of diagnosis of inpatient admissions of miscarriage between three data sources from January to June 2017 at a single, tertiary maternity hospital in Ireland. Kappa (k), sensitivity, specificity, positive and negative predictive value (PPV & NPV) were calculated using Stata. 3) Results: After excluding missing data, this study identified 304 diagnoses of miscarriage out of 370 records in the EHR, 291 out of 360 records in HIPE, and 219 out of 255 records in register books. Using the EHR as a gold standard, HIPE had a sensitivity of 96.3%, specificity of 97.3%, PPV of 98.3%, NPV of 90.0%, with a very good strength of agreement (k=0.92, p-value > 0.001). Using the EHR as a gold standard, register books had a sensitivity of 97.2%, specificity of 80.5%, PPV of 96.3%, NPV of 84.6%, with a good strength level of agreement (k=0.79, p-value > 0.001). Only 4.2% (n=16) were classified as missed miscarriage according to HIPE, whereas more than 40% of admissions were classified as missed miscarriage by EHR and register books (n=173, 44.9% and n=150, 39.9%). Almost 60% of admissions were incomplete miscarriage according to HIPE (n=231). 4) Conclusions: Our findings indicate that HIPE and EHR are reliable and valid databases for monitoring and reporting prevalence of miscarriage in Ireland. However, discrepancies were found when classifying miscarriage between the three data sources Standardisation of these classifications are essential in order to ensure hospitals are appropriately resourced for women who miscarry.

Ethics statement: This study received ethical approval from the Clinical Research Ethics Committee of the Cork Teaching Hospital on ECM 4 (I) 17/10/2017. A patient consent form was not required by the Ethics Committee because this was an observational study which did not include any intervention and which examined routinely collected data. Privacy was of the utmost importance precaution in this study. To assure this, all data were collected and stored within the hospital in strict confidence. In addition, only anonymous data were extracted and coded with a Medical Record Number (MRN).

Conflicts of interest: None


Keywords: concordance, validity, miscarriage, inpatient admissions, HIPE, electronic health

The communication between the pathologist and the parents for a neonatal autopsy: our experience in Patagonia, Argentina

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Since the first autopsies in the beginning of the Renaissance, there is a mysticism, superstition and/or unknowledge of the not scientific community, which leads many times parents to the refusal to perform the necropsy. When the doctors request for a neonatal autopsy, we observed in many cases, that parents do not have any knowledge of the procedures to follow over the fetal body. The pathologist has the tools and knowledge to remove doubts and fears of the word “autopsy”, which is immediately link with the concept of “morgue”, “death”, “fear”. In our experience, we check in most of the cases of fetal died, the obstetrician requests the necropsy without specific details to the parents of the procedure to follow. The family in an emotional stress due to the loss of the loved one, must be informed, that the autopsy will allow, in most of the cases, to prove the cause of death and remove fears, doubts and feeling of guilt in the family. And in specific cases will provide the basis for the genetic counseling of future pregnancies. We believe that communication between parents and pathologist is very important to obtain the authorization to do the fetal autopsy, to inform the treatment of the corpse, the delivery conditions for the elaboration of their due grief, etc. In our practice we have obtained, in almost all the opportunities, in which we have been able to carry out the interview with the parents, the acceptance of them for the realization of autopsy.Keywords: autopsy, communication parents-pathologist, Patagonia Argentina

Ethics statement: Ethical approval for the study was provided by the Ethics Committee Zonal Hospital Puerto Madryn (Reference N° 437, 26 March 2019).

Conflicts of interest: None


Keywords: autopsy, communication parents-pathologist, Patagonia Argentina

Cite as: The communication between the pathologist and the parents for a neonatal autopsy: our experience in Patagonia, Argentina. María Gabriela Manzzi, Rafael Santapau. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Classifying Stillbirths in a tertiary care hospital of Low middle-income country: simplified COD-AC versus ICD-PM

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1) Background: India shares the highest burden of stillbirths and it is crucial to classify these stillbirths. The purpose of any classification is to know the actual burden of any particular problem and its causes so that preventive strategies can be planned. There is a number of different classifications available to classify stillbirth in literature still, we lack a novel classification. Most of these classifications were applied to high-income countries which have very low stillbirth rate compared to LMIC which have tenfold higher SBR. Aim: The present study was aimed to examine the feasibility of ICD-PM classification system and Simplified CODAC to classify the Stillbirths who were delivered in a single Tertiary care center of northern India and discuss the interpretation of this newer classification system (ICD-PM) over the Simplified CODAC. 2) Methods: Application of simplified CODAC and ICD PM to stillbirths. Setting: Tertiary care hospital, India. All stillbirths delivered over a period of one year were grouped according to ICD PM along with Simplified CODAC. 3) Results: During the study period there were a total of 5776 births and 314 stillbirths in the facility. The stillbirth rate was 54 per 1000 total births. Half of these stillbirths (49.6%) occurred at 28 – 34 weeks of gestation. Total antepartum stillbirths were 70.7% whereas intrapartum 29.2%. 4) Conclusions: The ICD PM and CODAC classification both seem to be feasible in our setup. Although CODAC also captures the associated maternal and fetal conditions, ICDPM clearly correlates feto-maternal dyad together. The proportion of unexplained stillbirth has significantly reduced by classifying stillbirth according to ICD PM compared to simplified CODAC. However, there are inherent challenges especially in LMICs like logistics, delays and system failures which cannot be captured by any classification available.

Ethics statement: Permission from the departmental (Obstetrics & Gynecology) ethical committee given.

Conflicts of interest: None


Keywords: stillbirth, cod-ac classification, ICD-PM classification, ante partum stillbirth

Cite as: Classifying Stillbirths in a tertiary care hospital of Low middle-income country: simplified COD-AC versus ICD-PM. B. Sharma, N. Aggarwal, V. Suri. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
An Initiative towards reducing Stillbirth: Stillbirth Surveillance Review & Response (SBSRR)

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1) Background: India has the highest number of stillbirth in the world-592,100 in 2015 with an estimated Stillbirth rate of 23 per 1000 births. Towards better identification and documentation, stillbirth surveillance pilot was conducted in North India by WHO SEARO 10 hospitals between 2014 and 2018. This study is an attempt to showcase that surveillance is feasible but to understand and better plan preventive strategies there is need to know beyond counting stillbirth numbers.

2) Methods: The framework provided in “WHO Making every baby count” is followed and mortality audit for thematic cases is being done in six steps, (1) identifying cases, (2) collecting information, (3) analysis, (4) recommending solutions, (5) implementing solutions, and (6) evaluation.

3) Results: 360,736 total births were examined between 2014 and 2018, 14,167 stillbirths were identified, giving a stillbirth rate of 39 per 1000 births across ten hospitals. Stillbirth Surveillance review and Response (SBSRR) was introduced in one of the tertiary care. In a period of Eight months, out of 205 stillbirths (SBR 205/4094=50 per 1000 total births), 165 thematic cases were reviewed and recommendations were formulated like to strengthen obstetrics triage, start following fetal growth charts, strengthen the existing referral system and improve the communication skills of health care provider for better compliance. Some of these recommendations which have been implemented like Obstetrics triage protocols, to assess the fetal growth by measuring symphysio fundal height and follow growth charts, sensitization of doctors to emphasize on the danger signs and daily fetal movement count during antenatal care.

4) Conclusions: Conducting stillbirth surveillance review and response of thematic cases in low-middle income countries setting is feasible. As countries progress towards ending preventable mortality, this has the potential to serve as a key process in improving evidence-based and context-specific planning and preventive strategies towards improving quality of care.

Ethics statement: Ethical clearance from Institutional ethical committee given.

Conflicts of interest: None


Keywords: stillbirth, stillbirth surveillance and response, stillbirth rate

Improving consistency in the reporting of deaths at the threshold of survival: developing guidance for assessing signs of life

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Substantial variation exists between UK health care providers as to whether deaths of babies born before 24 weeks are reported as a late miscarriage or registered as a neonatal death. This leads to inequalities in parental access to financial aid and parental leave and also inappropriate comparisons of perinatal mortality between hospitals. While a small number of hospitals have developed policies, no national guidance exists. MBRRACE-UK (who lead UK-wide perinatal mortality surveillance) have established an inter-disciplinary working group to develop guidance to standardise the assessment of signs of life in babies born before 24 weeks gestational age for whom a clear decision has been made that active intervention/resuscitation is not planned. The group comprises representatives from all of the relevant UK clinical organisations, Government departments of Health, academic experts in extremely preterm birth and service user organisations. Face-to-face meetings, email discussion and wide consultation with stakeholders will lead to a consensus document. Key areas included: physical process of assessing signs of life, confirmation of signs of life by a medical professional, documentation of the death and emotional support for parents. The principal aim is that assessment of persisting visible signs of life should be undertaken while ensuring that care following birth is respectful and that the parents’ wishes regarding seeing and holding their baby are prioritised. This guidance aims to increase consistency in registration practice by clinicians for whom assessment of babies born at the threshold of survival may often be unfamiliar. Consistency of practice will reduce confusion and distress experienced by parents by supporting clinicians in their conversations at this difficult time and furthermore standardise perinatal mortality rate comparisons between regions improving identification of variation in perinatal care provision.

Ethics statement: Ethics approval was not required

Conflicts of interest: None

View with full poster: N/A

Keywords: stillbirth, neonatal death, registration, certification, signs of life, viability

Placental findings: a series of cases of Intra Uterine Fetal Deaths in Argentine Septentrional Patagonia using consensus terminology

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1) Background: We present a series of 28 cases of Intra Uterine Fetal Deaths (IUFD) with histopathology of the fetus and placenta. The series collects perinatal mortality data from 4 private health institutions in the cities of Puerto Madryn and Trelew. The objective of this presentation is to determine the frequency of placental pathology of the presented series of IUFD during the years 2006-2018. Placental pathology contributes to or causes stillbirth in 11 to 65% of cases in various classifications. We assessed perinatal deaths where placental disease is the main cause of death, focusing on maternal vascular malperfusion (MVM) and fetal vascular malperfusion (FVM).

2) Methods: Retrospective, cross-sectional, observational and descriptive design. The documentation consulted are the reports of fetal autopsies.

3) Results: During the period 2006-2018, all cases of stillbirths (≥24 weeks of gestation or birthweight ≥500 g) were included when placental disease was the main cause of death or an associated factor (n = 28). The mean gestational age was 32.2 weeks. With respect to the sex of IUFD: female sex 42.8% and male sex 57.1%. The average weight was 1751 grams. The placenta average weight was 240 grams. The ratio of placenta weight (PW) to birth weight (BW) (PW_BW_Ratio) was calculated from PW and BW. PW_BW_Ratio were 0.16 (all), female (0.19) and male (0.15). MVM and FVM were reported in 35.7% and 57.14% of stillbirths, respectively. There were 3 (10.71%) cases with both MVM and FVM. MVM was more common in males (70%). FVM was similar in females and males (50%). Co-existing pathologies included intra-uterine growth restriction (10% of MVM) and cord pathology (81.2% of FVM).

4) Conclusions: This paper presents local epidemiological data on the theme chosen in the delimited period. There are not, at the moment, publications in our environment that evaluate the impact of placental pathology in cases of MFU. The frequency of placental pathology is consistent with previous studies.

Ethics statement: The ethical approval for the study was granted by the Bioethics Committee of the Zonal Hospital of Trelew (Reference: 11/03/2019).

Conflicts of interest: None


Keywords: stillbirth, placental pathology, Argentina

PROVIDING BEREAVEMENT CARE
Project to care for professionals: "Code Caring For"


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Code caring is a project that takes place within the framework of the quality of care of the professionals involved and the care units in the process of perinatal grief. Who does not feel affected? When you have to attend a delivery of a deceased baby, a baby that has no chance of living outside the womb or when suddenly a baby dies in childbirth or in the first hours in an unexpected way? Psychological debriefing is a brief intervention that takes place in the first days after a traumatic event. The objective is to favor the intragroup support among the partners who have been involved in the same situation and in similar conditions. This group of people will meet to manage the emotional load accumulated after the experience. Directed by a psychologist, the meeting seeks verbal exposition of what has been experienced by those who have been present in the traumatic event. In situations of great emotional impact, professionals also suffer and need specific help. Debriefing offers a space of safety through which professionals will feel accompanied and guided therapeutically. Placement of code in the unit, in accesses to the unit of hospitalization an image, expressing that there is a farewell in the unit. Development of a farewell letter to parents from all the professionals involved. Actively work on the farewell needs. Development of souvenir box, with crafts made by professionals. Define tools that help us reduce the emotional impact that professionals involved in the process of grief or perinatal loss may suffer. Avoiding situations of work stress, burnout can develop psychosomatic, emotional and behavioral symptoms.

Ethics statement: Ethics approval no required.

Conflicts of interest: None

View with full poster: www.isa2019madrid.com/project-to-care-for-professionals-code-caring-for

Keywords: professionals, care, helping behavior, support grief, bereavement

Clinical practice guidelines for respectful and supportive perinatal bereavement care: A view from Australia

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1) Background: High quality perinatal bereavement care is critical for women and families following stillbirth or newborn death. Clinical practice guidelines that are based on a systematic review of evidence are important to optimising care for parents and guidelines have been developed in a number of countries. In 2019, the Perinatal Society of Australia and New Zealand (PSANZ) and the Australian Centre of Research Excellence in Stillbirth developed an updated guideline to assist health care professionals to deliver Respectful and Supportive Perinatal Bereavement Care.

