

Understanding Stillbirth Stigma: Why breaking the silence is not enough

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BEREAVED MUM

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What are we discussing today?

- What is stigma?
- Why are bereaved parents stigmatised?
- Bereaved parents experience of stillbirth stigma.
- Measuring Stigma
- Predictors of Stillbirth Stigma
- Health care providers and stigma
- Reducing Stigma



My Story

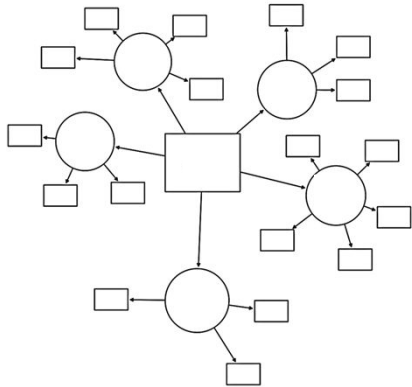


‘Perhaps the greatest obstacle to addressing stillbirths is stigma.’

Horton & Samarasekera, 2016, pg. 515



Mind Map



- What do you think stigma is?
- What are the experiences for those who are stigmatised?
- What are the sources of stigma?
- What can we do to reduce stigma?



Definition of stigma

“Stigma endeavours to devalue a person’s worthiness within society, which can be achieved by attacking (consciously or unconsciously) parts of /or their whole personal identity.”
(Goffman, 1968).



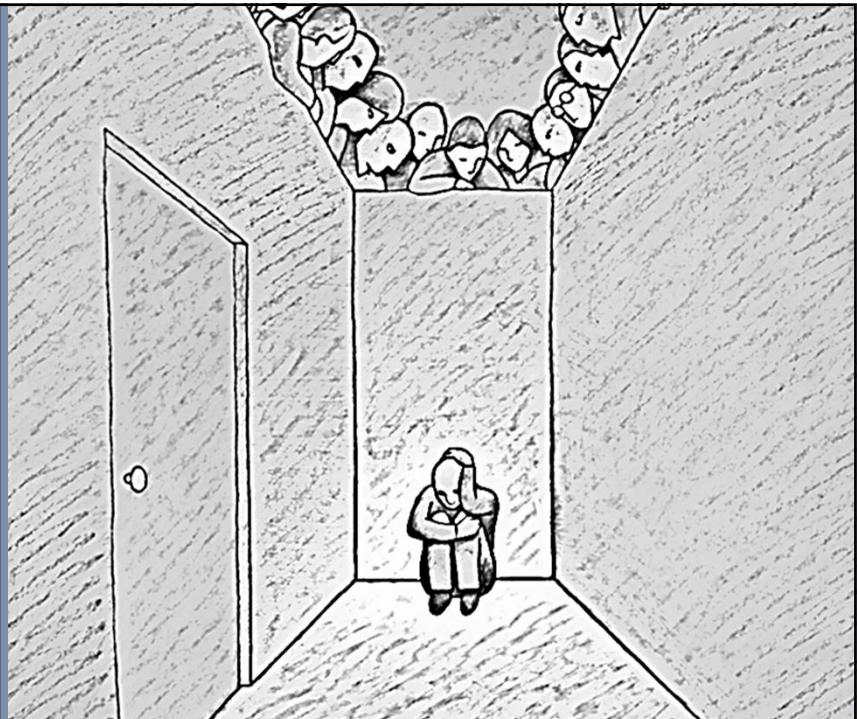
Link and Phelan

• Stigma is the convergence of:

- Discrimination & Status Loss
- Labelling
- Stereotyping
- Separation

- In the presence of power
- Explores the macro level approach.

(Link and Phelan, 2001)



Types of Stigma

Public (Enacted) Stigma	Anticipated Stigma	Internalised/Perceived Stigma
<ul style="list-style-type: none"> Actual experience of stigma <p><i>Example: Being denied pain medication whilst in labour</i></p> <ul style="list-style-type: none"> Negative attitudes and victim blaming. Forms of Discrimination 	<ul style="list-style-type: none"> The fear of judgement <p><i>Example: What will someone say when I tell them that I have had a stillborn baby?</i></p> <ul style="list-style-type: none"> Expectation of isolation/rejection and judged/ridiculed 	<ul style="list-style-type: none"> Accepting the social condemnation of their experience <p><i>Example: "I wasn't meant to be a mother as I couldn't protect my baby"</i></p> <ul style="list-style-type: none"> Lowered self-esteem, negative self-image Self-blaming Stereotype acceptance

Why should we explore stigma?

