Understanding Stillbirth Stigma: Why breaking the silence is not enough
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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
‘Perhaps the greatest obstacle to addressing stillbirths is stigma.’

Horton & Samarasekra, 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).

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**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

<table>
<thead>
<tr>
<th>Public (Enacted) Stigma</th>
<th>Anticipated Stigma</th>
<th>Internalised/Perceived Stigma</th>
</tr>
</thead>
</table>
| • Actual experience of stigma  
  *Example: Being denied pain medication whilst in labour*  
  • Negative attitudes and victim blaming.  
  • Forms of Discrimination | • The fear of judgement  
  *Example: What will someone say when I tell them that I have had a stillborn baby?* | • Accepting the social condemnation of their experience  
  *Example: ‘I wasn’t meant to be a mother as I couldn’t protect my baby’*  
  • 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

• 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, 2012; Ilic 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.

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

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ABSTRACT

Background. Every year, 2.3 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 attached to the stillborn baby. This study aimed to explore the experiences of bereaved parents who had endured a stillbirth.

Methods. A mixed-methods research design was adopted. A focus group (FG) with 13 parents (n=796 female; n=17 male) was conducted in high-income countries.

Findings. A few of the participants had shared their experiences of stillbirth stigma. The themes identified included: loss, sacrifice, guilt, and disbelief. In addition, the participants also reported the presence of a range of emotions, such as anger, sadness, and helplessness. The impact of stigma was felt at different stages of the bereavement process, including during pregnancy and post-delivery.

Conclusion. These findings highlight the importance of understanding the experiences of bereaved parents. Further research is needed to explore the extent and type of stigma felt by bereaved parents after stillbirth, and how stigma is impacting the health care professional’s ability to provide support.

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<table>
<thead>
<tr>
<th>Closed-ended questions</th>
<th>n</th>
<th>Yes</th>
<th>No</th>
<th>Prefer not to answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel since the stillbirth of your baby that you have been stigmatised?</td>
<td>817</td>
<td>313</td>
<td>477</td>
<td>27</td>
</tr>
<tr>
<td>Do you feel that there is a silence surrounding stillbirth?</td>
<td>816</td>
<td>785</td>
<td>31</td>
<td>-</td>
</tr>
<tr>
<td>Are you able to talk about your stillborn baby with friends and family?</td>
<td>815</td>
<td>702</td>
<td>99</td>
<td>14</td>
</tr>
<tr>
<td>Have you noticed since your stillbirth that you are perceived differently by others?</td>
<td>803</td>
<td>470</td>
<td>304</td>
<td>29</td>
</tr>
</tbody>
</table>

Stigma Dimensions

- Labelling
- Status Loss & Discrimination
- Discrimination
- Separation
<table>
<thead>
<tr>
<th>Stigma Dimensions</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Labelling</strong></td>
<td>“They say you are not a mother because you do not have physical children.”</td>
</tr>
<tr>
<td>• Am I a mother?</td>
<td></td>
</tr>
<tr>
<td>• How do I answer: ‘How many children do I have?’</td>
<td></td>
</tr>
<tr>
<td><strong>Stereotyping</strong></td>
<td>“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…”</td>
</tr>
<tr>
<td>• Mother must have done something wrong</td>
<td></td>
</tr>
<tr>
<td>• Feelings of being ‘contagious.’</td>
<td></td>
</tr>
<tr>
<td><strong>Separation</strong></td>
<td>“People have avoided me and excluded me while others have reached out in ways that they never had before… There is absolutely a feeling or removal from society, from events, and of being in too much pain to have around.”</td>
</tr>
<tr>
<td>• Isolation</td>
<td></td>
</tr>
<tr>
<td>• Blame</td>
<td></td>
</tr>
<tr>
<td>• Shame</td>
<td></td>
</tr>
<tr>
<td>• Concealment</td>
<td></td>
</tr>
<tr>
<td><strong>Status Loss and Discrimination</strong></td>
<td>“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.”</td>
</tr>
<tr>
<td>• Status loss for the baby and the parent occurred after stillbirth</td>
<td></td>
</tr>
<tr>
<td>• Discrimination of bereaved parents (Workplace)</td>
<td></td>
</tr>
<tr>
<td>• Discrimination of bereaved parents (Health Care Providers)</td>
<td></td>
</tr>
</tbody>
</table>

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

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

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
References


References


Longhurst, R., 2005. (Ad)ressing pregnant bodies in New Zealand: clothing, fashion, subjectivities and spatialities. Gender, place and culture, 12, 433–446.


Pollock, D., Cooper, M., Pearson, E., Ziaian, T., Warland J. Voices of the Unheard: Bereaved parents experiences of stillbirth stigma. Accepted waiting publication in Women and Birth