2) Methods: Review of published research, including recent systematic reviews, combined with an extensive consultation process to incorporate insights and experience from a large multidisciplinary guideline update group representing parent organisations, clinicians, policy makers and researchers.

3) Results: Perinatal bereavement care involves a broad scope of practice. An organising framework was developed to map practices according to five core goals of care: Good Communication, Recognition of Parenthood, Shared Decision-making, Effective Support, and Organisational Response. These goals of care drive the Guideline for Respectful and Supportive Perinatal Bereavement Care, which contains 49 recommendations of which 41 are for individual practitioners and 8 are for maternity care facilities.

4) Conclusions: Stakeholder engagement, best available research, parents’ lived experiences and maternity care providers’ insights have resulted in a guideline that consists of implementable recommendations to address the needs of bereaved parents in the Australian setting. Areas for further research have been identified.

Ethics statement: Ethics approval was not required as the study involved the review of information that was freely available in the public domain

Conflicts of interest: None


Keywords: stillbirth, perinatal death, bereavement, guideline, respectful maternity care

The economic case for trauma informed bereavement counseling for parents who have experienced perinatal loss

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1) Background: This study examines a practitioner-led, 1:1 tested and structured counselling response to the trauma of loss that is delivered in the UK by Petals. It examines the costs and outcomes of the service to determine the economic benefit of Petals’ counselling programme. It investigates how treating trauma, as well as grief, leads to improved outcomes for parents who have suffered loss, and the financial impact this has on the healthcare system. 2) Methods: The study uses a combination of survey data, economic analysis and financial modelling to determine the business case for government investment in a national counselling service for parents who experience loss. 3) Results: The evaluation calculates that national provision of counselling to 4,822 mothers in the UK (number experiencing loss/year) is £3.17m pa. This would create a national safety-net of support to help parents at this difficult time. The evaluation concludes that investing in a nationwide service would result in a net saving to UK Government of £8.6m pa. Reasons for this are: (A) Counselling provision is relatively cheap: £69.70/session, (B) Costs of unresolved trauma are high in terms of healthcare and benefit payments, (C) Counselling is effective at reducing the effects of trauma. 4) Conclusions: Counselling is inexpensive, effective and reduces UK Government expenditure. A national scheme to help people who are faced with the tragedy of loss during pregnancy/birth would benefit parents, families and Government. On average, £1 invested in Petals will return, net, £2.71. Petals is now working with The Centre to make the case to the UK Government for a national counselling service.

Ethics statement: Evaluation of Petals uses anonymised data and recognised national cost information so an Ethics Panel is not required. Individual case-studies used are from participants who have granted written consent.

Conflicts of interest: None


Keywords: petals trauma loss economics recovery policy

Cite as: The economic case for trauma informed bereavement counseling for parents who have experienced perinatal loss. N. O’Shea, K. Burgess. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Supporting patient choice in the mode of delivery after diagnosis of intrauterine death (IUD): cohort study of 5 maternal request caesarean section

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1) Background: Barking, Havering and Redbridge University Teaching Hospital (BHRUT) delivers 8,500 women per year. There is a dedicated Consultant Obstetrician Debriefing Clinic for women with a fetal loss >22/40. BHRUT stillbirth rate was < 10% below UK average (3.62/1,000 versus 3.93/1,000) MBRRACE Perinatal Mortality Report 2016. OBJECTIVE: Review patient choice of surgical mode of delivery after diagnosis of IUD. 2) Methods: Retrospective cohort case study of 5 women who had IUD. 3) Results: During nine months January - September 2018, total of 16 women had fetal loss at > 28/40 weeks gestation. Five (5) women requested and given caesarean section after counselling. Data analysis - (a) Ages: 28yrs-35yrs old; (b) All multiparous; (c) IUD 29+2/40 - 38+3/40 weeks; (d) All had reduced fetal movement; (e) Two (2) had previous caesarean section and both requested caesarean section delivery at booking; (f) Two (2) had previous IUGR with repeated IUGR confirmed on postmortem; One (1) had missed IUGR and no serial growth scans resulting in Serious Incident RCA investigation. (g) One (1) had DCDA twins with demise of one twin. 4) Conclusions: (1) Patient Feedback: All 5 women feedback their gratitude at the Consultant Postnatal Debriefing Clinic that request for caesarean mode of delivery was respected. (2) Clinical Governance: All 5 cases were reviewed by Maternity Governance and the Perinatal Mortality Review Toolkit (PMRT) meetings. Spot checks of antenatal notes was done to check fetal movement documentation. (3) LESSONS LEARNT - Patient Education and Reduce Fetal Movement Awareness Campaign; (3b) Patient Antenatal Notes - Introduction of new Reduced Fetal Page; (3c) Changes in IUGR Guideline - All women found with previous IUGR at booking dating scan, Ultrasonographers are empowered to automatically book serial growth scans (28/40; 32/40 and 36/40 weeks) at dating scan. Spot checks to review changes.

Ethics statement: None

View with full poster: N/A

Keywords: supporting patient choice, mode of delivery, IUD, stillbirth

The stillbirth checklist

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Following a stillbirth, the parents have to face a situation that they would probably never thought about: giving birth to a dead baby. Perinatal loss is still a taboo in our society. Even in the health sector it continues to be a situation very difficult to address. Health professionals and more so those who work in maternity units, often find their previous professional training in dealing with grief, which is often non-existent, put to test when faced with a perinatal death. The "avoidance" and "confusion" in these cases, the lack of specific and/or correct information from different professionals, who may even contradict each other, neither help families, but can worsen the grief process. At the Parc Sanitari Sant Joan de Deu (PSSJD hereafter), we considered the need to have a multidisciplinary care pathway to look after these families. The PSSJD’s guide provide the professionals with a checklist, to help the team members to know exactly in which point of the complicated process we are, what has been done or said and what is left to do or to explain to the parents. The identified checklist starts at the time of diagnosis, and follows the mother from admission to hospital discharge. All actions are recorded and included in the mother medical records. Recognizing our own lack of resources and / or knowledge in the care of families that have suffered a perinatal loss is the first step to improve the quality of the care we provide.

Ethics statement: No ethics approval required. Informed consent was sought from the parents involved, their confidentiality and anonymity is preserved, and there is no ethical conflict

Conflicts of interest: None

View with full poster: www.isa2019madrid.com/the-stillbirth-checklist

Keywords: stillbirth, checklist, perinatal death (loss), midwife, hospital care, perinatal

Cite as: The stillbirth checklist. T. Caballe Bel, R. Heras Trejo, I. Perez Pinedo, C. Garcia Terol, M. Brito Vera. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Death management in neonatal intensive care: psychological Training course for operators of Neonatal Intensive Care

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This paper intends to present a training project focused to the Nicu operators of four hospitals in the city of Turin. Perinatal death is a strong event in life, that touches the sensibilities of people, even in a professional dimension, are involved. Death in intensive care is a topic that requires a multidisciplinary confrontation aimed at the search for adequate and sustainable language and behavior - or perhaps that support both the fatigue of the operators and the pain of parents, in the comparison of different roles and positions. The training, now in its 3rd year, proposes to the Nicu operators to meet 8 times a group of psychologists and compare/experiment themselves, through simulations and mindfulness meditation practices, on the death event of a newborn in Nicu, on shared procedures and the critical issues. Medical and nursing NICU's staff need to learn skills and competences necessary to perform this task optimally, and also improve this aspect of assistance to the newborn and his family. Through group supervision we focus on the experiences that operators, with different qualifications and professional skills, encounter in NICU putting on the spotlight the person, meaning not only the “patient”. A further goal of supervision must be quality of life improvement, applied both to the doctor and nurse operators, highlighting how the identity of “worker” is consolidated by unity and sharing of emotional and cognitive aspects. Building a protocol for managing NICU death in the 4 participating hospitals, to make a homogeneous pool of interventions and care for families and operators.

Ethics statement: No ethics approval required.

Conflicts of interest: None


Keywords: perinatal death, working group, mindfulness

Developing a national bereavement care website

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Pregnancy loss is the most common complication of pregnancy. The end of a pregnancy or the death of a baby through miscarriage, stillbirth, neonatal and infant death can have a devastating and long-lasting impact on the woman and her family. The Implementation Group for the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death in Ireland has found that the information available to bereaved parents and health care providers alike differs greatly from area to area. We found that, increasingly pregnant women are accessing information about pregnancy and childbirth from the internet. Supported by funding from the Irish Hospice Foundation, the website, “PREGNANCY AND INFANT LOSS IRELAND” is an initiative of the afore-mentioned Implementation Group. A multidisciplinary working group, with a parent representative, worked to develop the website in collaboration with a commercial design company. This group researched similar websites and looked at their content and intended use. The Parents Forum from the Standards Implementation programme were asked what they thought would be useful to bereaved parents when accessing such a website. It was agreed by all involved that the website should be a resource for bereaved parents and health care professionals to signpost them to information and support structures. Then information was compiled and written by the Programme Manager in collaboration with the working group. The design company then designed and built the website around the information provided to them. The final design and content was shared with expert colleagues, at a National Bereavement Forum with their feedback considered. The website was publicly launched in April 2019. A website management group was set up to oversee the management of the website, to ensure content is up-to-date and to assess the need for further development of the website. A valuable resource for parents who experience pregnancy loss the website provides accurate and accessible information on a sensitive subject, shares the latest research on pregnancy loss, promotes emotional well-being, and offers details on how to access the appropriate support services.

Ethics statement: Ethical approval was not necessary for the development of the website.

Conflicts of interest: None

View with full poster:  www.isa2019madrid.com/developing-a-national-bereavement-care-website

Keywords: bereavement care, standards, parents, professionals, pregnancy loss, website

Building student midwives' confidence to care for grieving parents: impact of participation in an education/training workshop in bereavement care

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(1) UCD School of Nursing, Midwifery and Health Systems; (2) National Maternity Hospital

1) Background: Supporting the growth of student Midwives' confidence (bereavement support skills and knowledge) to provide bereavement care to parents following pregnancy loss and perinatal death. A bespoke interactive one-day Educational Training Workshop in Bereavement Care (ETWBC) was developed for student midwives (final year of BSc Midwifery Degree and Higher Diploma Midwifery (shortened programme for RNs) (N=41)) to help improve their confidence in clinical practice. The Workshop contained the following, Practical advice for students about communication – good and bad, Making memories with families, parents’ perspectives on the impact of bereavement, Interactive role-play, Poetry, Self-care, including reflection and a mindfulness hour. 2) Methods: A longitudinal sequential mixed methods design completed in two phases Outcome and Process was used to evaluate the ETWBC, the Outcome Evaluation is presented here. Primary Outcome: Confidence and Secondary Outcomes: Self-awareness, Organisational support, Self-Compassion were all measured at all 3 time points [pre ETWBC, post ETWBC and at 3-months follow-up] using the Perinatal Bereavement Care Confidence Scale [PBCCS] (Kalu et al., 2019) and the Self-Compassion Scale-Short Form [SCS-Sf] (Raes et al. 2011). 3) Results: Participation in the ETWBC increased student's midwives' bereavement support skills \[F (2,72) =21.150, p>.000,\text{ partial eta squared}= 0.370\] and knowledge \[F (1.6,60) =48.460, p>.000,\text{ partial eta squared}= 0.567\] to provide bereavement care. Improvement in students’ self-awareness \[F (17, 61) =30.387, p>.000,\text{ partial eta squared} 0.458\] was also found. There was no significant increase in the students’ perceptions of organisational support or level of self-compassion. 4) Conclusions: Participation in the ETWBC had a positive impact on building student midwives’ confidence and self-awareness. This workshop has been integrated into the Midwifery Curriculum and further development of the role play as a learning tool is ongoing.

Ethics statement: Due to the sensitive nature of the subject being discussed, there was a potential to cause distress to students during the workshop or in focus group interviews. Participation in the study was completely voluntary and the students were given the option to opt out at any time. Members of the bereavement team and clinical placement co-ordinators were present at the workshop and focus group to monitor students for signs of distress and provide support and or debriefing if required. Ethical Approval was granted by the Research Ethics Committee in the National Maternity Hospital Dublin and an Ethical Exemption was granted by the UCD Research Ethics Committee for the project.

Conflicts of interest: None


Keywords: bereavement care, education, student midwives, pregnancy loss, perinatal death

Introduction to good practices in care of perinatal mourning at Virgen de las Nieves University Hospital in Granada

Z. de la Rosa Várez, M. Gutiérrez Martínez, C. Ariza Salamanca

Midwifery, Hospital Universitario Virgen de las Nieves, Granada, Spain

1) Background: Virgen de las Nieves Hospital in Granada, is a third level medical center, apart from being a model in fetal medicine for Easter Andalucía. From this context, attendance is provided to a high percentage of pregnant women with obstetrical/fetal pathologies, some of which end up with the living experience of a perinatal mourning. For such reason, we needed to modify the way to attend such women and make suitable our practice according to the attention of perinatal mourning. Objective: To adapt the attention of perinatal mourning in our health centre to the last recommendations according to the scientific societies.

