

MEETING ABSTRACTS

Open Access

# Proceedings of the Summit for Perinatal Excellence 2025



Bloomington, MN, USA. 18-20 June 2025

Published: 15 September 2025

## Introduction

The Summit for Perinatal Excellence was held June 18-20, 2025 in Bloomington, Minnesota, USA. This was the 7<sup>th</sup> session of this biennial conference, previously known as the Stillbirth Summit. An international collection of researchers, health professionals, and industry advocates gathered to share their latest work and identify opportunities for future initiatives and collaborations.

A feature of the meeting was the recognition of perinatal loss as a continuum where different types of loss share many biological and emotional elements. Additionally, there was a focus on the interdisciplinary contributions to improving perinatal loss prevention and care for families around the world. Sessions included topics such as placental health, genetics, spirituality, social determinants of health, cultural influence, mental health, maternal health conditions, and more. In addition to the official presentations, discussions highlighted the value of partnerships and collaboration to continue improving pregnancy outcomes and bereavement experiences for families.

## About the International Partnership for Perinatal Excellence

The International Partnership for Perinatal Excellence (IPPE) is an education, networking, and certification program for health professionals who provide care before, during, and after pregnancy. The program focuses on the prevention and care of perinatal loss. Members are recognized as professionals who have dedicated themselves to elevating care for families and are leaders in the community. IPPE is a program of the Star Legacy Foundation, a non-profit organization based in the United States that is the nation's premier charity focused on reducing the incidence of miscarriage, stillbirth, and neonatal death and ensuring families impacted by these tragedies receive optimal care and support.

## Oral Presentations

O1:

### Perinatal health: learning from the past to create a better future

Lindsey Wimmer

Star Legacy Foundation, Eden Prairie, Minnesota, United States

**Correspondence:** Lindsey Wimmer (lindsey@starlegacyfoundation.org)

BMC Proceedings 2025, 19(25): O1

## Background

Perinatal loss prevention and care have experienced many challenges to progress over the last several decades. However, there have been positive developments that provide encouragement and information about how to build on those successes for future initiatives.

## Methods

The International Partnership for Perinatal Excellence (IPPE) was developed to provide education, support, networking, and resources for health professionals who are passionate about moving perinatal loss prevention and care above the minimum requirements. The interdisciplinary approach emphasizes the need for families to receive consistent messages throughout pregnancy care from all health professionals they interact with.

The core educational content focuses on loss prevention, bereavement care, and pregnancy after loss care. Prevention efforts highlight the importance of preconception health, identifying and managing fetal growth restriction, education about and responses to changes in fetal movement, and supporting maternal sleep hygiene and position. Bereavement care addresses communication, physical and emotional care processes, and pathology. Pregnancy after loss recognizes physical and emotional care elements as equally impacting pregnancy experiences and outcomes. Curricular threads in all sections include family-centered care, shared decision-making, social determinants of health, trauma-informed care, culturally-sensitive care, and empathic listening.

The health professionals complete education modules, an online exam, interviews, and clinical scenarios to demonstrate understanding of the content. Resources available to support progress include clinical tools, podcast episodes with researchers, referral directories, a research library, and networking with like-minded colleagues and clinical experts.

To date, 45 health professionals have completed the program, and 32 more are in process. Feedback is positive, and participants have noted no barriers to implementation. Resources for discussing prevention topics with expectant families and bereavement options for grieving families are identified as the most impactful components. Future plans include expansion to include topics such as infections, perinatal palliative care, self-care, and long-term maternal health



implications. Also planned are related programs for pathologists, organizations, and researchers.

#### Conclusions

Many health professionals desire a process to improve their knowledge and skills in the prevention and care of perinatal loss. Families have frequently expressed a desire to connect with providers who are willing to offer care that exceeds minimum requirements and includes them as partners in their care. IPPE is a newly-launched program that serves to address both needs while promoting partnerships as a key to improving perinatal outcomes.

O2:

#### Using novel approaches to understand how placental structure and function is altered in stillbirth

Alexander Heazell, on behalf of Igor Chernyavsky, Daniel Alexander, Paul Brownbill, Alys Clark, Simon Cotter, Michele Darrow, Diana de Oliveira, Kate Duhig, Lucy Higgins, Jo James, Oliver Jensen, Edward Johnstone, Josephine Naish, Gowshian Poologasundarampillai, Rebecca Shipley, Paddy Slator, Raoul van Loon, Carl Whitfield, Megan Sharps, Adam Stevens

University of Manchester, Manchester, England

**Correspondence:** Alexander Heazell (Alexander.Heazell@manchester.ac.uk)

*BMC Proceedings 2025, 19(25): O2*

#### Background

Placental dysfunction - the inability to meet fetal demands - can result in stillbirth and related pregnancy complications. Presently, microscopic abnormalities of placental structure, critical to optimal placental function, can only be identified by placental examination after birth. Abnormalities of placental structure can be broadly grouped into three types, those affecting i) placental structure, ii) changes in blood supply and iii) those relating to infection and inflammation.

#### Methods

We have employed a range of techniques to better understand placental structure and function including: magnetic resonance imaging (MRI) to describe placental perfusion and diffusion in utero, placental perfusion to assess oxygen and solute transfer, assessment of placental structure using objective measures of placental structure and synchrotron CT (sCT) and spatial RNA sequencing ex vivo. These techniques can then be used to inform mathematical models of placental function.

#### Results

Spatial transcriptomics can be used to identify different patterns of RNA expression in placentas depending upon their gestational age and whether they resulted in a baby with normal birthweight or fetal growth restriction (FGR). MRI scanning identifies novel metrics relating to placental perfusion which also change across pregnancy, and in pregnancies complicated by FGR or preeclampsia. These pathologies are also associated with changes in ex vivo perfusion including hydrostatic pressure and mean oxygen consumption. sCT offers the potential to assess the complexity of placental microstructure in 3D of larger amounts of tissue than previously possible; and can generate large volumes of data about intervillous space and the villous tree. Initial analyses suggest that this approach can identify differences in placental structure in participants with pre-existing diabetes and those with preeclampsia. This detailed information can be used to inform mathematical models to predict changes in the MRI signal from abnormal placentas and to assess how efficiently the placenta would exchange oxygen and nutrients.

#### Conclusions

These novel approaches give opportunities to better understand placental structure and function in placental conditions related to stillbirth. Improved understanding of the underpinning pathophysiology could improve antenatal testing to identify pregnancies at greatest risk of fetal compromise and could reveal therapeutic pathways which could be targeted to improve outcomes for mothers and babies.

