Bereavement care: Evidence & practice

Fran Boyle

Stillbirth Centre of Research Excellence
Mater Research Institute UQ

WHA Annual Forum on Quality & Safety in Maternity Care Best Practice in Stillbirth Prevention & Response 28-29 November 2017
Acknowledgements

Co-authors: Dell Horey, Anne Schirmann, Vicki Flenady

Lancet Survey participants: International Stillbirth Alliance member organisations; Lancet survey team; parents and clinicians

Worldwide

4.2 MILLION

women living with depression related to stillbirth

Stillbirth affects mothers, families, health services, society, and governments

What do we know about care after stillbirth?

• It matters greatly to parents
• Important short- and longer-term implications for wellbeing of women and families
• Parents value highly care practices that honour their baby and acknowledge parenthood
• Implementation of best practice care is uneven and inconsistent
• A highly challenging (but also rewarding) area of practice
To ‘end an epidemic of grief’¹ ……

Raise awareness to address fatalism, stigma and taboo and empower communities through strong parent and care provider partnerships and raising community awareness to meet the needs of parents and families

Improve bereavement care through research and implementing best practice including better training and support for health professionals

Reduce the numbers of stillborn babies Implementing known effective interventions and audit impact research to improve care, improving data quality

¹ Richard Horton, Udani Samarasekera, The Lancet 2016
Improve care around the time of stillbirth and in subsequent pregnancies
The Lancet Survey - Methods

- Multi-country survey of bereaved parents conducted for The Lancet Ending Preventable Stillbirths Series.
- Link to online questionnaire disseminated via International Stillbirth Alliance organisations from December 2014 to February 2015.
- Topics included stillbirth prevention, management and bereavement care.
- A mix of categorical items, open-ended items, ranking items, and rating scales.
Participants

4180 parents from 44 countries
- Data from respondents from countries other than Australia and New Zealand removed from analysis

496 parents from Australia and New Zealand
- Australia (n=444)
- New Zealand (n=52)

481 mothers
- Data from 15 fathers excluded from this analysis

460 mothers from Australia and New Zealand who had a baby stillborn at 20+ weeks
- Data from 21 mothers with an earlier loss excluded from this analysis
TREAT PARENTS WITH KINDNESS AND RESPECT
TALK IN A WAY PARENTS CAN UNDERSTAND
TAKE PARENTS' CONCERNS SERIOUSLY
LISTEN TO PARENTS
INVOLVE PARENTS IN DECISION-MAKING
SPEND ENOUGH TIME WITH PARENTS
GIVE PARENTS THE INFORMATION THEY NEED

Mothers who replied “always” (%)
Beyond the hospital

32%

RATED QUALITY OF FOLLOW-UP CARE AS POOR OR VERY POOR
I was very disappointed because I had no follow-up call, no midwife come to visit me at home, I felt very alone

I had to organise my own 6 week check-up ... when I arrived the staff didn’t know that my daughter had been stillborn and asked me how the baby was doing
Developing a framework for respectful care after stillbirth

- Literature review
- Analysis of parent responses to large online survey
- Consultation at 2016 PSANZ conference
- Review by 42 clinicians, researchers, parents
# RESPECTFUL CARE AFTER STILLBIRTH

Goals to inform practice

**Good communication**
- Finding the right words and approach

**Shared decision-making**
- Understanding decision-making preferences

**Recognition of parenthood**
- Acknowledging baby and impact of loss

**Effective support**
- Addressing short- and long-term needs
Good communication

Finding the right words and approach
We had a doctor come in and do an ultrasound. He said can you see there is no movement around the heart - do you understand what that means? Then he left. I am a midwife and I understood ... but my husband did not and I had to explain that the baby had died.

I was given a lot of brochures and written info, but actually talking to me more would have been better

I did not have an appointment to find out the results. They were posted to my house and I had to google what it all meant.
Shared and informed decision-making

Understanding decision-making preferences to support informed decision-making
Decisional conflict, limited information, and less involvement in decision-making predicts patient regret about medical decisions


National commitment to shared decision making

The only way to achieve truly person centred care

Gillian Leng deputy chief executive¹, Celia Ingham Clark medical director for clinical effectiveness², Kate Brian women's voices lead³, Gemma Partridge national medical director's clinical fellow¹


NICE and NHS England are working with the Shared Decision Making Collaborative to encourage shared decision making in England.¹ The collaborative, established in 2015, brings together over 40 individuals and organisations with a commitment to

People who are supported to make an informed decision by a healthcare professional seem to have better outcomes,¹ better experiences,¹ and less regret² about their decisions. Much is made of the need to reduce unwarranted variation in healthcare.
It was not my decision to make. It was highly distressful for me to know what they had done to [my baby]. I thought I was going to lose my mind, I felt helpless and had no control ...

There were many things I needed to know but didn't know about. I'm lucky I had excellent care providers who gave me the information I needed ...
Recognising parenthood

Acknowledging the baby and impact of the loss
It was like I’d never been pregnant and hadn’t delivered a full term baby. Because she never took a breath she wasn’t real and I was never a mother.

I wanted to know where he would be when he wasn’t with us and who would be with him.

I wish I’d been allowed to bath him.
Effective support

Addressing short- and long-term needs
We were so fortunate to be cared for by *a bereavement midwife* ... [*She*] helped us through organizing a funeral to counsellor and ongoing bereavement support group. Her support and guidance was and still is instrumental in our understanding and grieving for our baby.

My obstetrician was wonderful. He could not have done more. He always called me with any information or updates - and even just to see how we were going.
RESPECTFUL CARE AFTER STILLBIRTH
Goals to inform practice

- Clear communication
  - Finding right words and right approach

- Recognition of parenthood
  - Acknowledging baby and impact of loss

- Shared decision-making
  - Understanding decision-making preferences

- Effective support
  - Addressing short- and long-term needs

- Information about baby
- Seeing and Holding
- Care of baby
- Photos and mementoes
- Funeral/commemoration
- Partners, siblings, other family members
- Post-hospital and community care
- Support groups
- Subsequent pregnancies
- Capable and well-supported staff

- Breaking bad news
- Documentation
- Cultural safety
- Consent and decision-making
- End-of-life
- Birth options: Induction / Pain control
- Lactation inhibition
- Follow up: Autopsy/post-mortem investigations
- Making memories

Clinical Practice Guideline for Perinatal Mortality

Guideline update currently underway

Implications for practice

- Care experiences after perinatal loss are an indicator of quality of care
- Staff need training and support to provide best practice care
- Respectful care is coordinated, personalised and has clear goals
- The first step is to acknowledge the magnitude and scope of loss for parents
In conclusion

“in the case of a stillborn baby, everyone involved only has one chance to get it right”

Downe et al., 2013

Photographer: Matthieu Zellweger
The Lancet 2016 388, 2588-2599