2) Methods: Systematic revisión of the recomendations and publications by scientific societies focused on this topic. DataBase: PubMed, Scielo and Academic Google. Elaboration of a procedure on attention to perinatal mourning in our city, including good practices.

3) Results: Within the good practices standards, we have included the following ones: Identification of the wards where pregnant women are in such situation: considering art therapy in the process of attention to women and the placement of blue butterflies mandalas just by the door of the wards, Individual admission to women at the pregnancy ward, guaranteeing the relief of pain and offering families contact and babies farewell, Memories creation: box and white clay to collect babies memories, Elaboration of a “Informative Guide for parents after an intrauterine death, The elaboration of a protocol is being created for the attendance of perinatal death, A course financed by professionals is being organized about the attendance of pregnant loss.

4) Conclusions: To display all tools and resources the health system and social net have to face the perinatal mourning, including them in our daily practice, is an essential task to tackle as health professionals.

Ethics statement: Ethics approval not required.

Conflicts of interest: None


Keywords: perinatal death, grief, perinatal care, stillbirth, hospital care

Cite as: Introduction to good practices in care of perinatal mourning at Virgen de las Nieves University Hospital in Granada. Z. de la Rosa Várez, M. Gutiérrez Martínez, C. Ariza Salamanca. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Memories, pictures and giving bad News

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Midwifery, Parc Sanitari Sant Joan de Deu, Barcelona, Spain

1) Background: In 2009 the UMAMANITA Association, in collaboration with “El parto es Nuestro”, produced a pioneering guide: the “Guide to care for perinatal and neonatal death”, due in part to the lack of empathy and training on the part of health personnel. In the hospital “Parc Sanitari Sant Joan de Deu” (PSSJD) the desire to offer good care has meant that since 2010 this model of care has been adapted in different stages, with the Protocol of still-birth in that year, and revised in 2012 with the incorporation of “good practices”. Finally, in 2017, the “Perinatal Loss Action Guide” was drawn up, with which the professionals in the mother and child area of the PSSJD have made an effort to offer quality care in these situations. This work is intended to be a sample of three of the aspects contained in this guide. 2) Methods: Qualitative study with exhaustive review of each case: a) Delivery of a box with souvenirs and an offer to take photographs, b) Communication of bad news, c) Orientation to necropsy. 3) Results: The implementation of the Guide makes it possible to record the activities offered both quantitatively and qualitatively. Some shortcomings are still reflected, such as making visible the losses of the first trimester, refining the records of the second trimester, and recording all the actions carried out in the third trimester. 4) Conclusions: In these two years of implementation of the Guide, a better collection of data is observed, although there are still aspects that are not recorded or not taken into account, such as promoting the presence of the midwife when bad news is reported, writing down the contents of the memory box in the Medical History and encouraging people to take photographs.

Ethics statement: There is no conflict of interest.

Conflicts of interest: None


Keywords: perinatal loss, clinical guide, gestational mourning, memories

Attention to patients with grief after pregnancy loss and perinatal grief as part of the Perinatal Mental Health Program at Hospital Puerta de Hierro

M. Díaz de Neira Hernando, M.A. Forti Buratti, L. García Murillo, I. Palanca Maresca

Psychology/psychiatric services, Hospital Puerta de Hierro Majadahonda, Madrid, Spain

The Perinatal Mental Health Program has been developed by Child and Adolescent Psychiatry and Psychology Department at Hospital Universitario Puerta de Hierro Majadahonda. It aims to promote family mental health, since pregnancy, to facilitate the development of a healthy parent-to-infant bond. Pregnancy loss and perinatal loss are two situations that may affect family stability and family mental health. Within the program we have included clinical activities as well as liaison, teaching and research activities. 2.1 Clinical activities: We receive referrals from Gynecology and Obstetrics and Neonatology. In the case of perinatal grief, we include: Assessment and support of parents during hospitalization and after discharge. The goal of the intervention is to facilitate bereavement. Assessment and participation in group psychotherapy for pregnant women with previous perinatal or pregnancy loss. Intervention is orientated to facilitate the process of facing fears and worries of the current pregnancy and develop a healthy mother-to-infant bond with the coming baby. 2.2 Liaison activities: Liaison meetings take place weekly with Neonatology staff. We attend the multidisciplinary meeting on “Perinatal morbimortality” that takes place fortnightly. We also provide support and advice in particular cases in order to help improving communication between medical staff and families. 2.3 Teaching and research activities Teaching activities on these topics are developed at the hospital or in other facilities. Research has been done in the field of perinatal mental health. As part of the attention to families going through perinatal grief, we do not only see families as patients but also liaise with other services, we develop training programs and do research in the field.

Ethics statement: No ethics approval required.

Conflicts of interest: None


Keywords: perinatal mental health program, stillbirth, grief

Cite as: Attention to patients with grief after pregnancy loss and perinatal grief as part of the Perinatal Mental Health Program at Hospital Puerta de Hierro. M. Díaz de Neira Hernando, M.A. Forti Buratti, L. García Murillo, I. Palanca Maresca. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
The National Bereavement Care Pathway in the UK: improving standards in bereavement care

M. Harder

Sands UK, United Kingdom

The loss of a baby at any gestation is devastating for parents. Poor bereavement care from the moment of first diagnosis and breaking of bad news, only exacerbates the profound pain felt by parents. Whilst approaches to bereavement care in the UK have greatly improved in recent years, inconsistencies remain in the care that is delivered, resulting in geographical variations. Inconsistency in care is also encountered between different types of loss. Many parents whose babies died in earlier trimesters compare their lack of bereavement care poorly with the experience of friends who lost a baby at later stages of pregnancy. Parents should be able to access high quality, sensitive, individualised care, regardless of circumstance, gestation or postcode. Thus the All-Party Parliamentary Group on Baby Loss asked Sands to lead a collaboration to implement the National Bereavement Care Pathway (NBCP). The aim is to ensure that all bereaved parents receive equal and excellent bereavement care that meets individual needs. The scope encompasses five experiences of pregnancy and baby loss: miscarriage, termination of pregnancy for fetal anomaly (TOPFA), stillbirth, neonatal death and Sudden Unexpected Death of an Infant (SUDI). Since March 2017 the project team has created guidance documents, training packages and other materials for professionals to support parents. A Parent Advisory Group has supported many elements of the pathway’s development. In October 2017 eleven NHS Trusts began piloting the pathway, in April 2018 a further 21 sites joined Wave 2. An independent evaluation, surveying professionals and parents, demonstrated the positive impact and effectiveness of the pathway in delivering greater consistency and quality. The pathway has now been expanded into Scotland and more Trusts in England have signalled their intention to adopt the NBCP in 2019/20, with a roll out plan centred on nine core bereavement care standards.

Ethics statement: The Health Research Agency confirmed (Jan. 2018) that “the [NBCP] project is not considered to be research and does not require review by an NHS Research Ethics Committee.” Parents approached to complete the NBCP survey for their views on their bereavement care were given clear information regarding the use and confidentiality of their data and agreed to a series of relevant statements before completing the survey. Throughout the survey they were also provided with the contact details of their Trust and of Sands and other support organisations.

Conflicts of interest: None


Keywords: bereavement care, quality, standards, parent voice, implementation, partnership

Cite as: The National Bereavement Care Pathway in the UK: improving standards in bereavement care. M. Harder. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Irish inquiry reports on pregnancy loss services: what recommendations on staffing and training?

Ä. Helps (1-3), S. Leitao (2), L. O’Byrne (1), R. Greene (2), K. O’Donoghue (1,3)

1) Pregnancy Loss Research Group, Department of Obstetrics and Gynaecology, University College Cork, Ireland, 2) National Perinatal Epidemiology Centre (NPEC), University College Cork, Ireland, 3) The Irish Centre for Fetal and Neonatal Translational Research (INFANT), University College Cork, Ireland

1) Background: External inquiries are carried out following specific adverse maternal events and aim to identify issues in the maternity care provided to pregnant women and make recommendations to improve standards of care. The current work examines the recommendations made in these reports on the topics of staffing and training, and their link with the care provided to bereaved parents. 2) Methods: From the national inquiries into the Irish maternity services, 10 publically-available health-service-commissioned inquiry reports relating to pregnancy loss services (published between 2005-2018) were analysed. Qualitative data was collected by 2 clinicians, separately, using a specifically designed review tool. Thematic analysis of the findings and recommendations was carried out. 3) Results: The reports focused on maternity services in relation to pregnancy loss and/or clinical care provided around the time of the loss. The recommendations included: appointment of a bereavement officer in each maternity unit to liaise with families and multidisciplinary teams, and staff training in bereavement care to provide appropriate support to families. Insufficient workforce training (e.g. intrapartum monitoring, incident review) was highlighted and reflected in the recommendations. Recommendations to increase specialist services (e.g. perinatal mental health), as well as consultant obstetrician/midwifery staffing numbers to internationally accepted levels (including one-to-one ratio of midwife to woman in labour) were made. 4) Conclusions: These reports highlight the importance for an experienced, single point of contact and support for bereaved parents. Timely and well-executed adverse incident reviews provide essential learning to the hospital and key information for bereaved parents. An adequately trained and staffed workforce is essential to provide safe maternity care, and ensuring the reduction of risk of adverse outcomes.

Ethics statement: Only publicly-available reports were analysed, therefore no ethics approval was required.

Conflicts of interest: None


Keywords: pregnancy loss services, external inquiries, bereavement care training

Care following perinatal loss does not end at hospital discharge

R. Heras Trejo, I. Pérez Pinedo, T. Caballé Bel, C. García Terol, M. Brito Vera

Department of Obstetrics and Gynaecology, Parc Sanitari Sant Joan de Deu (PSSJD), Barcelona, Spain

At the Parc Sanitari Sant Joan de Deu (PSSJD) the care we offer to families who suffer the death of their baby is based upon our own multidisciplinary guide. We established the differentiation between hospital care and outpatient follow-up. During the cases review we undergo on a monthly basis, a gap between in-hospital and outpatient care was observed, therefore the “follow-up telephone call” was established for all parents, regardless gestational age. Maternity nurses’ team, and more specifically the nurse/midwife who established a closer relationship with the family will make the follow-up phone call. Prior to discharge the nurse/midwife will inform the family about the call and gain their consent. The call will take place 3 weeks after discharge. An specific register has been designed, where the nurse/midwife will resume the clinical details and the information gathered via the phone, including physical condition of the mother as well as the emotional state of both parents. The call allows the nurse/midwife to detect any change in their grieving process, clarify doubts and redirect to the appropriate professional if necessary. Contact via a telephone call offers the family a professional who “has not forgotten them”, someone to whom they can talk to freely about their worries which arise during the first days at home, someone who can offer them resources to integrate this tough experience into their lives.

Ethics statement: Informed consent was sought from the parents involved, their confidentiality and anonymity is preserved, and there is no ethical conflict.

Conflicts of interest: None


Keywords: stillbirth, follow-up, hospital discharge, outpatient care, nursing

Cite as: Care following perinatal loss does not end at hospital discharge. R. Heras Trejo, I. Pérez Pinedo, T. Caballé Bel, C. García Terol, M. Brito Vera. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Communication in Stillbirth: introduction of a protocol for health operator to prevent dysfunctional parent's psychological effects

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The literature on the subject shows us that the management of the communicative moment by health workers to parents as one of the phenomena that most affect their psychological system. The undesirable effects of an inadequate management of this important moment from a psychological point of view show signs of psychopathological consequences in the long time. The present work aims to prevent undesirable psychopathological phenomena through the adoption of a communication protocol for health professionals. 2) Methods: Through the realization of 3 focus groups we proceeded to analyze the communicative and emotional needs of the health and social workers of the obstetrics and gynecology ward, regarding the communication to the puerpas of unfortunate events, such as lethal fetal malformations or fetal endouterine deaths. According to the variables investigated, a communication protocol was drafted which was socialized with the operators through specific meetings. 3) Results: Through focus groups, we found out how difficult it was for health personnel to communicate with patients and family members. The aim of this work is to verify also through a subsequent qualitative investigation, the effects of the introduction of the protocol on two samples represented by operators and parents involved in the communication process linked to the Stillbirth event. 4) Conclusions: The undesirable psychological effects resulting from the management of Stillbirth communication in the immediate occurrence of the event, by the health worker, determines psychopathological consequences related to the mourning elaboration of caregivers. The introduction of a communication protocol that allows the adequate management of communication makes it possible to prevent the undesirable effects and to process mourning with sustainable methods

Ethics statement: In accordance with the rules of the regulation:
Meta-Code of Ethics accepted by the General Assembly of the European Federation of Psychological Associations in Granada, July 2005, it is stated that the present scientific work was conducted in full ethical observance of the cited norms

Conflicts of interest: None


Keywords: stillbirth, communication protocol, health worker

Supporting New Zealand health care professionals to provide holistic care when a baby dies

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1) Background: Health professionals involved in maternity care will be exposed to Stillbirths and Neonatal deaths. Caring for families whose baby dies can be traumatising and has concluded with health professional leaving their chosen profession. This research is a qualitative review of what knowledge health professionals have and what they find beneficial in supporting them when caring for a mother whose baby dies. 2) Methods: Participants completed online surveys prior to and at the conclusion of the “When a Baby dies study day.” Surveys prior to the workshop reviewed what knowledge and experience they have and what they believed they would learn from attending the study day. The post course surveys focused on whether they would be able to apply the new knowledge they have acquired on the course and if they were able to see positive improvements in their practice as a result of the course. 3) Results: 33 health professional completed the surveys they included midwives, nurses, doctors, social worker and chaplain. 100% of participants agreed they could apply what they learnt on the course and that they would see positive results and improvements to their practice. Comments include: “The whole day was interesting and valuable the variety of speakers from different disciplines made the day.” “This is a brilliant day about something so difficult” 4) Conclusions: This is an invaluable study day which enhance health professional knowledge and confidence. Ethics approval was not required for this volunteer survey of health professionals.