O3:

#### Restoring placental function to treat fetal growth restriction

Helen Jones

University of Florida, Gainesville, Florida, United States

**Correspondence:** Helen Jones (jonesh@ufl.edu)

*BMC Proceedings 2025, 19(25): O3*

#### Background

The short-term outcomes of placental insufficiency can range from stillbirth and fetal growth restriction through an extended NICU stay and neurodevelopmental delays. We have developed a nanoparticle mediated therapy for placental insufficiency which increases trophoblast Insulin-like growth factor I (IGF-1) expression.

#### Methods

Female Dunkin Hartley Guinea Pigs were fed ad libitum ( $n = 6$  dams, ctrl) or 70% of normal food intake from 4 weeks prior to mating until Gestational Day(GD) 30, then increased to 90%. At GD~35 (following growth restriction confirmation by ultrasound), 43, and 51, animals received ultrasound-guided intra-placental injections of nanoparticles containing either Cyp19-antisense ( $n = 6$  ctrl-Sham,  $n = 6$  MNR-Sham) or Cyp19-IGF1 plasmid ( $n = 5$  dams, MNR+IGF1). Fetuses and placentas were collected and weighed at GD~59 fetal and maternal blood was collected and Cortisol and blood glucose measures recorded. QPCR and Western blotting were performed on placental tissue to assess molecular responses in placental insufficiency and following intervention. In the placenta, trophoblast (CK-7) and labyrinth capillaries (Vimentin) were identified using immunohistochemistry, materno-placental microvasculature was assessed via NanoCT. Generalized estimating equations were used to determine differences between diet and nanoparticle treatment, including maternal environment as a random effect and gestational age as a covariate. Significance was assigned to a  $P$  value  $\leq 0.05$ . Plac1-IGF-1 nanoparticles were also delivered to control, pregnant (GD100) non-human primate macaques to assess immune response and pathology after 10 days.

#### Results

Following Cyp19-IGF-1 treatment placental efficiency, fetal weight, fetal cortisol and glucose levels were restored to control levels and significantly different to those seen in untreated cases of placental insufficiency. The placental labyrinth structure was normalized including the microvasculature density. Macrovascular structure which was expanded in placental insufficiency was normalized following Cyp19-IGF1 treatment. Maternal cortisol was also reduced to control levels following placental treatment. Furthermore, preliminary studies in control, pregnant non-human primates demonstrate no evidence of immune response, or increased histological lesions, and maternal CBC, progesterone and estradiol levels remained within normal range

#### Conclusions

Nanoparticle-mediated IGF-1 attenuates placental insufficiency and corrects fetal growth in a guinea pig model of FGR. These placental structure, function and fetal growth improvements demonstrate the potential of the treatment to attenuate placental abnormalities in pre-existing FGR.

O4:

#### Impacts of perinatal loss on physical health, mental health, and social determinants of health: mitigating factors and implications for practice

Alisha Reginal

Remembering My Child, Stone Ridge, Virginia, United States

**Correspondence:** Alisha Reginal (hello@rememberingmychild.com)

*BMC Proceedings 2025, 19(25): O4*

#### Background

Losing a child has the potential to impact every aspect of health and wellness. From mental and physical health to social, economic, and spiritual health, perinatal loss intersects with health and social determinants of health (SDOH) across various domains. For example, in the domain of mental health, research shows that mothers whose children were stillborn have significantly higher prevalence of anxiety and

depression in subsequent pregnancies, yet the care provided during subsequent pregnancies often inadequately takes this into account, exacerbating mental health challenges. Furthermore, research demonstrates that bereaved parents often experience financial and social stressors after losing a child. These SDOH, in turn, may amplify mental and physical health outcomes, creating a detrimental cycle for parents after losing a child.

This presentation provides insights on the multifold ways that child loss impacts bereaved parents' health and SDOH in the short-, medium-, and long-term; mitigating factors for clinical and nonclinical birth workers, mental health practitioners, policy makers, and others to better support bereaved parents in each respective area of life; and highlight implications for future care and interactions with bereaved parents.

#### Methods

Through a review of existing literature, as well as insights from lived experiences and narrative evidence, this presentation sheds light on the profound impacts of perinatal loss on bereaved parents. By integrating academic research with personal and anecdotal accounts, this approach offers a nuanced understanding of the challenges faced by families navigating the death of a child.

#### Results

This session presented a framework to depict the interdependent effects of child loss on mental health, physical health, and SDOH. Key points included how losing a child touches every area of life and has different impacts, mitigating factors, and implications in the short-, medium-, and long-term periods after a child's death. Mitigating factors include employing narrative medicine practices, promoting multidisciplinary training on perinatal loss, and conducting operational gap analyses to improve bereavement care processes, among other mitigating tools. Health professionals are encouraged to better provide person-centered, grief-sensitive, compassionate care to support the holistic well-being of bereaved parents whom they encounter in their professional and personal lives.

#### Conclusions

This presentation underscores the importance of addressing social determinants of health when discussing perinatal loss and emphasizes the necessity for interdisciplinary collaboration to improve the ongoing support that is provided to bereaved parents.

O5:

#### Raising the bar: residency education for the care of loss families

Heather Florescue<sup>1</sup>, Ponnilla Marinescu<sup>2</sup>

<sup>1</sup>University Gynecology & Childbirth Associates, Rochester, New York, United States; <sup>2</sup>University of Rochester Medical Center, Rochester, New York, United States

**Correspondence:** Heather Florescue (Heather\_Florescue@urmc.rochester.edu)

*BMC Proceedings 2025, 19(25): O5*

#### Background

Pregnancy and infant loss is ubiquitous. It not only profoundly affects the families involved but also takes an emotional toll on the OBGYN resident teams caring for them. There is considerable need for the provision of formal OBGYN residency curricula to both improve the care of this patient community and to reduce resident burn-out. We address these education deserts with a unique educational model that combines online modules, standardized patients, and patient panels, along with informal discussions.

#### Methods

Here we present a novel approach for integrating Perinatal Loss care into OBGYN residency education. Our curriculum incorporates both formal and informal components.

Formal Components:

- Formal Lecture: Addresses the workup, management, lactation care, and follow-up for families experiencing loss.
- Simulation: Plays out a scenario in which an OBGYN resident in the OB ED must inform a patient of fetal demise, followed by an

observed interaction with a standardized patient and constructive feedback.

- Parent Panel: Provides an opportunity for residents to hear personal stories from parents who have experienced loss and creates a safe space in which residents can explore the emotional and psychological aspects of Loss care.

Informal Component:

- Perinatal Loss Provider Safe Space Gatherings: Bi-monthly, informal gatherings at the home of our OBGYN attendings where residents can discuss the emotional challenges of caring for families who have experienced loss and support each other in a safe, empathetic environment.

#### Conclusions

Perinatal Loss education is a critical constituent of OBGYN residency training. Our multimodal care model is designed to help achieve comprehensive provider training and emotional support in Loss care and will strengthen the provision of comprehensive care to the Loss community.