Stigma research in other areas (Mental health, HIV/AIDs, STIs) suggest:

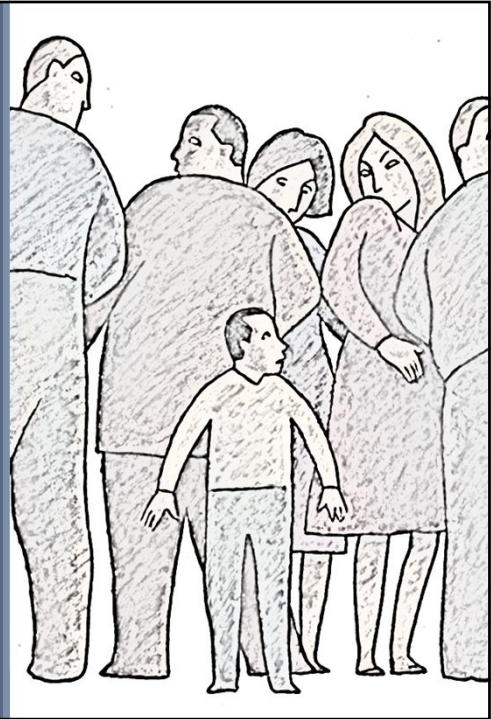
- Stigma is seen as a barrier for help seeking,
- Increases social distance,
- Increases depression and anxiety.

(Herek, Saha & Burack., 2013; Ilic et al., 2013; McGrath, 1992).

Consequences of Stigma

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- Stigma is seen as a barrier for help seeking,
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(Herek, Saha & Burack., 2013; Illic et al., 2013; McGrath, 1992).



Stillbirth Stigma

- Very little evidence on stillbirth stigma.
- Interactions between professionals, family, friends, colleagues, and causal acquaintances.
- We need to reconceptualise how we think about stillbirth stigma.
- Stigma is not just a bereaved parent issue; it is a systems issue.
- More questions than answers at this stage.

(Brierley-Jones, 2014)





Why are the bereaved stigmatised?

- Disenfranchised grief
 - Timeline
- Babies aren't meant to die.
- Stillborn babies don't have a well-established identity.
- They represent a physical limitation and are associated with negative images and myths.
- Stigma associated with a serious illness is dependent on whether the individual can be blamed or held responsible for its occurrence.

Publication

- Online Survey
- International:
 - United States of America
 - Canada
 - Australia
 - United Kingdom
 - New Zealand

- 817 participants (Female: n=796; male: n=17).
- Mostly Caucasian and educated.

38% of bereaved parents believed they had been stigmatised.

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Voices of the unheard: A qualitative survey exploring bereaved parents experiences of stillbirth stigma

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ABSTRACT

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.

Aim: This study aimed to explore the stigma experiences of bereaved parents who have endured a stillbirth.

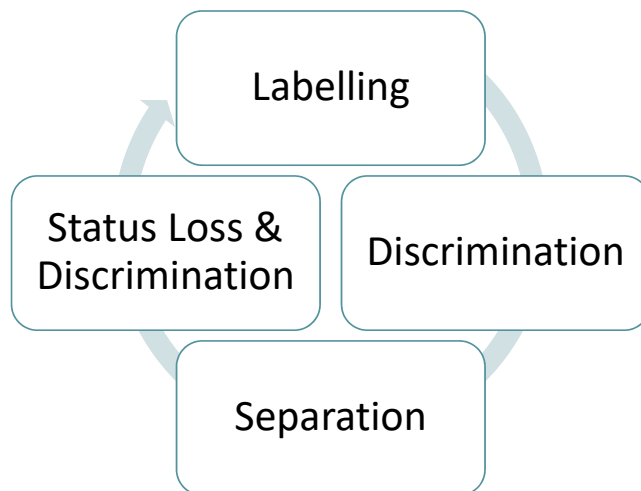
Methods: An online survey of closed and open-questions with 817 participants (n = 796 female; n = 17 male) was conducted in high-income countries.