Ethics statement: Ethics approval not required

Conflicts of interest: None


Keywords: stillbirth, neonatal death, holistic care, health professional wellbeing

Cite as: Supporting New Zealand health care professionals to provide holistic care when a baby dies. D. Leishman. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Born to die: healthcare for deaths of unviable babies in the Province of Granada (Spain)

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1) Background: Babies that are born alive and die instants or minutes later, due to their extreme prematurity or unviable malformations with life, and resuscitation maneuvers or maintenance of life are not performed due to their futility, are usually separated from the parents and left to die in solitude. Although in most hospitals in Andalusia and Granada there are protocols for care at Perinatal Death, it seems that the option for these unviable babies to die with their mothers and families has not yet been routinely implemented. The objective of this study is to analyze the existence of recommendations in the care protocols for perinatal death in the hospitals of Granada (Andalusia, Spain), so that these babies die with their mothers and families, and identify the real scope of this practice. 2) Methods: The protocols on care for perinatal death of the five hospitals in the province of Granada where deliveries are attended were analyzed qualitatively and the relevant managers were interviewed. 3) Results: In all hospitals analyzed there are protocols for the care of Perinatal Death that include the recommendation that parents see and be with their children as long as they consider necessary when they are born dead or die shortly after. However, in daily practice, with unviable babies, there still seems to be reluctance among some professionals to offer this possibility. 4) Conclusions: Despite the advances reached in the knowledge of perinatal grief, the implementation of protocols and the continuing education for professionals in hospitals in Granada, there are still certain limitations in practice that can be related to myths or beliefs on the part of health providers, making traditional paternalism prevail. Therefore, greater effort is required to apply good practices, and further research to identify the specific causes of this in some hospitals in Granada.

Ethics statement: No ethics approval was required. The personal data are confidential and were treated in accordance with the Organic Law of Protection of Personal Data 3/2018. The information obtained was used exclusively for the specific purposes of this study. The authors of this study declare that they have no conflict of interest

Conflicts of interest: None


Keywords: stillbirth, perinatal death, grief

Cite as: Born to die: healthcare for deaths of unviable babies in the Province of Granada (Spain). E. Martinez Garcia, M.T. Rivas Castillo, B. Arrabal Delgado. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Applied drama techniques in obstetrics: a novel educational workshop for the management of stillbirth

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1) Background: Obstetricians have described feeling shocked and isolated in the aftermath of a stillbirth. Research shows that few receive adequate training in how to care for parents following a stillbirth, or on their own self-care skills. We developed a new innovative workshop for obstetricians, in collaboration with the drama department from the Irish National theatre, which uses applied drama to teach obstetricians skills in communication, self-care and self-efficacy in breaking bad news. The aim of this study was to evaluate this new workshop. 2) Methods: Senior trainees in Obstetrics and Gynaecology (n=74) were invited to attend and complete a post-workshop evaluation questionnaire. Five point Likert scales were used to assess participant’s feedback on the workshop. A paired-sample t-test with a significance level set at 0.05 was used to test for self-reported changes in the skills and attributes of the trainees following the workshop. 3) Results: 39/59(66%) trainees who attended completed the evaluation questionnaires. Most had received no prior formal training in stillbirth management(34/39, 87.2%). Following the workshop, there was a statistically significant improvement in trainee’s level of confidence in breaking bad news, communicating clearly with the family when breaking bad news, recognising the emotional needs of the family, recognising their own emotional responses and supporting their colleagues. Trainees were overall positive about the course content and would recommend the workshop to a colleague. 4) Conclusions: This study evaluated the impact that a novel educational workshop had on improving obstetricians’ awareness of compassion, communication and self care around the time of stillbirth. We identified a subjective improvement in some of the key skills that obstetricians must have when caring and communicating with bereaved parents. We recommend that this training should be incorporated into the core postgraduate curriculum in Obstetrics.

Ethics statement: This study received full ethical approval from the RCPI Ethics Committee ( RECSAF17). Participation in this study was via voluntary feedback and signed consent forms were obtained from each participant prior to inclusion in the study

Conflicts of interest: None


Keywords: communication, self-care

Maternity care providers' involvement in research

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1) Background: Despite a widely acknowledged importance of research for improving patient care and outcomes, research in pregnant women is lacking. Many challenges innate to conducting research in pregnant women may discourage maternity care providers from engaging in research. To date, there is limited data examining research involvement by maternity care providers. Thus, the objective of this study is to assess maternity care providers’ involvement in research, their perception of research, as well as facilitators and barriers to participating in research.

2) Methods: A total sample of 145 maternity care providers were recruited from Cork University Maternity Hospital in Cork, Ireland. Maternity care providers were defined as midwives, nurses, sonographers, non-consultant and consultant obstetricians. Participants completed a cross-sectional survey, including a 5-point Likert Scale, between May and October 2018.

3) Results: Overall, 50.3% of maternity care providers who participated in the present study reported ever taking part in conducting research. Medical staff were more likely to report being given the opportunity and to have ever conducted research compared to midwives (p>0.05). Participants agreed that medical research is important to maintain the quality of care provided to women (Mean=4.86) and reported that they disagreed that they have no interest in research (Mean=2.32). However, medical staff were more likely to report understanding research methodology and feeling competent to undertake research (Mean=3.85 v 3.28, p=0.002, Mean=3.56 v 2.60, p>0.05) compared to midwives.

4) Conclusions: The findings suggest future strategies aimed at increased opportunities for midwives to be involved in research as well as additional research training will likely support maternity care providers conducting research with pregnant women. An increase in maternity care research will improve the evidence base ultimately contributing to enhanced maternity care.

Ethics statement: The present study received ethics approval by University College Cork, Clinical Research Ethics Committee.

Conflicts of interest: None


Keywords: maternity care, improving care, education

Critical discourse analysis of the Joint Committee Meetings on the Eighth Amendment of the Constitution of Ireland

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1) Background: The 1983 Eighth Amendment of the Irish Constitution stated that the right to life of a pregnant mother and her unborn were equal, which meant pregnancy terminations were illegal in Ireland. Due to increasing opposition, a parliamentary committee was formed to deliberate arguments for and against repealing the Eighth Amendment. This study evaluates the issues raised and how information was presented during the committee meetings on the Eighth Amendment.

2) Methods: Published transcripts from the committee meetings on the Eighth Amendment were accessed online for analysis. The committee's deliberations occurred from September 20 to December 14, 2017. This qualitative study applied a critical discourse analysis, which evaluates language in its social and cultural context. Critical discourse analysis allows for the deconstruction of language to gain an understanding of socially produced meanings, recognising the ability for language to perpetuate inequalities and power dynamics.

3) Results: Throughout the committee meetings, research evidence was often misrepresented in order to spin findings in support of members' arguments. Anecdotal evidence, including emotionally-laden narratives, was used to persuade members with divergent views to change their moral and political opinions about what is socially acceptable. When discussing the risk and practical issues of introducing termination of pregnancy, the matter of conscientious objection and maternity hospitals with religious governance were debated, illustrating the influence of cultural and religious ideologies over the health of the population.

4) Conclusions: The discourse throughout the meetings likely influenced the committee members' perception of key issues, consequently impacting the pregnancy termination legislation created in 2019. This study reveals the potential for underlying bias in political structures and prevailing religious beliefs to sway healthcare legislation, ultimately shaping women's health in Ireland.

Ethics statement: Only data which were publically available were collected and no attempts were made to contact any individual therefore no ethical approval was sought for this study. Despite these data being publically available there is still an onus to ensure that ethical standards are met. Therefore any identifiable information have been removed.

Conflicts of interest: None


Keywords: pregnancy termination, critical discourse analysis, legislation

Quality of care provided to women requesting a late termination of pregnancy in a tertiary hospital

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1) Background: Termination of pregnancy (TOP) is a complex process not only for the parents but also for health providers. The perinatal grief is an emotional and painful process which the families go through, in which feelings and doubts that are very difficult to manage arise. It is crucial to a) identify the aspects which most concern these families and b) adapt our resources to their needs. 2) Methods: The perinatal grief care group in our Center designed a questionnaire including 16 questions (valued from 1 to 10) to specifically retrieve information on aspects related to the quality of care provided. 20 families undergoing a late TOP (> 22 weeks of gestation) were invited to answer anonymously the survey at the end of the process. The standard approach for families undergoing a TOP is by far focused on guaranteeing information on all aspects of induction and delivery, pain relief, time with the baby after birth, memory of their footprints and an individual room. 3) Results: The overall score of the care provided was 9.45 (0-10). However, 60% (12/20) of the families would have liked to receive other memories such as a birth certificate (15/20, 75%) or a photograph (10/20, 50%). Moreover, 65% (13/20) of the families said they would have spent more time with their baby. Environmental noise in different hospital facilities and delivery-to-discharge time scored 5.98 (0-10) and 6.22 (0-10), respectively. Finally, 55% (11/20) of the families reported the need for more emotional and/or psychological support, both during hospital admission and the postpartum period. 4) Conclusions: The overall assessment of the care provided was very good although some aspects might be improved. Conducting a survey to families undergoing a late TOP is a useful method to evaluate the quality of care provided and to design future actions.

Ethics statement: Patient selection was performed in accordance with the Declaration of Helsinki and applicable local regulatory requirements after approval from the Ethics Committee of the Hospital Clinic on 26 January 2019 (Reg. HCB/2019/0121). All data were acquired and analysed anonymously, after the patients understood and accepted to participate in our study.

Conflicts of interest: None


Keywords: quality, termination of pregnancy, perinatal grief

Cite as: Quality of care provided to women requesting a late termination of pregnancy in a tertiary hospital. E. Moreno, A. Peguero, A. Martínez, M. Palacio, Á. Arranz, O. Gómez. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Stillbirth: professional support to help parents cope with loss

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1) Background: Stillbirth is traumatic for parents, who react in a complex way, and they could be emotionally scarred for life. In this paper we review the good practices to help parents cope with their loss.

2) Methods: Systematic search of four bibliographic databases: PubMed, Medline, PsycINFO and SciELO. 19 articles included, published from 2000 to 2019. We propose to include studies that report the good practices for coping with a perinatal loss and studies about the process of grief. Health Sciences Descriptors were used to clarify keywords.

3) Results: The following interventions were included: to allow parents to talk about their feelings and get the frustration out, to offer them the option of seeing and holding their baby and storing keepsakes, to offer them support and listening, to offer them useful help, to allow minor children of the family to stay with their parents, to offer information about the grief and support group services, to avoid pharmacological interventions in the case of normal grief, consider a sign on the door for perinatal loss (it’s the way for staff to be forewarned).

4) Conclusions: Parents need not feel alone, so professional support and emotional support are both provided by midwives and other health care provider. Good practices are very important to help parents and family cope with their loss.

Ethics statement: Ethics approval not required

Conflicts of interest: None


Keywords: grief, stillbirth, evidence-based practice, midwifery

Experience of a support circle for women as a mechanism of resilience in mourning for neonatal and gestational death

V. Forero Rubio (1), A.M. Muñoz Carrillo (2)

(1) Tamá’s mother, Politologist, doula, and leader of the Circle of knitting and love in mourning; (2) Juan Isaac’s mother, lawyer, doula of death, leader of the Circle of Knitting and love in mourning and founder JIC Fundación de apoyo ante la muerte gestacional y neonatal.

We will present the experience personal of the circle of support called “Circle of knitting and love in mourning”. This group is based in Bogotá, and is currently constituted by 25 moms in the process of grieving over the death of their unborn babies or babies who died shortly after birth. This circle is led by Angela Muñoz and Valeria Forero who founded it after overcoming the death of their own babies and discovering that there were no similar support groups in Bogotá. Founders decided to create a space to talk about motherhood in mourning and to help moms to build a new sense of life after the death of their children. During the group meetings, every mother learns to knit a mochila Arahuaca (traditional purse knit by Arahuaca indigenous communities during women pregnancy) in memory of her baby died. Knitting the mochila represents the resignification of the mom’s grieving experience. The main topic of the exposition will be the founders analysis, in which they will be exploring how the circle serves as a mechanism that allows its members to properly validate their children’s grief from resilience. The exposition will also describe how through the circle, grieving moms have achieved to transcend their painful experiences into helping others by volunteering in a foster home, that has accomplished to transform grieving pain in love, and it works as a tribute to the life of each of the circle mom’s dead babies. This exposition will describe the importance of the circle for women in the process of mourning for gestational and neonatal death, to the extent that the space it offers, favors the expression of emotions and the empathy generated when a mom can identify her own experience in others. Also, the circle helps to validate this not physical motherhood, women in the circle may feel supported, and encouraged to develop strategies of coping and transformation, receiving their personal experience from resilience and constructing a new sense of life based on it.