O6:

#### Beat the clock: detecting placental aging to signal stillbirth risk

Anya Arthurs

University of Adelaide, Adelaide, Australia

**Correspondence:** Anya Arthurs (anya.arthurs@adelaide.edu.au)

*BMC Proceedings 2025, 19(25): O6*

#### Background

Unexplained stillbirth may occur due to premature placental ageing, with unexpected deterioration of placental function for gestational age. Circular RNAs (circRNAs) are enzyme-resistant RNA molecules that accumulate in ageing tissues. CircRNAs can directly bind to DNA, forming circRNA:DNA complexes which induce DNA breaks that damage or kill cells.

Given the above, we investigated circRNA accumulation with gestational age in healthy and stillbirth placentae and determined whether circRNAs directly interact with placental DNA causing DNA damage. We further investigated the potential for circRNAs to be measured in maternal blood during ongoing pregnancy as a surrogate marker of placental ageing, signalling increased risk of stillbirth.

#### Methods

Placenta samples ( $n = 60$  term uncomplicated;  $n = 4$  unexplained stillbirth) were assessed for DNA damage using alkaline Comet Assay. Expression of 6 candidate circRNAs and their linear transcripts, and senescence-associated genes, were quantified using qPCR. Physical interaction of circRNAs with DNA was confirmed by DNA:RNA Immunoprecipitation (DRIP). The effect of circ\_0009000 in HEK293T cells was assessed following transfection with either a siRNA (designed to knock down circ\_0009000) or a scrambled siRNA control at multiple concentrations using Lipofectamine RNAiMax. Appropriate statistical analyses were undertaken (SPSS).

#### Results

Compared with earlier gestations (37, 38, 39 weeks), placental DNA damage and expression of all candidate circRNAs, but not their linear transcripts, were increased in 40 and 41+ weeks' gestation samples, and in stillbirth (despite the samples' earlier gestational ages). DRIP-qPCR confirmed that all candidate circRNA loci bind to placental DNA. circ\_0009000 depletion by specific siRNA in HEK293T cells, significantly reduced DNA damage compared to control, and reduced expression of senescence-associated genes. Senescence-associated gene expression was increased in 40 and 41+ weeks' gestation, and in stillbirth, samples.

In gestational age-matched (28 weeks') maternal blood samples, abundance of candidate circRNAs was significantly increased in samples collected from pregnant women who would go on to have an 'unexplained' stillbirth within 4 weeks, compared to women who had healthy uncomplicated pregnancies.

### Conclusions

circRNAs accumulate in the late gestation placenta as it ages. Stillbirth placentae show accelerated ageing with premature accumulation of candidate circRNAs (first evidence in humans) at levels consistent with older gestation tissue. Importantly, these circRNAs bind DNA, causing DNA breaks in placental cells. circ\_0009000 plays a role in placental ageing and associates with stillbirth, likely via DNA damage and induced cellular senescence, reducing placental function. Finally, quantification of candidate circRNA levels in maternal blood is a promising indicator of stillbirth risk in ongoing pregnancy.

O7:

### Working toward a widely-adopted, standardized placental pathology report

Mana Parast

University of California San Diego, San Diego, California, United States

**Correspondence:** Mana Parast (mparast@health.ucsd.edu)

*BMC Proceedings 2025, 19(25): O7*

### Background

Placental pathology is under-utilized both in the clinical and research settings. In the clinical setting, this under-utilization occurs despite both existing guidelines for clinical indications for placental examination, most recently updated in 2023, and diagnostic criteria for the main patterns of placental injury, established at the Amsterdam Workshop in 2015.

The four main patterns of placental injury include: 1) Maternal Vascular Malperfusion (MVM), characterized by a small placental disc with decidual vasculopathy, accelerated villous maturation, and villous infarction, and often associated with maternal hypertensive disorders of pregnancy; 2) Fetal Vascular Malperfusion (FVM), characterized by fetal vessel thrombosis and avascular villi, and often associated with structural abnormalities of the umbilical cord; 3) Acute Chorioamnionitis (ACA), characterized by infiltration of fetal membranes with maternal neutrophils, and sometimes accompanied by a fetal inflammatory response, often in response to an amniotic fluid infection; and 4) Villitis of Unknown Etiology (VUE), characterized by maternal T cell infiltration and fetal macrophage (Hofbauer cell) proliferation within chorionic villi, often considered a failure of maternal tolerance to the fetal-derived placenta.

The barriers to use of these criteria are many, including lack of consensus among obstetricians and neonatologists regarding the clinical utility of the report; however, among pathologists, the main obstacles to use of these criteria include lack of training, particularly of community pathologists, as well as lack of a standardized reporting template (e.g. synoptic reporting of tumors). To address the latter, the Society for Pediatric Pathology recently assembled its Perinatal Practices Committee, charging it with establishing such a template, detailed enough to "capture the nuances of placental pathology and its clinical contexts."

The Committee, which comprises both academic and community pathologists with training in perinatal/placental pathology, has met monthly over the past year and created a draft template. The committee recently invited several additional stakeholders, including obstetrician-gynecologists, maternal-fetal specialists, neonatologists, as well as members of patient advocacy groups with lived experience in pregnancy complications including stillbirth, to review, comment on, and help further edit, the draft reporting template. Once completed, the committee will undertake publication of a consensus statement, along with the template, and will follow up to educate relevant medical professionals in its use and interpretation, starting with pathologists, and extending to other clinical care providers.

### Conclusions

Ultimately, placental pathologic findings need to be incorporated into ongoing, prospective clinical trials, which include follow-up of pregnant people and their offspring after delivery, in order to maximize their utility.

O8:

### Stillbirth surveillance & review at the community level in districts of Haryana, India

Bharti Sharma, Abhishek Sharma, Ankit Raina, Neelanja Chaturvedi, Vanita Suri, Neelam Aggarwal

Postgraduate Institute of Medical Education and Research Satellite Centre, Sangrur, India

**Correspondence:** Bharti Sharma (drbharti22@gmail.com)

*BMC Proceedings 2025, 19(25): O8*

### Background

Globally, approximately 2 million stillbirths occur annually, and India accounts for the highest number of stillbirths in the world, with an estimated stillbirth rate of 12.2 per 1000 total births in 2021. In facility-based surveillance, it was found that nearly 75% of stillbirths that reach healthcare facilities show absent fetal hearts. Thus, this study was conducted to evaluate stillbirths at the community level to understand the barriers and gaps in accessing optimal healthcare in a timely manner.