Findings: Based on self-perception, 38% of bereaved parents believed they had been stigmatised due to their stillbirth. Thematic data analysis revealed several themes consistent with Link and Phelan's stigma theory: labelling, stereotyping, status loss and discrimination, separation, and power. One more theme outside of this theory- bereaved parents as agents of change was also discovered.

Conclusion: 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 disseminating and distributing resources to pregnant women.

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Closed-ended questions	n	Yes	No	Prefer not to answer
Do you feel since the stillbirth of your baby that you have been stigmatised?	817	313 <u>38.3%</u>	477 58.4%	27 3.3%
Do you feel that there is a silence surrounding stillbirth?	816	785 <u>96.1%</u>	31 3.8%	- -
Are you able to talk about your stillborn baby with friends and family?	815	702 85.9%	99 12.1%	14 1.7%
Have you noticed since your stillbirth that you are perceived differently by others?	803	470 57.5%	304 37.2%	29 3.6%



Stigma Dimensions

Stigma Dimensions	Quote
Labelling <ul style="list-style-type: none"> Am I a mother? How do I answer: 'How many children do I have?' 	<i>"They say you are not a mother because you do not have physical children."</i>
Stereotyping <ul style="list-style-type: none"> Mother must have done something wrong Feelings of being 'contagious.' 	<i>"In the early days I felt branded as if I was marked by death and what I had was somehow contagious. The way some people avoided me was sickening and just added to the isolation, it was, and it is hard to understand..."</i>
Separation <ul style="list-style-type: none"> Isolation Blame Shame Concealment 	<i>"People have avoided me and excluded me while others have reached out in ways that they never had before... There is absolutely a feeling of removal from society, from events, and of being in too much pain to have around."</i>
Status Loss and Discrimination <ul style="list-style-type: none"> Status loss for the baby and the parent occurred after stillbirth Discrimination of bereaved parents (Workplace) Discrimination of bereaved parents (Health Care Providers) 	<i>"People are afraid to talk to you; health care professionals are weird to you and blame any health issue you have on 'stress from losing the baby.' And don't look any further into your condition and make you feel dismissed and second class to anyone else with the same problem."</i>

Power

"People are very unwilling to talk about it. Anytime in conversation, when I am asked about having kids, and I feel comfortable enough to tell the person, the subject is quickly changed. It is not talked about with my other or friends. It is not talked about in the media, or on social sites (unless you follow pages about stillbirth). It is not even talked about at medical facilities. I had so much faith in modern medicine. I thought stillbirths were a thing of the past; I had no idea how common is still is because it is never talked about."

How can we reduce stillbirth stigma?

First, we need to be able
to measure it!

Stillbirth Stigma Scale

- Developed from literature, lived-experience researchers, Still Aware, adapted stigma scales from other areas.
- **Phase one:** 88 items piloted on 100 bereaved Australians
 - Exploratory factor analysis revealed four-factors found.
- **Phase two:** 20-item scale used with 889 bereaved mothers.
- 20-item scale
- Total Stigma scores range from 20 to 100

Name of Factor	Items	Example	Explained Variance	Cronbach alpha (α)
Perceived Devaluation due to Stigma	6	Most people will not look you in the eye when you speak about your stillbirth	32.87	.81
Discrimination	7	I have been discriminated against by my friends because of my stillbirth	12.84	.89
Self-stigma	4	I feel blemished	8.25	.73
Disclosure	3	I feel the need to hide my stillbirth	6.50	.80
Total Scale Structure	20		60.48	.77

		Perceived Devaluation	Discrimination	Self-Stigma	Disclosure	Total Stigma Score
Score Range		6-30	7-35	4-20	3-15	20-100
N		887	887	883	889	879
Mean		20.41	17.60	15.52	8.39	61.91
Std. Deviation		5.18	6.48	3.58	2.94	13.77
Minimum		6.00	7.00	4.00	3.00	20.00
Maximum		30.00	35.00	20.00	15.00	99.00
Percentiles	25	17.00	13.00	13.00	6.00	52.00
	50	21.00	17.00	16.00	8.00	62.00
	75	24.00	22.00	18.00	10.00	72.00



Who is at increased risk for higher levels of stigma?

- No prior living children
- Years since stillbirth (still to be determined how long)
- Prior history of mental illness (non-specific)
- Diagnosis of Mental illness after stillbirth.
- Living with a disability*

What if health care providers are a source of stigma?