Ethics statement: The video that will be shown with QR Code and the information that will be exposed in the poster about the circle, has the approval of each of the women members, who have given their written authorization to JIC Fundación para el apoyo ante la muerte gestacional y neonatal, and its leaders Angela María Muñoz and Valeria Forero.

Conflicts of interest: None


Keywords: support groups, mourning for gestational and neonatal death, resilience

Cite as: Experience of a support circle for women as a mechanism of resilience in mourning for neonatal and gestational death. V. Forero Rubio, A.M. Muñoz Carrillo. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Using educational DVDs in teaching perinatal bereavement communication to undergraduate healthcare students

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1) Background: Compassionate bereavement care has been shown to enhance parental experiences. Communication skills are a key component of good care. Third-level, healthcare programmes deliver communication skills education on caring for bereaved women and their families. Aim: To quantitatively evaluate the utility of educational DVDs as a teaching resource. 2) Methods: Following full ethical approval from the local hospital ethics committee data were collected via anonymised paper questionnaires designed and piloted, with input by expert clinicians. Medical students, undergraduate and post graduate midwifery students, and non-consultant hospital doctors were asked to complete pre and post viewing questionnaires pertaining to two DVDs. One was developed with bereaved parents (‘When My Baby Died’) around their experiences of stillbirth and the second with healthcare staff (‘Why My Baby Died’) explaining the perinatal post-mortem process. Data were cleaned, coded and inputted into Microsoft Excel and SPSS (Version 24) for data analysis. 3) Results: In total 125 participants viewed ‘When My Baby Died’ and 75 viewed ‘Why My Baby Died’ DVDs. 83% of participants had a better understanding of stillbirth and 66 % said they would feel more comfortable talking with parents who had experienced a stillbirth after viewing ‘When My Baby Died’. 82% reported that this DVD was a useful method of teaching communication and care skills. 84% of participants felt more knowledgeable about the perinatal post mortem examination and would feel confident explaining the process to parents post viewing. 88% of participants agreed that the short film “Why My Baby Died” should be used as an educational training tool. 4) Conclusions: The DVDs were shown to be a useful and acceptable method of teaching perinatal bereavement communication and care. Post DVD viewing knowledge levels increased among all student groups. DVDs are low cost and innovative way of educating and stimulating dialogue on perinatal bereavement care by presenting the lived experiences of bereaved parents and information from healthcare staff.

Ethics statement: Full ethical approval for this study was obtained from the Local Hospitals Ethics Committee and the Local Information Governance Group (LIGG). Data access was approved by the LIGG and limited to the named authors. All data were anonymised and securely stored.

Conflicts of interest: None


Keywords: stillbirth, bereavement care, education, innovation

Cite as: Using educational DVDs in teaching perinatal bereavement communication to undergraduate healthcare students. T. O’Sullivan, M. Murphy, A.M. Verling, K. O’Donoghue. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
The role of the clinical midwife specialist in bereavement and loss: a service review

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1) Background: In Ireland in 1998 A report of the Commission of Nursing identified the need for the development of clinical nurse and midwife specialist roles. This year, over 20 years later, following the recommendation of the National Bereavement Standards in the Maternity Services, a CMS in bereavement CMSb) has been appointed to all 19 Maternity Units in Ireland. The Role of the CMS is defined as having five core competencies: clinical, education, consultation, advocacy and research and audit but work has not been undertaken to evaluate the role in practice. We wished to establish to what extent these competencies were met in a maternity unit in which the role of CMSb is long established. 2) Methods: Both the CMSb in post in a large maternity unit in Ireland, each of whom work 29.25 hours, giving a total of 58.5 hours, contemporaneously recorded their working activities for one week. This data was analysed in detail and compared to the CMS competencies. 3) Results: Clinical focus involved 45% direct patient contact and 30% indirect patient care and planning. Time spent in education, professional role development, service development and research accounted respectively for 6%, 3%, 4% and 4% of the time. Time to present and attend at a bereavement conference (16 hours) was within personal hours within this week. 4) Conclusions: It is notable how a relatively large part of time was spent in clinical focus i.e. 75% of the week. While there is overlap between the CMSb core competencies this left relatively little time is left to facilitate the tasks directly associated with advocacy, consultation and research/audit including role and service development. This was however further addressed in the CMSb personal time in this week.

Ethics statement: Ethical approval was not required as this work was a review of service provided by authors.

Conflicts of interest: None


Keywords: bereavement midwife specialist, role review

Support guideline for families with perinatal grieving: care follow-up and continuity

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Death and perinatal grief support should be a continuous work of the entire health care team. This work requires adequate training of all the professionals involved. The project describes the development and implementation of a guideline for perinatal bereavement care follow-up and continuity at Hospital Universitario Fundación Alcorcón. The objectives of the guidelines were to define the necessary skills of the health professionals to provide tools to the families, that allow them to grieve normally and to be able to recover their physical and emotional well-being. To ensure care continuity through follow-up by a multidisciplinary team. To offer resources when discharging patients, support groups. A multidisciplinary team of recruitment, follow-up and referral coordinated with specialized and primary health care ensuring care continuity was established. The guideline that was developed establishes protocols for action and communication with parents and relatives from admission to hospital discharge. After ten days from hospital discharge, the midwife contacts the parents by phone offering them a follow-up appointment after which, they will be offered further visits or consultation over the phone. They are also contacted via e-mail by a coordinator, who will request an assessment by their primary care doctor, midwife and nurse and refer them to the psychologist if necessary. Additionally, booklets with recommendations for parents, relatives and friends at hospital discharge were developed and distributed. Therefore, since the implementation of this guideline in January 2018, the research team is developing a research project to learn about the experience of these families and health professionals in the grieving process, with the aim of improving our scientific and human quality as well as the excellence and continuity of our care for all and by all. January 2018, the research team is developing a research project to learn about the experience of these families and health professionals in the grieving process, with the aim of improving our scientific and human quality as well as the excellence and continuity of our care for all and by all.

Ethics statement: No ethics approval required.

Conflicts of interest: None


Keywords: perinatal grief, health care, stillbirth, guidelines

Critical discourse analysis on the influence of media commentary on fatal fetal anomaly in Ireland

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1) Background: Fatal Fetal Anomaly (FFA) has generated international media attention as termination of pregnancy (TOP) for FFA was legislated for, for the first time in Ireland. Media offers an insight into health-related information available to the public. Media has the power to represent social topics in a particular way and effects are of particular relevance where a certain opinion or influence are intended by political or social stakeholders. This study aimed to examine how TOP for FFA and perinatal palliative care (PPC) information were framed in Irish published media.

2) Methods: A critical discourse analysis, which examines the relations between discourse and social and cultural phenomena was implemented. Shirazi’s framework facilitated an objective analysis to facilitate interpretation and understanding of socially produced meanings. A broadsheet and online journal, with daily outputs and both having a daily readership in excess of 300,000 were chosen. An online search of FFA, PPC and TOP for FFA was undertaken.

3) Results: Dated from 2012 to 2017, 130 articles were identified. Themes of power and politics, international influence, ethical dilemmas and emotional appeal were embedded in the discourse, creating political influence and emotionally appealing to the reader to influence perceptions and views. The use of different terminology e.g. ‘FFA’ versus ‘life-limiting condition’ and the word ‘fetus’ versus ‘baby’ were evident throughout the results. Terminology were chosen by different ideological perspectives in attempts to create varying contexts and support arguments.

4) Conclusions: This study highlights misrepresentations in the information delivered to the public, particularly in relation to supports available to women who receive a diagnosis of a FFA. Language is not neutral emphasising the importance of analysing the health information being delivered to the public and to those responsible for change in health service provision on controversial social issues.

Ethics statement: Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref. No: ECM 4 (q) 050917).

Conflicts of interest: None


Keywords: congenital anomaly, palliative care, termination, media, discourse analysis

Burnout after perinatal LOSS in Midwifery: results of the BLOSSoM study

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1) Background: Perinatal death and stillbirth are dramatic events, and the care of mothers, fathers and babies is usually perceived as an intense and stressful experience by professionals, often unskilled in coping with such a tragic and unexpected termination of pregnancy. Here we report the results of a nationwide investigation conducted in Italy in a sample of 534 healthcare professionals (mainly midwives and obstetricians) involved in perinatal loss care.

2) Methods: Each subject was administered the Lucina questionnaire to explore professionals’ beliefs on perinatal loss, the Revised Impact of Event Scale (RIES) oriented on stillbirth experiences, and the Maslach Burn-Out Inventory (MBI) to assess the level of professional burn out.

3) Results: The mean age was 33.6 ± 9.2, the mean number of working years was 9.0 ± 7.2. The levels of event impact and professional burnout scales were not significantly different between the various healthcare professions. The total number of stillbirths assisted during the career significantly correlated with the level of burnout dimensions (p>0.01). Correlation analysis showed a significant relationship between perceived event impact and professional burnout. In particular, the presence of avoidance symptoms after the event was associated with emotional exhaustion at work (rho=0.27, p>0.01) and with problems in personal accomplishment (rho=0.28, p>0.01).

4) Conclusions: According to our experience in Italian settings, addressing the stress of professionals facing stillbirth and perinatal death is of paramount importance, since this experience could lead to professional burnout and emotional exhaustion. High level of burnout could in turn impair communication skills of caregivers, resulting in a poor quality of assistance for bereaved parents, a well-known factor in determining long-term psychological distress and poor quality of life.

Ethics statement: According to Italian regulation, for this type of studies the approval by the Ethics Committee is not required (GU n. 76 March 31, 2008), data were collected in keeping with General Data Protection Regulation of European Union (GDPR, EU 2016/679) and written informed consent was obtained from all participants.

Conflicts of interest: None


Keywords: stillbirth, perinatal loss, burnout, professionals

Previous pregnancy loss and lactating behaviors: a post-hoc analysis of the Herbal supplements in Breastfeeding InvesTigation (HaBIT)

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1) Background: Perception of pregnancy- and breastfeeding-related difficulties and consequent use of complementary and alternative medicines (CAMs) may differ in bereaved women, in force of the distress related to previous loss. This Herbal supplements in Breastfeeding InvesTigation (HaBIT) post-hoc analysis explored the impact of previous pregnancy loss on the lactating behaviors and on the use of CAMs during breastfeeding. 2) Methods: A web-based survey was conducted among lactating women with no previous alive child, resident in Tuscany (Italy). Data on lactating behaviour and on CAMs use were collected and evaluated among women with previous pregnancy loss as compared to control women. 3) Results: Out of 476 women answering the questionnaire, 233 lactating women with one child were considered. Of them, 80 had history of pregnancy loss. Caesarean birth was significantly more frequent among women with history of pregnancy loss as compared to controls (41% vs 22%, p=0.004). Proportion and length of exclusive breastfeeding, and occurrence of breastfeeding-related complications, were comparable among the two cohorts. More than half of women used CAMs during breastfeeding. Use of CAMs was more frequent among women with previous pregnancy loss (54% vs 68%, p=0.050), specifically considering herbal preparations (16% vs 30%, p=0.018). Major advisors for CAMs use were midwives.18% and 23% of women without and with history of pregnancy loss declared no clear perception on CAMs efficacy and safety. 4) Conclusions: Overcoming the social taboo of pregnancy loss, and training healthcare professionals for an adequate management of the perinatal period is essential for an effective and safe care. Despite the common use and advise for CAMs use during breastfeeding, it is important to acknowledge that limited evidence supports their safety and efficacy during such critical period.

Ethics statement: According to Italian regulation, for this type of studies the approval by the Ethics Committee is not required (GU n. 76 March 31, 2008), data were collected in keeping with General Data Protection Regulation of European Union (GDPR, EU 2016/679) and written informed consent was obtained from all participants.

Conflicts of interest: None


Keywords: perinatal loss, breastfeeding, complementary and alternative medicine, safety

Treating perinatal mortality in muslim culture

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1) Background: Several studies highlight the lack of understanding and skills of healthcare professionals with regards perinatal mourning. This is especially true when it comes to foreign cultures, namely Muslim, whose population has increased in Andalusia over the last few decades. This paper aims to study the beliefs and costumes of the Muslim population with regard to perinatal mortality and mourning and to outline the aspects to be considered when dealing with them.

2) Methods: To this end, a revision of current scientific literature was undertaken.

3) Results: Birth and puerperium are considered to belong to the female authority and fathers do not participate. For Muslim people, death is the beginning of a spiritual life. Therefore, the subject of death is not considered as taboo. As regards grieving over their loss, they are restrained, since Muslim laws foster self-control of fear and rage. Since 17 weeks pregnancy, the foetus is considered as a person and is given a name: God sends an angel to breathe the ruh (spirit) into the baby. According to the tradition, before neonates die, their face must be oriented towards Mecca and sprinkled with holy water. In addition, parents must watch the baby while praying next to it. They do not wish to keep photographs or hand or foot prints, as these are considered as desecration. The body is sacred and it only belongs to God. It may feel pain and autopsy will be allowed only exceptionally. Cremation is forbidden. The baby must be buried within 24 hours, covered in a sheet, so that the soul will rest painless and in peace.

