



Caring for couples at the time of loss and in the pregnancy that follows

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**A TRADITION OF
INDEPENDENT
THINKING**



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Outcome

- Highlight the importance of clinical care at the time of loss and in the pregnancy that follows on couples' experiences.
- Identify gender issues that may affect couples experiences and decision making in entering a new pregnancy.



Introduction

- Perinatal loss is the most common complication of pregnancy.
- 1:4 pregnancies will end in a miscarriage.
- Exact figures are difficult to ascertain as many women may never present to healthcare services.



1 in 4 pregnancies end in miscarriage

<https://www.tommys.org/our-organisation/charity-research/pregnancy-statistics/miscarriage>

We can no longer remain **silent** about **stillbirths**

More than **2.6 million** babies are **stillborn** each year

(1.3 million of those babies begin labour **alive** and **die before birth**)

That means that every day

7,200 women

suffer the loss of their babies in the last three months of pregnancy



98% of all stillbirths happen in low & middle income countries...

...but high-quality care during pregnancy & labour would result in a **quadruple return on investment** preventing maternal & newborn deaths, as well as stillbirths, while also improving child development.



We need to:

- count stillbirths around the world
- break the taboo & stigma around stillbirths
- ask policymakers to act & invest in the issue

Lancet (2016) Ending Preventable Stillbirth Series

Background

- The majority of couples who experience stillbirth will progress to a subsequent pregnancy, often within a very short timeframe of their index loss (Wojcieszek et al 2018a)
- Perinatal death, grief of loss, and experiences of subsequent pregnancies all affect the couple dynamic with gender differences often apparent.
- A lot of work remains to be done in PAL. We have no RCTs of what is actually effective.
(Wojcieszek et al 2018a)

'Truths' About Grief

- Never fully 'completed'.
- As love endures so too does grief, no one ever 'gets over' a loss.
- Rather it is about integrating grief, moving forward, & trying to find meaning.
- The bereaved need continued support.



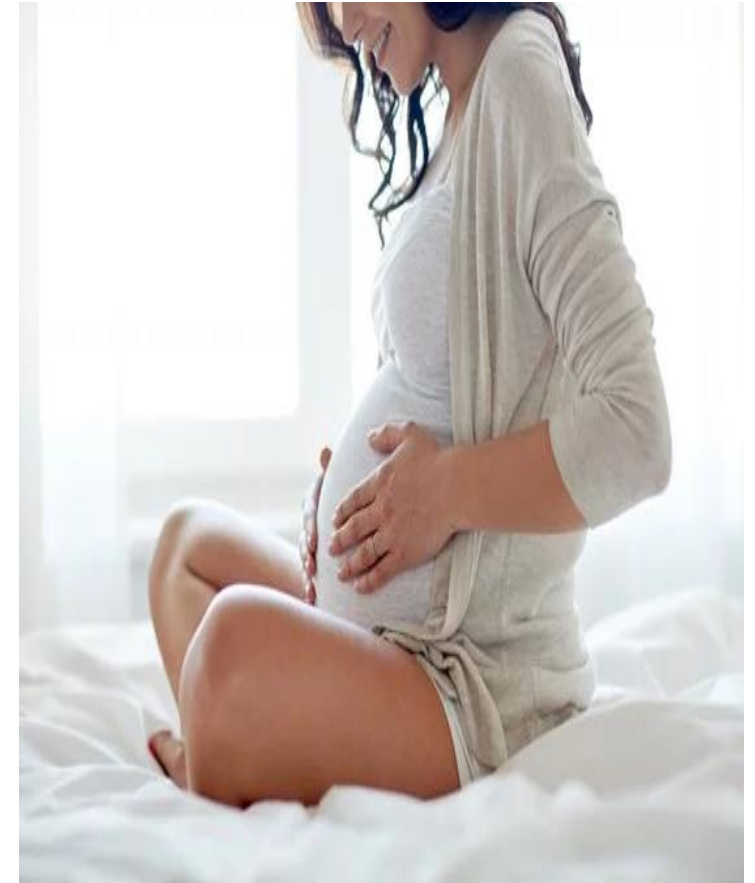
'Truths' About Grief

- Perinatal loss is unique.
- Combination of grief and trauma and often referred to as silent grief.
- In Pregnancy After Loss (PAL) there is new layer of grief or remourning.
- Anxiety is a key component and constant feature of PAL.