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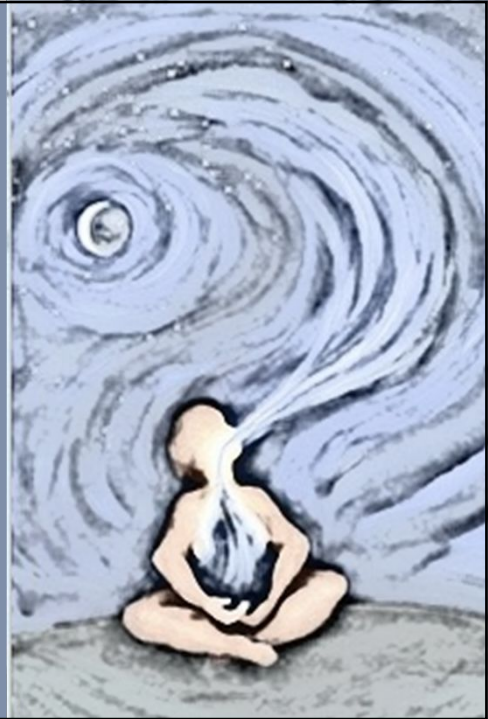
'We're passed off as paranoid mums': Former Big Brother housemate, 35, who suffered a stillbirth just two weeks before her due date says her warning signs were DISMISSED by a doctor

- A 35-year-old mother who suffered a tragic stillbirth has opened up about grief
- Bree Amer-Wilkes noticed her unborn baby's movements were slowing down
- The mother said she was turned away by the obstetrician twice despite concerns
- The midwife found baby boy Archie no longer had a heartbeat at 37 weeks
- Nearly two years after the loss of her child, Ms Amer-Wilkes fell pregnant again
- She and her husband Evan both have a nine-month-old son named Hunter

The Empowerment of Stillbirth

- To be stigmatised is not always a negative experience, it can also be empowering;
- A mother and father who have just experienced a stillbirth often have an innate desire to protect their child's memory .
- As a collective they can become a powerful force in attempting to challenge the status quo, yet research has often ignored the empowerment that can come from stillbirth.

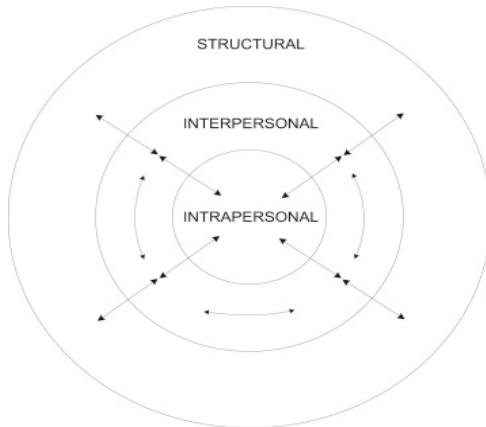
(Murphy, 2012)



Bereaved Parents as Agents of Change

"To me, it means making sure her death was not in vain by doing everything in my power to stop this from happening to other families and to support anyone I know who goes through it (or other tragic losses). As much as this felt like an unwanted burden in the immediate aftermath of my daughter's death, it has truly given my life purpose and meaning on a deeper level than I could have imagined before. I have done better for the world in the four years since my daughters' death than I had in the previous 28 years combined. I am a much better (kinder, more empathetic, less selfish) person today than I could ever have ever hoped to be without having been her mother, and I will always be grateful for that."

What is the ideal stigma intervention?



- Multi-level
- Bi-directional
- Multi-disciplinary

There is no ONE solution!



GM

Final thought on Stigma-reduction interventions

- We cannot place the sole responsibility of change on bereaved parents.

We need allies

- Education and increasing the general public tolerance is not enough.
- Interventions should **ALWAYS** be client-focused.
- Interventions at each level should support each other.

Conclusion

- More research needs to occur!
- Stigma remains an elusive issue for the stillbirth community
- Based on qualitative data, stigma experiences include separation, stereotyping, labelling, status loss and discrimination.
- 38% of bereaved parents reported feeling stigmatised.
- The stillbirth stigma scale is statistically sound; however, future research needs to occur.
- We need to be mindful of how stigma could be impacting bereaved parents.
- Interventions need to be multi-disciplinary, and target multiple levels within our society.

Questions?
Thank you

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