### Methods

The objective of the index study was to understand the factors attributed to stillbirth by capturing the lived experience of the woman and her family members with stillbirth using the WHO verbal autopsy tool. Population-based surveillance was done with the identification of all stillbirths that occurred either at home or in a health care facility in two districts of Haryana, and a Verbal autopsy was conducted. This study employed a concurrent/sequential mixed-methods approach, combining quantitative (QUAN) and qualitative (QUAL) strategies to meet the objectives of the research. The quantitative data was collected using the WHO verbal autopsy tool, and for qualitative data, in-depth interviews were conducted to capture the lived experience. The cause of death was assigned as per the ICD-PM system of classification.

### Results

During the study period of four months, a total of 3651 births occurred, out of 3651 births, 66 were stillbirths ( $\geq 28$  weeks of gestation) with a stillbirth rate of 18.0 per 1000 total births. Almost 2/3 rd of stillbirths were antepartum, i.e., fetal death occurred before the onset of labor. None of the women had a delay 2 i.e., difficulty in reaching the health care facility. The main hurdle that came out predominantly was delay 1 (Perceiving own healthcare requirement) and delay 3 (Receiving adequate care).

### Conclusions

Surveillance for stillbirths at the community level is feasible, and it can help capture the associated factors that are usually missed at the facility level of surveillance.

O9:

### Postpartum care: the potential flaws in traditional mental health screening for bereaved parents

Kathleen Massmann

Healing Moments Counseling, Monticello, Minnesota, United States

**Correspondence:** Kathleen Massmann, (kmassmann@healingmomentscounseling.com)

*BMC Proceedings 2025, 19(25): O9*

### Background

The prevalence of those who have experienced infant, pregnancy, and child loss is significantly greater than many people are currently aware. In the United States, one in four women will experience miscarriage, stillbirth, or perinatal loss in their lifetime. There is often misunderstanding surrounding the long-term psychological impacts of infant and pregnancy loss.

### Results

Current research amongst bereaved parents, shows a 4-fold increase in a positive screening for depression and a 7-fold increase in a positive screening for PTSD. There is a significant lack of understanding surrounding the grieving process and how it can and should be differentiated from depression and anxiety. Very few providers ever take a course specifically looking at thanatology or the grieving

process, leaving them ill-equipped to understand the important nuance that exists between grief and depression. This lack of understanding has at times led to the pathologizing of grief and increased isolation amongst bereaved parents. While grief and depression can exist together, they should not be treated in the same way. Misdiagnosing grief as depression can lead to inappropriate interventions and missed opportunities for compassion-centered care.

Of major concern is the measurements and scales that are commonly used to identify depression and anxiety. Tools such as the Edinburgh Postnatal Assessment, the GAD-7, and the PHQ-9 are commonly used with postnatal mothers and fathers—they are used by both medical and mental health professionals. When these scales are evaluated, one can easily see the significant overlap between grief, depression, and anxiety—this overlap could easily result in a misdiagnosis of depression or anxiety. While these scales and assessments can give us valuable information, they can only do so when used with proper understanding and training. Providers must be able to use these scales in conjunction with a thorough interview. Without a comprehensive interview, the scales are only able to give us quantitative information, and could conflate the concepts of grief, depression, and anxiety. If we continue to use these scales without a full understanding of the parents' lived experience, we continue to risk possible misdiagnosis, and unnecessary treatment for those that we serve.

#### Conclusions

It is imperative that we deepen our understanding of grief and mental health and the subtle but distinct differences that exist. Additional education within the medical and mental health system will improve our ability to understand the lived experience of bereaved parents while appropriately companioning with them on their unique grief journey.

#### O10:

##### Spirituality in perinatal loss: loss, love, connection

David Nuzum

University College Cork & Cork University Maternity Hospital, Cork, Ireland

**Correspondence:** David Nuzum (daniel.nuzum@ucc.ie)

*BMC Proceedings 2025, 19(25):* O10

#### Background

Perinatal death is recognized as being one of the most challenging experiences of bereavement with enduring impact for parents, families, and communities. It is also recognized as a disenfranchised grief - often described as a 'silent' grief - where parents, especially in earlier losses, encounter silence in public discourse and recognition of their pregnancy or baby. From a spiritual perspective perinatal loss raises deep questions about life, death and loss, and for many parents this is framed by the existential question 'why' which pertains to many layers of meaning. Perinatal death challenges belief and value systems and the spiritual beliefs and practices of parents and families. Although spiritual awareness and care is part of the role of most healthcare professionals, it is recognized in the published literature that many professionals experience discomfort and lack of confidence in recognizing and responding to spiritual areas in healthcare.

#### Methods

This presentation draws from clinical pastoral practice, the published research activity from the Pregnancy Loss Research Group at University College Cork, and wider literature on the spiritual dimensions of perinatal loss. In addition, the presentation engages the spirituality evidence with recognized grief theory - disenfranchised grief, the dual process model, attachment theory, meaning making- to explore how practitioners can identify the reality of spiritual distress as well as identifying how spirituality can be a resource for parents and families as they seek to process their loss.

#### Results

This reflective presentation provided an experiential opportunity for participants to engage with the deeper spiritual realities of pregnancy, attachment, love, and loss to foster a deeper engagement and appreciation of how perinatal loss can impact at a spiritual/existential

level for parents and their healthcare providers. Using interactive multimedia approaches, the presentation provided opportunities for participants to develop both awareness and professional competence in addressing spirituality for parents who experience perinatal loss, both from an anticipatory perspective following an antenatal diagnosis, as well as in bereavement care.

#### Conclusions

Drawing on research, clinical practice, bereavement care theory, and personal experience, this keynote presentation presented in an interactive, reflective, and participatory way the multidimensional reality of the spiritual impact of perinatal death and also how spirituality and beliefs/values can be a resource for parents, families, community, and healthcare professionals in perinatal bereavement. The experiences of love, loss and enduring connection shaped the overall framework.

#### O11:

##### From cradle to grave: cultural practices and rituals around perinatal loss

Erin Denney-Koelsch

University of Rochester Medical Center, Rochester, New York, United States

**Correspondence:** Erin Denney-Koelsch (Erin\_Denney-Koelsch@urmc.rochester.edu)

*BMC Proceedings 2025, 19(25):* O11

#### Background

The cultural and religious approach to perinatal loss is often different than other types of death. This presentation provides an overview of the basic beliefs, practices and rituals around death in the world's major religions and the primary cultural groups within the U.S. Rituals serve to cushion difficult transitions in life, such as marriage, pregnancy/birth, and death.

#### Results

Death rituals service a number of purposes: to honorably deal with a deceased person's body, to honor the life of the deceased, to praise a higher power, to ask for a better afterlife, to support the bereaved, and to create structure for mourning. In perinatal loss, there are many cultures in which there are no prescribed death rituals, which drives bereaved parents to find others who have experiences similar losses. Difficult cultures have varied beliefs around when the soul or spirit enters the fetus or infant and what happens after the person dies. We described how beliefs and practices are the same or different for fetuses or infants across groups.