4) Conclusions: Professionals involved in perinatal death must know the peculiarities of the Muslim culture in order to provide personalized, quality care and help go into healthy mourning.

Ethics statement: Este trabajo no requiere la revisión y aprobación del Comité Ético al ser una investigación secundaria o rebibliográfica/sistemática. No es necesario solicitar el consentimiento informado debido a que no se ha tratado con personas, encuestas, datos personales, datos clínicos o muestras biológicas.

Conflicts of interest: None

View with full poster: N/A

Keywords: perinatal death, cultural behaviors, Muslim, Islam

Multidisciplinary approach in obstetric and bereavement care in 8 stillbirth cases at Hospital of Motril

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Although infant mortality has been decreasing over the years thanks to medical advances, the same thing did not occur with the fetal mortality rate remaining stable. The diagnosis of Stillbirth is a devastating experience for the parents and one of the most difficult situations to face in the daily obstetric practice. We have compiled information about the care provided by the multidisciplinary team in 8 Stillbirth cases, 34+0 weeks and over of gestation at the Hospital of Motril in the last 5 years period (shown in Table 1). Although most of the recommendations from recent evidence are met (family support, admission in a single room, induction of labour with analgesia choices, attempted vaginal labour, offer post mortem contact, possibility of autopsy, follow-up in successive consultations and Mental Health services referral when requested), there are still areas for improvement in the assistance we provide. There are limitations in the published data as they are not reflected in the medical records consulted. The studies reviewed reveal that perinatal bereavement care in Spanish hospitals is an emerging field respect to other countries with similar economies. However, there is a growing interest in caring and supporting families in the grieving process, as it is widely known that it has psychosocial benefits for women and their families, therefore the strategies to improve care should be a high priority. However, the training and structural support offered from institutions to professionals, hospitals, health centres, is poor, and resources are basic aspect to be able to offer quality of care.

Ethics statement: All the data published in this poster are anonymous, guaranteeing the anonymity of the subjects. Ethical approval was not sought as it was not required for this study.

Conflicts of interest: None


Keywords: stillbirth, perinatal bereavement, multidisciplinary team

Cite as: Multidisciplinary approach in obstetric and bereavement care in 8 stillbirth cases at Hospital of Motril. M.T. Rivas, R. Sáez, M.J. Juanes. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Donation of breast milk in Spanish Milk Banks after a perinatal death


(1) University Hospital Getafe/CS Sector3, Getafe; (2) University Hospital Río Hortega, Valladolid; (3) University Hospital Virgen de las Nieves, Granada; (4) University Hospital La Fe, Valencia; (5) University Hospital 12 de Octubre, Madrid; (6) Blood and Milk Bank Zaragoza

1) Background: Breastmilk donation after a child death has a positive impact on the grief experience and allows milk banks to have high quality breast milk. Our objective was to describe how Spanish milk banks currently approach donation of milk after a child death, in order to detect areas for improvement. 2) Methods: Descriptive observational study. The information was collected in the first trimester of 2019 through an electronic questionnaire sent to all 14 Spanish Milk Banks. Collected data included the number of donors whose child had died, time of death and donor milk volume from 1st January 2016 to 31st of December 2018. The qualitative variables are described by relative frequencies and the quantitative variables by central tendency and dispersion measures. 3) Results: A 100% response rate was obtained. 74 women donated breast milk after their child’s death. In 6.8% of the cases the death occurred antepartum or intrapartum and in 93% it was after birth. In 59.5% of the cases, breast milk was pumped before the child death, in 31.1% it was pumped after the child’s death and in 9.5% there was an alive nursing sibling. The median donation volume was 2.48 (p25-p75,1-5.86) liters. From 14 banks, 93% permitted the donation of milk pumped before death and 79% after death during the natural inhibition of lactation and 64% without intention to inhibit lactation. Regarding information included in Milk Bank guidelines after a perinatal death, 57% did not collect this information. 64% had specific care procedures for these women, although 93% did not receive specific training. 71% of the Milk Banks considered that donating milk in these situations helped these women overcome their grief, and 50% intended to improve care, in particular changing milk bank protocols and providing information. 4) Conclusions: A high percentage of Spanish Milk Banks recognize the importance of donation from women who have lost a child and point out the need to make changes in order to improve care.

Ethics statement: The authors declare that there is no ethical conflict. The confidentiality and anonymity of bereaved donors are preserved.

Conflicts of interest: None


Keywords: milk bank, donor milk, infant death, bereaved donor, grief

The revised Universal Charter on the Rights of Childbearing Women: expanding the Charter to include newborns and stillborn infants

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(1) Johns Hopkins School of Public Health; (2) White Ribbon Alliance

1) Background: In 2011, the Universal Charter on the Rights of Childbearing Women was published. The Charter draws on universally-agreed-upon principles of human rights, ratified by almost all governments. These articles are written in plain English and have been translated into multiple languages. The Charter, which has been posted in health facilities worldwide, has been used as an advocacy tool with ministries of health, the media, and patients and providers themselves.

2) Methods: With the recognition that the Charter focused almost exclusively on the rights of women, an effort began in 2018 to update and expand the charter to explicitly include the rights of newborns. A systematic review of scientific literature, as well as a review of legal and regional guidance documents, was undertaken, and multiple consultations were held with families, patients, providers, and policymakers.

3) Results: The systematic review explored the previously-identified categories of mistreatment - including non-consented care, non-confidential care, non-dignified care, discrimination based on specific attributes, and denial of care – to ascertain how these applied to care or mistreatment of newborns. Most rights are shared by the mother and infant, including the mother’s right to consent for birth and bereavement options, but that there may be rare potential conflicts between multiple parents/caregivers, or the parents and the interests of the child, which may need to be resolved on a case-by-case basis.

4) Conclusions: Not only were exampled identified of mistreatment in most of the pre-existing categories, further categories specific to newborns were identified: (1) the legal right of each infant to a birth certificate and nationality, as well as a death certificate, regardless of age at death, and (2) the right of families to bereavement care, including their rights to decide if and how to celebrate or memorialize a deceased infant. The revision, launched in June 2019, was a necessary, but complex, update, and should continue to be improved over time.

Ethics statement: No ethics approval required

Conflicts of interest: None


Keywords: human rights, stillbirth, families

How do we include fathers when a baby dies?

M.G. Sich, A. Vamberg, O. Schriver

Unit for Perinatal Loss, Aarhus University Hospital, Denmark

When a baby dies both mothers AND fathers are bereaved of their child, but the literature primarily focusses on the mothers. Most studies that include men assess the differences between men and women and little is known about how men actually experience the loss of their baby, how they cope and what kind of support they need and what they are actually offered following a loss. Nevertheless, we do know something about how men in general react when confronted with a crisis and also which styles of communication they prefer. When women tend to use emotional strategies and verbalise their feelings, men tend to use problem-solving strategies and need factual information. Men in general have a strong need for autonomy and control and being active and able to act is a necessity for most men. In Danish hospitals, when it comes to caregiving, the culture is to a high degree shaped by women and female values and we have to ask ourselves the question: do we offer bereaved fathers the appropriate support after a perinatal loss? At Unit for Perinatal Loss, Aarhus University Hospital, nearly all tasks (induction of labour, assistance during birth, postpartum care, bereavement support groups and antenatal care in a following pregnancy) are performed by specialised midwives - who are all women. Fathers are to a high degree neglected in the care provided at many hospitals. In this presentation we will demonstrate how we, at the unit for perinatal loss at Aarhus university Hospital, have deliberately reformed our care to ensure a better inclusion of fathers.

Ethics statement: No ethics approval required

Conflicts of interest: None

View with full poster: www.isa2019madrid.com/how-do-we-include-fathers-when-a-baby-dies

Keywords: perinatal loss, fathers, caregiving

Cite as: How do we include fathers when a baby dies? M.G. Sich, A. Vamberg, O. Schriver. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Improving the quality of care in mourning in the Neonatal Intensive Care Unit at the Hospital Clínic - Seu Maternitat, Barcelona

I. Valle, E. Moreno, M. Roca, M. Vidal, A. Balada, R. Cortés, M. Alsina, S. Lera, M. Perera

Hospital Clínic - Seu Maternitat, Barcelona, Spain

The death of a child is a tragic experience and it affects the person in both, biopsychosocial and spiritual fields. The society we live in tends to mask this situation and, with greater emphasis, if this situation happens around perinatal death, the multi-professional, collaborative and integral accompaniment in the death process will create a high emotional impact with the words, silences and actions of those who care for these newborn children and their families. These will set the way in which they will later develop their mourning. This project aims to provide families with the best quality and care during the process of loss, know their opinion and improve the internal circuit of neonatal death. This is a descriptive and retrospective study whose study population are the families of newborn children whose death occurred in the NICU during 2018. All the families over 18 years old and without language barriers who wish to participate will be included. A nurse and a psychologist from the nicu mourning and palliative care team will meet with the family 3 months after the loss, ask how they are and conduct the survey. Afterwards, the answers will be introduced into the excel database and the different study variables will be analyzed: lighting, attention received from the professionals and from the whole team, farewell according to beliefs, memory box, information on administrative procedures, on the first steps of mourning and on the necropsy, emotional support and current help in the mourning process and suggestions for improvement. Despite working and training ourselves to improve care for neonatal loss, we are sure that after these surveys and the incorporation of the psychologist into the circuit, the experience of the families will improve.

Ethics statement: We have requested approval to our work center for the presentation of this project. At the moment that we must initiate the surveys, ask for de express consent of the participants to be able to make use of the results later.

Conflicts of interest: None


Keywords: mourning, NICU, quality care, neonatal death

Cite as: Improving the quality of care in mourning in the Neonatal Intensive Care Unit at the Hospital Clínic - Seu Maternitat, Barcelona. I. Valle, E. Moreno, M. Roca, M. Vidal, A. Balada, R. Cortés, M. Alsina, S. Lera, M. Perera. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Midwives training on perinatal grief

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The aim of this work is to value the perinatal grief theoretical and practical training of the midwifery students of the Midwifery Teaching Unit of Valladolid-Segovia, and more precisely the training relative to the Gynecological Emergency care to women who suffer pregnancy losses, in order to implement improvement actions. Contents included in the Spanish Midwifery Training current regulation and teaching methodology to improve the hidden curriculum for the purpose of training in management of women who suffered early pregnancy losses, were reviewed. Then, a comparison with content and methodology available in our Teaching Unit and the possibility to include self-reflective methods for improving the future midwife’s confidence to address professionally women and their partners care was discussed. The grief can be regarded as a difficult situation or a critical incident. To give special attention to the hidden curriculum that includes skills as clinical reasoning, communication, relationship to patient and professionalism, is needed to address it. Effective methodologies to improve the hidden curriculum such as interactive workshops, critical incidents reports and feedback, are defined. Currently, competences in this area are worked in our Teaching Unit thorough the following tools: 1. Formal curriculum: It is acquired through the theoretical knowledge acquisition (virtual platform, master classes). 2. Hidden curriculum: Competences which implies are acquired through simulated and real practical skills acquisition (OSCE, LBP and Evaluation Competences Handbook). However, we consider that it is necessary to ensure tools which enables midwifery student and their mentors to discuss casework of the real practice that can be generated insecurities and internal conflicts. In this sense, we have raised two improvement areas: -To include in the resident book critical incidents reports, -To train mentors in advance.

Ethics statement: No ethics approval required.

Conflicts of interest: None

View with full poster: www.isa2019madrid.com/midwives-training-on-perinatal-grief

Keywords: perinatal grief, midwifery training, hidden curriculum

Development of a website for first trimester miscarriage

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It is estimated that one in four pregnancies result in a first trimester miscarriage. For many women, this loss is often compounded by the silence and stigma associated with pregnancy loss and the lack of reliable and accessible information about miscarriage. Previous research identified the need for an information resource that is accessible and sensitive to a general population audience needing information on miscarriage. The aim of this work was to design a website specifically focused on first trimester miscarriage in an effort to respond to this need. During the development phase, the information was written by a CMS and Parent Advocate and the website was constructed in collaboration with the design team. The layout and visual aspects were key components of its development, in addition to sourcing a host site and creating a domain that would be accessible to parents and staff. Feedback was sought from a variety of clinical and academic staff and a group of bereaved parents. Recommendations were compiled and adjustments made where appropriate. Following feedback, it is envisioned that the website will be publically launched in 2019. The website will provide information on, Pregnancy, Pregnancy Concerns, Miscarriage Symptoms, Types, Management and Services, Feelings and Emotions, and Pregnancy after Miscarriage. While the site is specific to the services operating in CUMH, the information is relevant to maternity services nationally and internationally. Medically accurate, accessible information that is written in a sensitive and visually appealing way is the ethos for this website. It is hoped that the website will become a valuable resource for parents who develop miscarriage concerns or experience first trimester miscarriage, guiding them about what to do and how to access appropriate care services. It can also be referred to by clinical staff who care for bereaved parents through the difficult journey of miscarriage.