Maternal attachment and transition to motherhood

- Begins once the diagnosis of pregnancy is confirmed.
- Baby 'becomes real' over time.
- Physical and emotional attachment to baby.

(O'Leary & Thorwick 2008)



Paternal attachment and transition to fatherhood

- Cognitive relationship to the baby.
- Assisted by vicarious acts e.g. pregnancy test kits, ultrasonography, fetal movements.
- Baby may not 'become real' until after the birth, delay reported in exclusive breastfeeding studies.
- Attachment and transition not completed until the baby born.

(Draper, 2003; Condon et al. 2004)



Expected Anxiety

- Anxiety is a key component and constant feature of PAL.
 - Fear of another loss
 - Increased anxiety around appointments
 - Hypervigilance/Overprotection
 - Stress and worry
 - Conflicted emotions
 - Isolation
 - Detachment (Henke 2019)
- Need to reframe the issue of 'anxiety' in PAL.

Aim of study

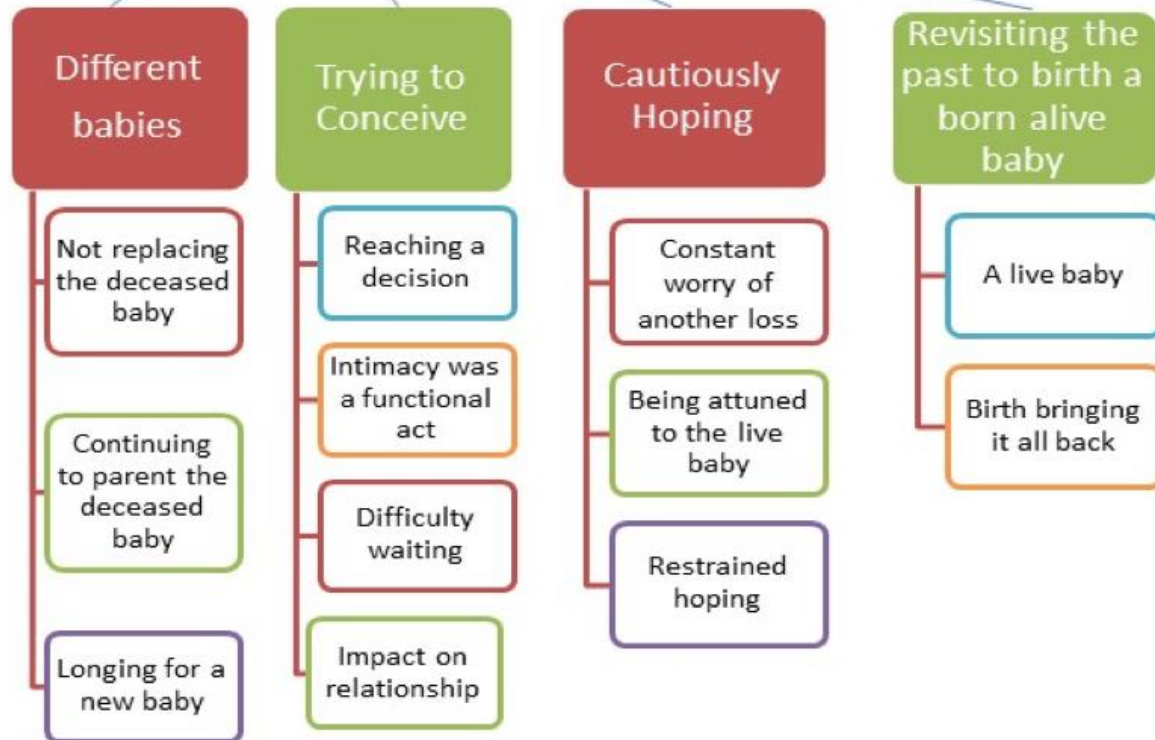
- To explore the experiences of couples in immediate pregnancy after loss.
- Research to date has focused on the pathological effects of PAL
- As a midwife, I wished to explore the issue with a salutogenic (health) focus.
- Ethical approval obtained from Local Hospital Ethics Committee.