We also reviewed the role of the interdisciplinary health care team and community support systems for parents with perinatal loss. And to end, we talked about how to work with families around perinatal loss, to co-create rituals or to facilitate rituals that are unique and special to them.

#### O12:

##### The ripple effect of perinatal loss

Joann O'Leary

Star Legacy Foundation, Eden Prairie, Minnesota, United States

**Correspondence:** Joann O'Leary (jandj@pro-ns.net)

*BMC Proceedings 2025, 19(25):* O12

#### Background

The ripple effect of perinatal loss, grounded in attachment theory and meaning reconstruction, applies to family members and bereaved parents who are impacted by the loss of a baby during pregnancy or the newborn period. This includes grandparents, children alive at the time of loss, and the child that follows.

#### Results

Siblings alive at the time of loss lose the deceased sibling and parents they knew before the loss. The loss and experiences of siblings—both those alive at the time of loss and those born afterward—are frequently overlooked, and their grief remains largely unacknowledged within families and society. Grandparents suffer a double loss of not

only their grandchild but the adult child they knew before the loss, and their grief is often unacknowledged, too. This disenfranchisement can compound feelings of isolation, misunderstanding, and emotional complexity for families.

#### Conclusion

The death of a child has significant, long-term repercussions upon a family system, which causes a ripple effect upon bereaved parents, surviving siblings, siblings born after, and grandparents. This ripple effect is often not understood by others. It is important for all professionals who interact with families where there has been a perinatal loss to be aware of all family members' grief, too, and gain an awareness of how to provide support.

O13:

#### Investigating genetic contributions to stillbirth in families

Tsegaselassie Workalemahu  
University of Utah, Salt Lake City, Utah, United States

**Correspondence:** Tsegaselassie Workalemahu (tsegaselassie.workalemahu@hsc.utah.edu)

*BMC Proceedings 2025, 19(25):* O13

#### Background

Stillbirth (SB) is common and devastating, with approximately 50% of cases remaining unexplained. Though some genetic etiologies have been identified, few inherited genetic risk factors have been linked to SB. Family-based studies offer a unique opportunity to identify genetic contributions by examining multiple affected individuals. Recent research has suggested that SB clusters in families, and that increased familial risk of SB indicates inherited genes are important contributors.

#### Methods

Using the Utah Population Database, we previously identified Utah pedigrees with high familial risk of SB. High-density single-nucleotide polymorphism genotyping was conducted on eight SB placentas from five high-risk SB pedigrees. Shared genomic segments analysis was used to identify chromosomal regions shared by multiple affected individuals. Additionally, as part of our collaboration with the Star Legacy Foundation, we are currently sequencing the DNA from a stillborn baby, their maternal grandmother, parents and adult siblings and their partners to explore the genetic links to stillbirth in a family from Australia. Fourteen DNA samples (saliva) were collected from these relatives, along with a hair sample from the stillborn baby.

#### Results

Among high-risk SB pedigrees in Utah, we identified a region at 15q26.3 with genome-wide significance, which was shared by two SBs in one pedigree and by two others in a separate pedigree. This region contains several coding variants in the insulin-like growth factor 1 receptor (IGF1R) gene, which plays a key role in fetal development. Another significant region was identified at 14q32.2, which was shared by three SBs in another family. The 14q32.2 region contains variants in DLK1 and RTL1, paternally imprinted genes implicated in growth restriction. Currently, the Australian family sequencing project is in the DNA extraction phase, with WGS analysis pending. Once completed, this data will provide insights into the presence of inherited mutations potentially linked to SB and recurrent pregnancy loss.

#### Conclusions

Our findings suggest that inherited mutations in genes involved in fetal growth and placental health, such as IGF1R, DLK1, and RTL1, may contribute to SB risk. Knowledge of inherited genetic risk factors may provide valuable insights into genetic screening strategies for families with a history of SB. Further investigation of the identified genes including functional validation may determine avenues for novel therapeutic targets and guide efforts for SB prevention.

O14:

#### Metabolic syndrome and insulin resistance impact pre-conception, pregnancy and beyond

Claire Roberts  
Flinders University, Adelaide, Australia

**Correspondence:** Claire Roberts (claire.roberts@flinders.edu.au)

*BMC Proceedings 2025, 19(25):* O14

#### Background

Traditional risk factors for pregnancy complications such as preeclampsia, gestational diabetes mellitus (GDM) and stillbirth include maternal age, BMI and ethnicity. Emerging evidence suggests that both insulin resistance and metabolic syndrome in the mother increase risk for pregnancy and birth complications.

#### Methods

Data from our own recurrent miscarriage clinics, pregnancy cohorts and postpartum clinics (6 and 18 months after birth of the baby) have been analyzed. Metabolic syndrome was diagnosed according to internationally accepted criteria as having 3 or more of a cluster of risk factors (high waist circumference, fasting glucose, blood pressure, triglycerides and low HDL cholesterol). Our own systematic reviews and meta-analyses, plus those of others, have assessed the impact of metabolic syndrome and insulin resistance in women with a history of infertility, preeclampsia, GDM and pregnancy loss.

#### Results

Our own data show that women with metabolic syndrome at 12-15 weeks' gestation are more likely to have required assisted reproduction techniques to conceive, are 4 times more likely to develop GDM and twice as likely to develop preeclampsia or gestational hypertension. Two-thirds of women with a history of recurrent miscarriage had insulin resistance (hyperinsulinemia) between pregnancies and this conferred a 6 times greater risk of developing GDM in a subsequent ongoing pregnancy. Systematic reviews and meta-analyses show that women with a history of infertility, preeclampsia and GDM, as well as those who have suffered recurrent pregnancy loss are more likely to develop cardio-metabolic risk factors including hypertension and type 2 diabetes, and heart disease and stroke later in life.

#### Conclusions

Maternal health should be considered as a continuum from pre-conception, through pregnancy and beyond. Metabolic syndrome and insulin resistance are not normally assessed in young people including women of reproductive age and during pregnancy. However, assessment of metabolic health is likely to be an important tool to identify women at risk of infertility, pregnancy and birth complications, as well as future chronic disease. Women at risk should be offered lifestyle counselling particularly around diet and physical activity and mental health when necessary to empower women with the information and tools to reduce risk and prevent the preventable.

O15:

#### Treatment of maternal sleep disorders to improve pregnancy outcomes

Louise O'Brien  
University of Michigan, Ann Arbor, Michigan, United States

**Correspondence:** Louise O'Brien (louiseo@med.umich.edu)

*BMC Proceedings 2025, 19(25):* O15

#### Background

The healthcare burden of poor pregnancy outcomes such as hypertension, gestational diabetes, depression, preterm birth, pregnancy loss, and stillbirth is over \$45 billion per year. Despite a focus on treatment interventions, challenges remain. One important but often overlooked risk factor for adverse pregnancy outcomes is sub-optimal sleep. This presentation summarizes several key sleep-related interventions as novel strategies to improve maternal and fetal health.