Ethics statement: Ethics approval not required.

Conflicts of interest: None


Keywords: website, miscarriage, accessible information, parents, resource

Identifying the educational needs of staff in the provision of bereavement care in a tertiary maternity hospital in Ireland

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1) Background: Bereavement care is central to the provision of support in all maternity settings however, staff express fear and anxiety in caring for this patient group. Research suggests that this is often due to lack of specific training and education. The aim of this study was to obtain feedback from staff on their training needs. 2) Methods: A survey was designed to explore staff opinion on the preferred format for education on pregnancy loss and bereavement care including the prioritisation of topics for such training sessions. This study was conducted at Cork University Maternity Hospital, a tertiary unit with 7,500 births per annum. 3) Results: 94 staff completed the survey over a 4-week period. 83% (n =78) were Midwives, 13% (n=13) were Doctors, and the remaining 3% (n=3) were Allied Health Care Professionals. Interestingly 73% of staff (69/94) responded that their educational needs in this area were currently inadequate, 75% (70/94) of staff responded with their preferred formats for education. A total of 84 suggestions were received. Thirty three percent of suggestions (28/84) proposed regular formal training days, 16% (13/84) proposed information/education sessions, 10% (8/84) recommended ward-based information sessions, 7% (6/84) small-group sessions, 6% (5/84) group discussion. Regarding education topics, staff highlighted some key areas of need including communication, investigations performed after a pregnancy loss, services and resources for parents & staff, grief counselling, documentation, and staff care. 4) Conclusions: The survey determined the specific educational training needs and suggestions from healthcare staff to support them in their provision of care for bereaved parents and families. Our plan will be to roll out training sessions for staff in keeping with their requests and to re-evaluate the programme after a 12-month time period. Maternity hospitals need to prioritise time and resources to facilitate learning in the area of bereavement care.

Ethics statement: Full ethical approval for this study was obtained from the Local Hospitals Ethics Committee and the Local Information Governance Group (LIGG). Data access was approved by the LIGG and limited to the named authors. All data were anonymised and securely stored.

Conflicts of interest: None


Keywords: education, bereavement care, healthcare professionals, staff, maternity hospital

Cite as: Identifying the educational needs of staff in the provision of bereavement care in a tertiary maternity hospital in Ireland. A.M. Verling, T. O’Sullivan, I. San Lazaro Campillo, K. O’Donoghue. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Experiences of fatal foetal anomaly informing maternity and bereavement care

A. Walsh, J. Ryan, C. Cullen Delsol, S. Donohue

Termination for Medical Reasons, Technical University Dublin, Ireland

The question of termination of pregnancy after a diagnosis of fatal anomaly was widely debated in Ireland during the recent campaign to repeal the eighth amendment to the Irish constitution. The referendum, held on the 25th May 2018, passed with a majority of 66.4%. The subsequent ‘Termination of Pregnancy Bill’ came into law on 1st January 2019 allows for termination of pregnancy in some circumstances. One being if two medical doctors diagnose the foetus with a condition ‘that is likely to lead to the death of the foetus either before, or within 28 days of, birth.’ It was the stories of women who had received diagnoses of fatal anomaly in pregnancy and were denied access to termination in Ireland that caused more extensive public discussion on the issues of abortion access. This paper considers how these personal experiences can inform maternity care pathways and bereavement standards for patients diagnosed with a severe or fatal anomaly in pregnancy. The gap in the literature between abortion access and pregnancy loss is detrimental to all people. When discussed, abortion is mostly presented as a choice that a woman makes when she does not want to become a mother as in Ann Rossiter’s ‘The Abortion Trail’ and ‘The Irish Journey’ by the Irish Family Planning Association opposed to a decision that a grieving mother makes in the best interest of both the mother and the baby. This paper will examine the stories shared by the group Termination for Medical Reasons during the referendum campaign to shed new light on the previously misunderstood connections between abortion access, maternity care, and loss. By carefully examining these stories and interviewing the women who shared them, this paper will inform the rarely acknowledged issue of maternity and bereavement care for women and families who receive a diagnosis of a severe or fatal anomaly in pregnancy and wish to end their pregnancy.

Ethics statement: The authors will submit the research to the board & members of Termination for Medical Reasons (TFMR) Ireland for a full ethical review. Following the principles of research ethics, we will ensure that: 1. The research does not harm the participants; 2. All the participants know that they have the right to withdraw from the research; 3. Informed consent is willingly given by each of the participants; 5. We engage in a process of editing and review with the participants; 6. All disseminations of the research will be in a format and context approved by the participants.

Conflicts of interest: None

View with full poster: N/A

Keywords: fatal anomaly, bereavement, abortion, personal experience, maternity

Cite as: Experiences of fatal foetal anomaly informing maternity and bereavement care. A. Walsh, J. Ryan, C. Cullen Delsol, S. Donohue. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Dealing with secondary trauma and loss: personal and professional difficulties for caregivers

E. Zsak

PhD student, Institute of Behavioural Sciences, Semmelweis University, Budapest, Hungary

1) Background: Grief and emotional trauma caused by pre- and perinatal loss often develops into a phenomenon of complicated or even pathological mourning or professional burnout, a heavy burden for the parents, for their environment and for the health care personnel especially, due to the demanding chronic emotional burden it causes. Objective: (1) Analyse presently applied practices in preselected healthcare institutions, (2) compare the valid protocol with the effective support provided and (3) examine the effects these events have on the helping personnel professionally and psychologically. 2) Methods: In-depth interviews and questionnaires with the involved personnel (33, 80 respectively). The research focuses on the practice of the institutions regarding overall support of the bereaved families, on the existing and wanted theoretical and practical competencies, on personal attitudes regarding death and loss and on the experienced difficulties. 3) Results: Facing pre- and perinatal loss is a specially demanding task for healthcare personnel in Hungary, with difficulties in communication, when helping families cope with loss, or when coping with the recurrent emotional difficulties, with their own feelings, all these leading to a higher risk of burn-out and compassion fatigue. 4) Conclusions: Trainings, psychoeducative courses with specific focus on loss and grief are to be implemented on all levels of the formative processes to improve coping strategies, communication and adequate supporting skills and competencies aimed at providing better support for the patients and offering self-protecting measures for the involved professionals.

Ethics statement: Ethics approval by the Semmelweis University, Regional, Institutional Scientific and Research Ethics Board, 8/2015. SE TUKEB, dated 4th Feb. 2015

Conflicts of interest: None


Keywords: perinatal loss, personal and professional difficulties, coping

Predictors of complicated grief following intrauterine death

P.R. Cassidy (1,2)

(1) PhD student, Universidad Complutense de Madrid; (2) Researcher, Umamanita (Stillbirth charity), Spain

1) Background: Following stillbirth or TOPFA women are at risk of complicated grief and other mental health problems. The objective of the study was to identify possible predictors of complicated grief in a Spanish population in order to better inform bereavement care strategies. 2) Methods: A cross-sectional descriptive design with an online instrument, including women who had a stillbirth or TOPFA within 5 years prior to participation. The analysis used binary logistic regression to test for statistically significant (p>0.05) predictors of complicated grief (dependent variable), measured by being above the midpoint on a 12-item sub-scale of a Spanish validated version of the Perinatal Grief Scale. 3) Results: Responses from 788 women were analysed. Controlling for “time since the loss” (in months), the analysis found significant odds ratio for “being a foreign resident” (aOR 2.77, C.I. 1.32-5.82), “experiencing a crisis of spiritual/religious belief” (OR 2.80, C.I. 1.85-4.23, p>0.001), receiving “low” (aOR 2.84, C.I. 1.52-5.32) or “medium” (OR 1.90, C.I. 1.21-2.87) social support, having been “administered sedatives in the hospital” (aOR 2.13, C.I. 1.47-3.07), “perceiving medical negligence in the death” (aOR 2.17, C.I. 1.47-3.19), “not being accompanied by a partner/other during the birth” (aOR 0.56, C.I. 0.38-0.83). In the ≤12 months group “not being accompanied during the birth” and “being a foreign resident” were dropped by the model. In the 13-60 month group “time since the loss”, “low social support” and “medium social support” were dropped while “having no living children” (aOR 2.60, C.I. 1.09-5.82) was introduced. See attached table. 4) Conclusions: Time, faith, hospital care, social support and reproductive history are all predictors of complicated grief. Interactions between these predictors most likely complicate the grief process by interfering in personal and social processes of meaning reconstruction, sense making and benefit finding, as well as identity.

Ethics statement: The author’s institution (Universidad Complutense de Madrid) did not require ethics approval for non-clinical studies. Consent was given through informed participation in the online survey.

Conflicts of interest: None


Keywords: stillbirth, TOPFA, complicated grief, predictors

Cite as: Predictors of complicated grief following intrauterine death. P.R. Cassidy. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Conscientious objection in medicine: psychological consequences in women who face legal termination of pregnancy in the Region of Murcia

F.V. Constán (1,2), A. Rivas Molina (1)

(1) Asociación de Psicología Perinatal Murcia; (2) Universidad de Murcia

**1) Background:** Perinatal loss is a stressful situation in women's life (and their families). Furthermore, losses due to legal termination by medical criteria carry several traumatic moments hard to recover from without professional support. Periodic meetings with women who join the group “Apoyo a Familias en Duelo Gestacional y Neonatal (Murcia)” offered an opportunity to observe some behavior associated to symptoms of Posttraumatic Stress Disorder (PTSD) in most of these participants. The aim of this study is to explore these symptoms in relation to the medical care received during the pregnancy termination and other personal and pregnancy variables of interest. **2) Methods:** An ad-hoc questionnaire collected information about characteristics of the loss and the evaluation of the medical received care (Likert scale). In addition, the PCL-6 was used to measure possible symptomatology associated with PTSD. **3) Results:** Broadly, receiving the news of having to make the decision to terminate the pregnancy and the process itself is a highly traumatic situation (high PCL-6 scores). Higher PCL-6 scores correlate negatively with Medical Care Satisfaction results. This situation magnifies by the poor clinics' conditions where these cases are derived (outside the Region of Murcia because is a region with medical conscientious objection). Women from Murcia Region showed worst care perception (Medical Care Satisfaction). The results are also discussed according to other variables related to the abortion. **4) Conclusions:** Healthcare must assist not only the pregnancy period until the approval notification of the termination, but also the process itself and its recovery (ideally including psychological assistance).

**Ethics statement:** The voluntary participation of mothers attending the activities of the association "Psicología Perinatal Murcia" was requested, informing them of their anonymity and the use of data for scientific dissemination purposes.

**Conflicts of interest:** None


**Keywords:** ITP, conscientious objection, perinatal loss trauma, PTSD

**Cite as:** Conscientious objection in medicine: psychological consequences in women who face legal termination of pregnancy in the Region of Murcia. F. Vera Constán, A. Rivas Molina. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Talking about life and perinatal death with children in a workshop on pregnancy and childbirth

M. Contreras García (1,2), B. Ruiz Soto (2,1), M.L. Martín Parada (2)

(1) Association El Hueco de mi Vientre; (2) Midwifery unit, The Marqués de Valdecilla University Hospital, Santander, Spain

1) Background: Death is a taboo subject both in society and at school. Perinatal death even more so. Both children and society as a whole could benefit from a pedagogy that deals with death. This could contribute to the development of greater resilience amongst bereaved individuals and society. Pedagogy of death is an emergent approach with few pedagogical resources in which teachers has a scarce academic training. Could a workshop on pregnancy and childbirth, given by midwives, be an appropriate teaching resource? 2) Methods: A descriptive phenomenological study. We interviewed 22 teachers whose 6 to 12 year old students had received a workshop on pregnancy and childbirth. The objective was that the teachers would describe the perceptions of the workshops in which prematurity and perinatal death are the subject matter. Data collection was done through individual semi-structured interviews of the teaching staff. The analysis took the four categories of topics discussed in the interview into account: training elements, impact on children, pedagogical resources used and conversations on perinatal death and prematurity. 3) Results: Teachers perceived that the workshop helps children to comprehend the process of pregnancy and childbirth and provides them with the tools to confront the death of a loved one. They considered the way of dealing with perinatal life and death in the workshop were “very natural and positive” and the children’s reaction as well. Through the workshop, the majority of the teachers realized the necessity of introducing or strengthening the pedagogy of death in the classroom, for which they perceive a lack of training and resources. 4) Conclusions: From the teachers’ perspective, the workshop is a suitable resource for both prenatal and death pedagogy, which contributes to fight the taboo that revolves around death and the protectionism towards children in our society.

Ethics statement: The study received approval from the Clinical Research Ethics Committee of Cantabria. Interviews are conducted with prior consent.

Conflicts of interest: None


Keywords: perinatal loss stillbirth grief siblings death education school

Learning from a grieving grandmother: An experience to share

N. Díaz

Grieving grandmother and Psychologist, Palliative Care Unit, Hospital E. Tornú- Federación Médica de la Provincia de Buenos Aires, Argentina.