Methods

- Over 6-month period, 8 heterosexual couples agreed to participate.
- Joint, face-to-face interviews, lasting 70-120 minutes were conducted at a place and time of participant's choosing.
- Interviews were transcribed verbatim and analysed Interpretive Phenomenological Analysis (IPA) principles.
- Resulted in the generation of themes.

EXPERIENCES OF COUPLES IN PREGNANCY AFTER STILLBIRTH

HOPING FOR A BORN ALIVE BABY



JOURNEY OF LOSS



Journey begins with baby who died

Care at the time of loss

"I felt she came and minded us. She was like our mother for the week, even though they've all been fantastic to us like but she's been, just kind of, did everything".
[Nadine]

"Yeah, at the end of the four days when we were going away. She was crying, we were crying, it was like we were losing a friend as well as (the baby). She was just heartbroken for us as well and you could see it in her face. You could see it in her eyes." [Jonah]

Journey begins with baby who died

'Knowing' the baby

"Yeah, I am very clear, I have three children" [Amy]

*"Like it is very, very sad, but it's different to me losing Larry or John (older sons) to Conor. I knew Conor for 4 or 5 days, Amy knew him for 22 weeks, she knew the person. I didn't know the person, so."
[Brian]*

Getting pregnant again after loss

Deciding to get pregnant

"I come from a big family you know so I'd love loads of kids if I could. So the decision I suppose was always there and I knew that Adam was on board, he loves kids and he wanted kids as well." [Grace]

"I suppose coming back to the decision thing, before we ever got the results we had agreed on it really, if there was no answer to what happened we weren't going to try again, if we got an answer we would try again" [Doug]

Getting pregnant again after loss

Trying to conceive

"Every time I got my period it was like; oh I was a mad woman." [Jill]

"She gave out to me one time. 'What's wrong with you, what's wrong with you?' ... It was like, seriously, it was like homework." [Adam]

Journey of sustaining hope & revisiting birth

Sustaining hope

"For this pregnancy we have picked up a few things...Maybe we are trying to say to ourselves, yes you will need this stuff or what I don't know what it is." [Jill]

"...just trying to encourage Grace. But just like I'd always say to her just try to think positive all the time about things" [Adam]

Journey of sustaining hope & revisiting birth

Revisiting birth

"I have to really try to look at this as a totally different and positive experience. I can see that it might bring back...but it is not, it's going to be very different"
[Kim]

"We're just hoping, come on let's get the birth through and finished with it and then we'll start. Just getting the birth out of the way"
[David]

Recommendations

- Importance of clinical care at the time of loss.
 - Sensitive, empathic clinical care.
 - Give couples the opportunity to parent their baby.
 - This is particularly important for fathers, as for many, they may view it as the only opportunity to parent their baby.

Recommendations

- Continuity of carer, both at time loss and in PAL.
- Deciding to get pregnant again is a negotiated decision that couples make. Communication is key.
- Revisiting birth is challenging for couples as their previous experience of birth was coloured by death.

Conclusion

- Birth experiences at the time of loss affect women and men perpetually, especially in the pregnancy that follows.
- Those caring for couples at the time of loss and in the pregnancy that follows need to be cognisant of these experiences.
- Couples can benefit from exploring their experiences of stillbirth, to prepare them for revisiting the birth space again.

Conclusion

- PAL is unique for couples.
- They have care needs that are different to the non-loss population.
- Couples engage in sustaining hope, making meaning, and fostering a relationship with their unborn baby as they continue to grieve their deceased child.



Words of Thanks

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THANK YOU

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