#### Results

Treatment of maternal sleep problems was associated with improvement in key health measures. Obstructive sleep apnea impacts up to 50% of hypertensive pregnancies and use of positive airway pressure has been shown to decrease blood pressure, with a pooled analysis of six studies found to reduce the risk of gestational hypertension and preeclampsia by 30-35%. In addition, positive airway pressure has been demonstrated to improve insulin secretion/sensitivity, although glucose levels did not demonstrate improvement. Importantly, treatment appears to improve fetal growth; women with obstructive sleep apnea have fetuses that fall across the growth centiles, whereas those who receive positive airway pressure show similar fetal growth to fetuses of control women. Insomnia, which affects ~40% of women by

the third trimester, can be treated with cognitive behavioral therapy. In pregnancy, most people with insomnia have high cognitive arousal. Using mindfulness-based insomnia therapy, reduction of sleep effort and nocturnal cognitive arousal appear to be key mechanisms for alleviating insomnia and depression. In addition to sleep disorders, poor sleep behaviors are associated with adverse outcomes. For example, supine sleep position has been linked with late trimester stillbirth. Interventions to reduce supine sleep position have shown promise, with reductions of supine time by about 30 mins. Indeed, a randomized-controlled trial of positional intervention in a cohort of Ghanaian women found that positional therapy not only reduced supine sleep time but also reduced the proportion of babies born small-for-gestational-age from 24% to 14% ( $p = 0.17$ ).

#### Conclusions

Optimization of sleep during pregnancy offers a window of opportunity to improve the health trajectories of both the mother and the baby. Thus, interventions to improve sleep in pregnancy is likely to ultimately decrease healthcare costs.

#### O16:

##### Working with indigenous nations to co-design stillbirth awareness for prevention resources (WINDS project): imperfect ally or strong advocate?

Jane Warland

University of Adelaide, Adelaide, Australia

**Correspondence:** Jane Warland (jane.warland@adelaide.edu.au)

*BMC Proceedings 2025, 19(25): O16*

#### Background

In Australia, Stillbirth disproportionately impacts Aboriginal and Torres Strait Islander families. Still Aware won funding in 2022 from the Australian Government for a 2-year project with the aim of co-design, co-dissemination, and co-evaluation of stillbirth awareness for prevention resources with and for First Nations families.

#### Methods

We co-designed resources by reaching out to more than 15 Aboriginal and Torres Strait Islander communities and visiting nine (by Elder invitation). Then holding community yarning sessions (WINDS workshops) to co-design Stillbirth awareness for prevention resources with more than 120 individuals from five different communities.

#### Results

The suite of the resources co-designed with and for Aboriginal and Torres Strait Islander communities includes:

- Project Shirt (featuring a painting by a Senior Aboriginal woman from the Pilbara in Western Australia)
- Keep Bubba safe and strong! Brochure. Messages co-designed for the brochure included: 1. What is stillbirth? 2. Learning Bubba's movements. 3. Going to sleep on your side. 4. Trust your mum feelings and 5. When to go see your midwife or Doctor
- Keep Bubba safe and strong! fridge magnet. Co-designed with mob to complement the Brochure
- 3 minute Animated Video (WINDS workshop participants co-designed messages for what Stillbirth is and keeping Bubba safe in pregnancy)
- 3 Minute 'talking heads' video (Larrakia Nation WINDS workshop participants sharing how to keep themselves and Bubba safe in Pregnancy)
- Project mural (60 8x8 canvas paintings depicting WINDS workshop participants views of what stillbirth awareness for prevention meant to them)
- Project Tote Bag (featuring project mural as well as Safe bubba messages in the Gusset)

When asked to describe in one word (or a short sentence) their impression of the Safe Bubba resources, participants provided unanimous and very strong support for the project resources.

#### Conclusions

This presentation will provide information about how a non-Indigenous Australian not-for-profit charity successfully worked with Indigenous communities to co-design Stillbirth awareness for prevention resources. This presentation will outline the approach we took to engage Aboriginal and Torres Strait Islander communities, lessons learned, dissemination and evaluation activities as well as to show the complete suite of resources we co-designed with and for Mob.

#### O17:

##### Hunting for life-saving treatments that tackle preeclampsia

Stephen Tong

University of Melbourne, Melbourne, Australia

**Correspondence:** Stephen Tong (stong@unimelb.edu.au)

*BMC Proceedings 2025, 19(25): O17*

#### Background

Preeclampsia is a severe pregnancy complication that annually claims the lives of 70,000 mothers and >500,000 babies. We still lack a single disease-modifying drug to treat the condition.

Given the injuries caused by preeclampsia reverse upon removal of the placenta, it has been apparent for centuries that some sort of toxin in the body causes it. Treatments used during the 1930's, in a bid to remove this 'toxin', included colonic washouts, inducing vomiting and bloodletting. It is unlikely any of these worked. Even today, the only treatment to 'stop' the disease is removal of the placenta. A treatment that slows disease progression could save the lives of both mothers and babies and improve lifelong health outcomes for both.

#### Methods

For over a decade, our team has hunted for life-saving drugs to tackle preeclampsia. We have a bench to clinical trials research program that is global. We first perform laboratory studies, testing potential drugs in multiple assays that simulate the disease process. Drugs surviving this preclinical screening are tested in clinical trials run in Cape Town, South Africa.

Our preclinical studies have identified a trove of potential candidate drugs. These include esomeprazole, sulfasalazine, metformin and pravastatin. We have completed double blind randomized clinical trial of some of these drugs. Esomeprazole did not prolong pregnancy in women with preterm preeclampsia (Cluver et al AMJOG 2018; PIE trial). However, our second trial identified metformin as potentially the first disease modifying drug for preeclampsia (Cluver et al BMJ 2021, P12 trial).

We are part of a network of three concurrent metformin trials seeking to validate its effectiveness - Cape Town (P13 trial), Sweden (P14 trial) and Netherlands (P1-NL). Furthermore, we and others are turning to biologics as potential next generation treatments. Comanche Biopharma is examining an siRNA to reduce production of soluble fms-like tyrosine kinase-1 (sFlt-1), a disease driver of preeclampsia. Our team is evaluating DM199, a protein drug with positive effects on the maternal vascular system. These include vascular protection, blood pressure reduction and vessel dilation to increase blood supply to distant maternal organs sickened by preeclampsia. Partnering with Diamedica Therapeutics (manufacturers of DM199), our team is running phase I trials of in Cape Town.

#### Conclusions

We are hopeful discoveries of breakthrough drugs to slow the disease are around the corner. Within 10 years we may finally see new agents introduced around the globe to save the lives of many touched by preeclampsia.