Grandchildren can play a decisive role in the lives of grandparents, as they help to strengthen the bond with their children and promote experiences of legacy and transcendence at different stages of the life cycle. Perinatal loss of a grandchild implies double suffering: the loss of a grandchild and the witnessing of their own son or daughter’s suffering. Upon the death of a newborn baby in the family, the grandparents often remain alone with their pain, deprived of any emotional support and obliged to show strength for their children. Sharing the lesson learned is costly for both the direct suffering parts (parents), and for those closely related to the same loss. Although the experience of mourning is unique and personal, it may be very useful to share it, especially when the type of grief does not receive all the social support it deserves. Based on the author’s personal experience whose daughter, first-time mother who lived in a foreign country (UK), experienced the unexpected devastating loss of her newborn baby. This work describes some of the most relevant lessons learnt in the process of healing which goes from the post-traumatic stress caused by the loss to the conviction that sharing, meeting other grandparents in similar situations, and talking about what happened, can be a healer and help to the community. What to say and what to avoid, how to manage emotions, how to accompany the daughter/son in grief, when to ask for help, and the possible growth after pain. These are some of the main topics to be shared with other grandparents, health professionals, parents and other family members. Sharing what has been learned in a peer group as well as transmitting it to professionals in contact with relatives bereaved as a result of perinatal losses has a psycho-educational objective: as an aid in process of grief, and to give meaning to the suffering experienced.

Ethics statement: No ethics approval required.

Conflicts of interest: None


Keywords: perinatal death – bereavement care – grieving grandparents

Cite as: Learning from a grieving grandmother: An experience to share. N. Díaz. The International Stillbirth Alliance, Conference Proceedings of the 15th Annual Conference on Perinatal Mortality and Bereavement Care, 5-6th October 2019, Madrid, Spain.
Differences in coping with perinatal grief in the couple: a clinical vignette

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The birth of a child that will not live is an emotionally intense experience for the parents. However, both parents do not always experience it the same way. We present a clinical vignette in order to analyse causes and effects of this differential approach within the couple. We had a referral of a couple whose child died after premature birth (23 weeks + 2 days). Initially, they both showed an avoidant pattern towards the loss. However, the mother slowly experienced changes in her way of coping with bereavement, showing a more active attitude. She connected with her pain, sadness and guilt. His partner though, maintained an avoidant pattern, making an effort in avoiding his sorrow. However, when he started to show anxiety symptoms (anxiety attacks) he did not connect them to the grief. These symptoms increased the couple stress. Psychological support was focused in increasing mentalizing abilities in the couple through this experience. When looking for factors that may affect this gender differences we found: personal and life variables, differences in mother-to-child and father-to-child bond during pregnancy, and cultural variables in relation to gender attributions. In this case we illustrate how the conflict the couple is experiencing when coping with the baby loss in different ways affect the normal process of bereavement in perinatal loss.

Ethics statement: Consent was given by the patient to present this poster. Steps were taken to ensure the patients anonymity.

Conflicts of interest: None


Keywords: perinatal grief, coping styles, couple

The Grief Podcast

T.G. Kalstad

Norwegian SIDS and Stillbirth Society

Death affects us all. Nevertheless people find it hard to talk about the psychological, social or existential consequences of grief. Grief is often profoundly misunderstood. Increased knowledge about how grief affects our perspectives of life and influence our daily life can ensure a better understanding of the reactions and expressions of the bereaved. We do experiences that both bereaved families, dependents and health personal find it helpful to listen to personal stories of loss in combination with professional teaching. To strengthen our public education work on grief Norwegian SIDS and Stillbirth Society decided to create the first podcast in Norway addressing grief from various types of losses. We have made 11 episodes, 1) Grief – from myths to knowledge, 2) Grief and prestige, does some groups of bereaved suffer from lower status than others, 3) When the body grieves, 4) The grief of children, 5) Is it possible to help yourself when grieving?, 6) Are you still there for me? When a mum and dad suffers differently, 7) Posttraumatic growth – can severe pain live side by side with gratitude and happiness? 8) How to work while grieving, 9) Talking about death is talking about life, a philosophical perspectives 10) When a close friend dies and 11) What happens to the family dynamic when someone dies? One episode last for 30-40 minutes and there are mostly two guests. One being a bereaved mother or father, sibling, friend or a child, and one is a professional. The Grief Podcast with 11 episodes is available on Spotify and Pippa, and is therefore easily accessible. Increased knowledge and sharing experiences helps the bereaved to cope with grief. We also believe that the grief podcast will help to exploit the potential of social support, both from family, friends and colleagues and ensure good quality of the help offered from health personal.

Ethics statement: Ethics approval not required

Conflicts of interest: None

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Keywords: grief, bereavement support, coping, education, sharing experiences

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Reducing post-traumatic stress disorder (PTSD) and complicated grief (CG) after stillbirth (SB): a logic model-informed research agenda

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1) **Background:** PTSD and CG are poorly studied during and after pregnancy. Our objectives are to a) construct a logic model (LM) review and analysis and action plan for perinatal PTSD/CG and b) inform personal, family, medical provider, payor, policymaker and community means to prevent and reduce severity of PTSD/CG.

2) **Methods:** We used available electronic resources (PubMed, Google, Medline, others) to identify and analyze available research using the search terms “PTSD” and “complicated grief,” 1970’s to the present.

3) **Results:**
   A. PTSD in more common than clinically recognized (birth @4%).
   B. Perinatal loss (4-7%).
   C. Over 600 controlled trials regarding PTSD treatment were identified and included supportive, psychologic and physiologic behavioral treatments.
   D. Complicated grief remains little studied.
   E. PTSD and CG appear more common than recognized by clinicians.
   F. Cognitive and behavioral approaches most commonly applied in non pregnancy-associated circumstances.
   G. Few carefully controlled trials (Cochrane Analysis) or pharmalogic studies were identified.

4) **Conclusions:**
   A. Research as to preventing and treating PTSD/CG in reproductive care is urgently needed.
   B. Logic Model-informed approaches and risk remain to be identified for patients, providers, families, and communities.

**Ethics statement:** No patients were involved. No institutional consent required/obtained.

**Conflicts of interest:** None


**Keywords:** post traumatic stress disorder, birth, stillbirth, grief, abnormal grief

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Investigating how art can help to break the taboo on stillbirth

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The psychological effects of stillbirth on the surviving parents are incompletely documented and can be misunderstood. Many parents report feeling isolated and stigmatized after their baby has died and feel that society at large increases their sense of loss through underrepresenting it and keeping it a taboo. Both Lancet Stillbirth Series have called for a breaking of the taboo on stillbirth, but these are deeply ingrained in society and are not easily annulled. Art can play an important role in the breaking of taboos through giving a voice to people who are otherwise isolated. Collaborative projects like Still Born and Each Egg a World address stigma and aim to help reduce the taboo on stillbirth. In this collaboration, artist Adinda van ‘t Klooster made a body of work on the theme of stillbirth between 2010-2017 and commissioned poets to respond through poetry and obstetrician Alexander Heazell through academic writing. Results were compiled in the Still Born book with the exhibition shown in Manchester in 2017 and Newcastle in 2018. Initial feedback from public and professionals found they were challenged by the works and felt positively about their experience of the exhibition and the book. New work will include the Each Egg a World digital interface where bereaved parents can name a dot in the artwork after their baby and add a short statement of their experience of stillbirth. These combined statements (up to 30,000 can be entered through this online interface which will open before the exhibition tour) will help to show how the experience of stillbirth can impact differently on parents. These two art projects show alternative ways to help reduce the taboo on stillbirth. Findings from the Each Egg a World Digital project might also help to improve bereavement care and it is hoped that participation in itself will give those who have experienced stillbirth a feeling of community and recognition.

Ethics statement: Ethics approval has not been sought as participation in the Each Egg a World interface will not show any personal details of the parents and only the first name of the child, thus making it impossible to track back who has provide which statement.

Conflicts of interest: None

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Keywords: breaking taboo on stillbirth, art and science collaboration, stigma

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Italian translation and validation of the Perinatal Grief Scale

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1) Background: Perinatal Grief Scale (PGS) is a complete instrument used to assess the grief after a perinatal loss: it has good validity and reliability and it could lead to the identification of women at major need for specific support. To date, an Italian version of PGS is missing. Thus, the purpose of this study was to translate the PGS into Italian and to test the validity of the translated scale in a pilot study. 2) Methods: The English version of PGS by Potvin et al. was translated by a professional mother tongue English translator into Italian and modified according to the suggestions of two experts in the fields of gynaecology and psychology. The survey was administered at 3 different times to 16 Italian/English bilingual women who had experienced a perinatal loss, following these steps: (1) translated Italian version (Ita), (2) original English version (Eng) after 10 days, (3) same Italian version (Ita2) after other 10 days. The reproducibility among the three administrations was assessed calculating the Cronbach’s alpha coefficient, while concordance was assessed using the Cohen’s kappa coefficient. 3) Results: Considering the PGS, median score ranged from 74.5 (58.5-94.5) to 78 (64-95), with no significant difference among the three questionnaire administrations (p=0.616). No significant difference emerged among the three administered questionnaires for subscales: p=0.095, 0.410 and 0.410 for “active grief” (AG), “difficulty in coping” (DC) and “despair” (D) scores, respectively. Weighted Cohen’s Kappa was 0.76 for the comparison of Ita vs Eng versions, 0.79 for Ita vs Ita2 versions, and 0.84 for Eng vs Ita2 versions, showing a good to very good concordance among all questionnaire administrations. 4) Conclusions: This Italian version of the PGS can be used by clinicians to assess Italian women’s responses to stillbirth and perinatal loss, as well as by researchers for research purposes.

Ethics statement: According to Italian regulation, for this type of studies the approval by the Ethics Committee is not required (GU n. 76 March 31, 2008), data were collected in keeping with General Data Protection Regulation of European Union (GDPR, EU 2016/679) and written informed consent was obtained from all participants.

Conflicts of interest: None


Keywords: perinatal grief scale, perinatal loss, psychology, gynaecology, postpartum care

Forever Mama: a bereavement journal for mothers of stillborn babies

S. Verhoeven

We lost our son after 23 weeks of pregnancy. In the following grieving process, I was looking for ways to get a grip on the rollercoaster of emotions. Professionals helped me by listening and reflecting. But no one could give me an answer on how to mourn. ‘Do what you think is best for you,’ that is what I heard a lot. I kept on searching for something to hold on too. Something to make sense of my feelings and to help me remember. What helped me most was keeping a diary. I continued writing in my pregnancy diary. In between the happy pictures of the diary I wrote about the hospital visits, the DNA-test, my sadness and my struggles with every domain in life. I wrote letters to my son and phrases of my daughter about my son. It was my way to hold on to memories and the love for my son. After a while I decided to develop a diary that is especially for bereaved mothers of stillborn babies. It aims at giving mothers some grip and direction in their grieving process in a way that doesn’t prescribe them what to do or feel. The diary contains of twelve chapters. Six chapters about the months of being pregnant up until the funeral and six chapters about different domains in life (taking care of yourself, your relationship, other children, family, friends and getting back to work). Every chapter consists of a short introduction on the theme and my personal experiences, blank pages for their own stories, reflective questions and creative exercises. All meant to help a mother remember their child and the love they feel for ever. I’m certain a bereavement diary would have helped me in my process. But will it help other mothers? In my session I would like to start a dialogue about ways to contribute to the grieving process of bereaved mothers. What instruments do you have? In what way do they help and how might a diary contribute to your practice?

Ethics statement: No ethics approval required.

Conflicts of interest: None


Keywords: bereavement care, grieving process, instrument, diary

Understanding the spirituality of parents following stillbirth: a qualitative meta-synthesis

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1) Background: It is known that the experience of stillbirth is a challenge for the parents. However, parents’ spirituality and its relation to coping after a stillbirth remains insufficiently understood, in contrast to other findings from literature reviews. Nurses need to better understand the issues at the spiritual level in order to assist parents to soften suffering. The purpose of this review is to synthesize qualitative evidence from primary studies to more fully understand the experience of spirituality of parents and its relationship to adapting following stillbirth. 2) Methods: This qualitative meta-synthesis used the following steps from Sandelowski and Barroso approach: literature search, quality appraisal, analysis and synthesis of findings. We analyzed studies (N = 21) searched in five databases (PUBMED, CINAHL, PsycINFO, LILACS, and SCOPUS) and the findings concerning spirituality was synthesized using the thematic synthesis approach. 3) Results: Findings were integrated into two analytical themes. Firstly, Spiritual suffering following stillbirth, that is characterized by the four descriptive themes: conflicting expressions of hope and lack of hope, dealing with profound questions and lack of meaning, experiencing spiritual struggles, and disconnectedness from the self and the surrounding world. Secondarily, the theme Moving through spirituality to adapt to the loss describes and explain the four descriptive themes: renewing the connection with the deceased baby, ensuring the ideal whereabouts of the deceased baby, embracing facilitating beliefs, and gaining strength in themselves, others, and nature. 4) Conclusions: This meta-synthesis highlights the parents’ spiritual suffering and their spiritual strategies to promote an increased sense of life and hope following stillbirth. The findings can inform a more culturally and spiritually sensitive approach to care, which takes into account the parents’ beliefs, folk customs, religion, values, and spiritual needs.

Ethics statement: Ethics approval was not required.

Conflicts of interest: None

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Keywords: stillbirth, parent, spirituality, religion, review