#### O18:

##### Thrombosis, cardiometabolic inflammation and infertility

Gregory Piazza

Brigham and Women's Hospital, Boston, Massachusetts, United States

**Correspondence:** Gregory Piazza (gpiazza@partners.org)

*BMC Proceedings 2025, 19(25): O18*

## Background

The relationship between thrombosis, inflammation, and recurrent pregnancy loss (RPL) has been often-debated and underrecognized due limited data and guidelines recommendations that do not reflect the most recent studies.

## Methods

A literature review was conducted using Pubmed (<https://pubmed.ncbi.nlm.nih.gov>) to identify the most recent high-impact, peer-reviewed literature focused on thrombosis, inflammation, and recurrent pregnancy loss and infertility.

## Results

While aneuploidy and anatomical or functional abnormalities may explain some of RPLs, many patients are left without an explanation for these miscarriages, and more importantly, without a clear therapeutic strategy for successful conception and live birth. Epidemiological data continue to suggest thrombophilia, including inherited states, and inflammation as possible etiologies for RPL, but due to inconsistency in the data and limited understanding of causal mechanisms, guidelines have not widely endorsed testing. While the subject of a number of promising studies, implementation of treatment strategies to prevent RPL, such as antithrombotic therapy and antiplatelet therapy, has been likewise hindered by lack of high-quality data. Limited funding, lack of industry interest, lack of public awareness, and enrollment challenges have been obstacles to the acquisition of the data needed to advance the field.

## Conclusions

While we should not abandon randomized controlled trials for understanding the role of anticoagulant and antiplatelet therapy in RPL, we must also be pragmatic and understand that alternatives, innovative study designs will not only help us design the most-likely-to-succeed trials but can, when done in a scientifically rigorous fashion, generate crucial hypotheses and occasionally answer important questions in the care of patients with RPL.

O19:

### Recurrent pregnancy loss

Ronald Librizzi, Megan Hanson

Recurrent Pregnancy Loss Association, Seattle, Washington, United States

**Correspondence:** Ronald Librizzi ([librizzi2@comcast.net](mailto:librizzi2@comcast.net))

*BMC Proceedings 2025, 19(25): O19*

## Background

Recurrent pregnancy loss (RPL) is commonly defined as two or more consecutive pregnancy losses before 20 weeks of gestation and affects approximately 1–2% of couples attempting conception. RPL has multiple potential causes, including genetic, anatomical, endocrine, immunological, and thrombotic factors. Despite thorough evaluation, up to 50% of cases remain unexplained, which presents clinical difficulties for diagnosis and management. Recent developments in reproductive medicine have emphasized comprehensive assessment, but the varied nature of RPL continues to complicate both diagnosis and treatment approaches. Understanding the mechanisms involved and recognizing the emotional impact may contribute to effective interventions, enhanced patient counseling, and improved reproductive outcomes.

## Methods

This presentation discussed current perspectives on professional attitudes, investigative techniques, and management strategies for couples experiencing recurrent pregnancy loss. It included a review of a patient's experience and examined contemporary methods aimed at reducing unexplained pregnancy losses. The presentation also described how progress in placental pathology, genetics, and immunology can impact future management plans and potentially improve outcomes. Many pregnancy losses occur in women without identifiable health issues, and assessments conducted may provide information relevant to their future health risks.

## Conclusions

Managing patients and couples with recurrent pregnancy loss remains complex. There is a need for clinician education that encompasses not only the physical aspects but also the psychological and emotional effects of pregnancy loss on individuals, couples, and families. Most

national women's organizations, apart from those specifically focused on reproductive endocrinology, currently have limited educational resources addressing these concerns. Various local and national support groups are available to assist affected couples. Ongoing efforts are required to enhance medical provider education regarding both the physical and mental health considerations involved in caring for individuals and couples experiencing recurrent pregnancy loss.

O20:

### Communicating an intrapartum stillbirth diagnosis when working with culturally and linguistically diverse bereaved parents: recommendations for practice

Tosin Popoola

The University of Newcastle, Callaghan, Australia

**Correspondence:** Tosin Popoola ([popooltos@gmail.com](mailto:popooltos@gmail.com))

*BMC Proceedings 2025, 19(25): O20*

## Background

Breaking the bad news of stillbirth remains a challenging experience for healthcare providers. The way stillbirth disclosure is handled has ramifications for immediate and long-term bereavement outcomes, and this has led to the development of many tools and practice guidelines to help healthcare providers manage disclosure. However, many of these tools are more applicable to antepartum stillbirths, where parents go into labor knowing what to expect. In intrapartum stillbirths, both parents and healthcare providers are not prepared for stillbirth, which creates many issues, such as communication delays that can cause more distress to parents.

While intrapartum stillbirths are rare in high-income countries, they make up half of stillbirths in many low-income countries such as Nigeria. In contexts where intrapartum stillbirths are high, healthcare providers are also faced with the challenges of navigating entrenched cultural and societal beliefs, which can pose even more challenges for stillbirth disclosure. In light of this, this study examined the stillbirth bereavement practices of Nigerian midwives in order to facilitate the development of a more personalized disclosure model in stillbirth.

## Methods

Eleven midwives were individually interviewed about their stillbirth bereavement practices, with a specific focus on the process of stillbirth disclosure after diagnosis. The data was thematically analyzed.

## Results

This study found that midwives' stillbirth disclosure practices are influenced by three opposing factors: the midwife's beliefs, the value of the family/significant other, and the woman's maternal bonding instincts. Negotiating these competing factors was a challenge for midwives, and in most cases, family values eventually subjugated women's individualized needs.

## Conclusions

Limited understanding and procedures for managing intrapartum stillbirth disclosure, especially in highly cultural contexts, are driving ethical dilemmas and unmet bereavement needs. This study's findings informed a set of recommendations for healthcare providers faced with intrapartum stillbirth disclosure when practicing within and across cultures.

O21:

### Lessons learned: how culturally appropriate care directs perinatal bereavement training in Uganda

Sue Steen<sup>1,2</sup>, Lynn Zdechlik<sup>2</sup>

<sup>1</sup>Maple Grove Hospital, Maple Grove, Minnesota, United States; <sup>2</sup>Birth with Dignity, Edina, Minnesota, United States

**Correspondence:** Sue Steen ([suesteen56@gmail.com](mailto:suesteen56@gmail.com))

*BMC Proceedings 2025, 19(25): O21*

## Background

Ugandans traditionally hold a very different view of how to handle a stillbirth or the death of a newborn. The mother may not be told that the baby has died or may be told that the baby is in the neonatal unit. Often, the stillborn baby is whisked away without the mother seeing

the baby and taken back to the village for immediate burial. Women in Uganda face a large amount of stigma after a stillbirth, a mother-in-law may even encourage her son to divorce his wife.

After many years of training hundreds of midwives, physicians, and students across Uganda, the authors learned that global standards of bereavement care, often used in the western world, can be adapted, received and embraced by health care providers and families. Birth with Dignity (BWD) is a program based in Uganda that was developed to promote this effort.

#### Methods

The BWD mission is to equip Ugandan midwives with information and resources to reduce maternal and perinatal deaths while providing bereavement care in loss. A pre-test/post-test competency is successfully used to introduce midwives to bereavement content and address some of the culturally different aspects of care. During the trainings, parent interviews and videos allow midwives to grow in an emotional manner, understanding the needs and rights of the mother.

The bereavement training has allowed midwives to educate families and communities on the actual causes of stillbirth. The mothers have then received support, rather than condemnation. Families who had never heard of bereavement care are being counseled by midwives during labor. Mothers and fathers not only received the care but also expressed gratitude for seeing and holding their stillborn babies. They also gladly accepted photos of their babies and the blanket in which the baby was wrapped.

#### Conclusions

While respecting culture, a high standard of bereavement care can be practiced by health care workers that allows families to be informed and to have options of how they would like to handle the birth of their stillborn baby.

#### O22:

##### Improving care in pregnancy after loss

Alexander Heazell

University of Manchester, Manchester, England

**Correspondence:** Alexander Heazell (Alexander.Heazell@manchester.ac.uk)

*BMC Proceedings 2025, 19(25): O22*

#### Background

Pregnancies after loss (including late miscarriage, stillbirth and neonatal death) are at higher risk of complications in subsequent pregnancies compared to those from women who have not experienced a perinatal death. In addition, birthing mothers and their partners have increased symptoms of anxiety, post-traumatic stress and depression. Consequently, specialist clinical services have been established to screen for these additional complications and to meet families' additional need for support.

#### Methods

Since 2014, we have conducted a translational research program to establish a specialist clinical model for pregnancy after loss – the Rainbow Clinic. This model is based on systematic reviews and meta-analyses to describe the frequency of adverse outcomes in pregnancy after loss, parents' needs in pregnancy after loss as well as identification of causes and associations of adverse outcomes in subsequent pregnancies. The Rainbow Clinic model of care has been iteratively developed and continues to be developed as further research studies are conducted. Qualitative and quantitative studies have been used to evaluate the impact of the Rainbow Clinic model of care in the UK.

#### Results

Our initial meta-synthesis of 14 studies identified three main themes: co-existence of emotions, helpful and unhelpful coping activities and seeking reassurance through interactions. UK and international studies indicate that while antenatal care is modified to meet these needs in some cases, this is not the case for all parents in pregnancies after loss. Studies from the UK, the Netherlands and Italy identify that placental problems, particularly those relating to problems with blood flow through or inflammation in the placenta have a higher chance of adverse outcome in subsequent pregnancies. Implementation of the Rainbow Clinic of care improved patient experience in pregnancy after loss, providing a protective environment which enabled parents to

feel a greater sense of control. Implementing a model of care including continuity of carer, regular ultrasound scans, including placental assessment at 23 weeks' gestation has been associated with a reduction in preterm births and recurrent losses in two separate UK centers. Implementation of the model is also associated with improved patient experience.

#### Conclusions

Families with a history of prior pregnancy loss are at increased risk of adverse pregnancy outcomes and negative psychological impacts. Provision of focused, specialist antenatal care appears to improve outcomes. Additional analysis of over 1,700 participants in the Tommy's National Rainbow Clinic Study conducted in multiple UK sites will provide additional information about the effectiveness of this model of care.

#### O23:

##### The importance of parent perspective in training and peer support for pregnancy after loss clinical care

Stacey Fletcher<sup>1</sup>, Susannah Leischer<sup>1</sup>, Melissa Baker<sup>1</sup>, Robert Silver<sup>1</sup>, Brenda Gulliver<sup>1</sup>, Rana Jawish<sup>2</sup>

<sup>1</sup>University of Utah Health, Salt Lake City, Utah, United States; <sup>2</sup>Huntsman Mental Health Institute, Salt Lake City, Utah, United States

**Correspondence:** Stacey Fletcher (stacey.fletcher@hsc.utah.edu)

*BMC Proceedings 2025, 19(25): O23*

#### Background

The Utah Pregnancy After Loss (UPAL) Program provides care for parents who have experienced stillbirth, newborn death, termination of pregnancy, recurrent loss, and placental disorders. In alignment with the International Rainbow Clinic Network core principles and the U.S. Pregnancy After Loss Network protocols, staff and clinicians receive training specific to pregnancy after loss care. This training is delivered by a parent and clinical educator.

In addition to parent-driven training, the UPAL Program has furthered its dedication to parent voice by incorporating peer support within its clinical setting. Dedicated to providing patients with a three-pronged approach to care, the UPAL Program emphasizes physical care, mental health accessibility, and peer support availability and resources.

We aimed to emphasize the value of parent lived experience in both training and patient care, and we report here on our initial findings.

#### Methods

A set of training modules was developed iteratively by a team of parents, clinicians, and clinical educators, including basic data on stillbirth, how pregnancy loss affects parents, an introduction to the clinical protocol, and resources for staff and clinician support. A team of one clinical educator and one stillbirth parent educator delivered multiple 90-minute training sessions to 200+ university/clinical personnel, including researchers, admin. team, clinic staff, RNs, ultrasound department, and individual doctors. Most trainings were in person, and training modules were slightly adapted for each trainee group. All trainees were requested to provide feedback via paper or digital questionnaire.

Continuing the implementation of parent voice, the UPAL Peer Support Program consists of a parent who is embedded during clinic hours. This parent meets with pregnancy after loss patients, providing compassionate conversations, valuable local and national support resources, and a monthly labor and delivery tour as a means of exposure therapy. The peer support specialist charts visit information in the University's patient medical records system. In three months, the peer support specialist has logged 100+ patient visits.

#### Results

Feedback was positive. Many training individuals commented on the importance of having a parent as one of the educators and appreciated the ability to ask and hear about personal experiences. Recommended quality improvements included a better trigger warning to ensure adequate emotional preparation, and more specific advice for individual departments, including action items to reduce stillbirth rates and autopsy consent information. In clinic, peer support was very well received by both patients and clinicians, with program expansion in the near future.

### **Conclusions**

Understanding parent perspective is key for clinicians who provide care in pregnancy after loss. Our experience of a collaborative clinical/parent trainer team shows how parent perspective can be successfully integrated into clinical training that is useful and acceptable to trainees. Further work is needed to understand whether this training model translates into improved patient experience. The embedded peer support program has been a valuable addition to pregnancy after loss patient care. Patient and clinical team feedback has been positive, and plans to further utilize parent voice and experience in different areas of study is in development.

### **Publisher's Note**

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.