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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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Statement of significance

Problem or issue

The wider literature often reports there is a stigma associated with stillbirth, however, little research on the extent, and experiences of the bereaved parent has been explored.

What is already known

Bereaved parents often report feeling silenced, shamed and blamed for their stillbirth.

What this paper adds

Evidence that bereaved parents do endure stillbirth stigma at a micro and macro level and examples of stigma experiences. Insight into the possibility that stillbirth stigma does not just impact bereaved parents, but also influences health care professionals during the provision of antenatal care.

1. Background

Losing a baby before they draw breath is devastating to expectant parents, family, friends, and their respective communities. According to the World Health Organization (WHO) 2.6 million babies worldwide after 28 weeks gestation will be stillborn every year.¹ There is an inconsistency with the definition of stillbirth between

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countries.¹ Australia considers stillbirth after the death of a baby from 20 weeks gestation and/or 400 g gestational weight.² However, this can range between high-income countries (HIC) from 16 weeks to 28 weeks gestation.^{2,3} Therefore, there are many stillbirths in high-income countries; which are not counted within the World Health Organizations (WHO) global rates.

A bereaved parent can experience a plethora of poor outcomes after a stillbirth, such as depression, anxiety, Post-Traumatic Stress Disorder (PTSD), marital and financial difficulties.^{4–6} One of the most reported outcomes by bereaved parents though is being silenced about discussing their experience and stillborn baby, for example, not being able to say their baby's name.^{7–14} Silencing is a social tool that can reinforce the stigmatising relationships between the stigmatiser and stigmatised.¹⁵ The stigma of stillbirth is seen as possibly one of the greatest barriers in reducing stagnant stillbirth rates and supporting bereaved parents.^{16,17} Several calls have been made to reduce the stigma surrounding stillbirth globally, notably, the 2011 and 2016 Lancet Stillbirth Series made a 'call to action' to reduce stillbirth by 2020.^{16,18–20} However, there continues to be little research directed at exploring, conceptualising and measuring stillbirth stigma.¹⁸

Stigma, according to Goffman²¹ is the spoiling of an individual's identity. Goffman proposed that stigma serves to discredit the individual due to possessing an attribute that is against the social norms. Goffman,²¹ identified three attributes that people commonly stigmatise against- blemishes of character, the abomination of the body, and tribal stigma. The first two are pertinent to the experience of stigma associated with stillbirth. The bereaved parent who has experienced a stillbirth can feel "blemished".⁷ The mother, in particular, may also feel 'abomination of the body'²² in that her body did not meet her, or societal expectations of producing and bringing home a healthy, living baby.⁷ Link and Phelan²³ have built upon Goffman's²¹ theory and suggest that stigma is the convergence of labelling, stereotyping, separation, status loss, and discrimination, with the presence of power. Stigma is a form of power and is used by people to achieve their intrinsic and extrinsic motivation of creating an 'us' vs. 'them' mentality.^{23,24} Bereaved mothers are often considered to be in the minority of their respective communities and therefore may not possess the cultural, economic, political or emotional power to change. Mothers and fathers often come from a position of 'full citizenship,' however, once the stillbirth occurs, their power is reduced⁷ because instead of a citizen, they are the 'woman/man who lost their baby,' they may be devalued, avoided and their grief minimised.

Within the broader literature, the stigma associated with other health outcomes such as mental illness has been associated with multiple poor outcomes, including a barrier to seeking assistance,^{25,26} increased isolation,^{27–29} and depression.²⁹ However, there are no studies which have directly explored the relationship of stillbirth stigma and adverse outcomes. The limited research which has been conducted on stillbirth stigma is often qualitative using a grounded theory approach in which 'stigma' was discovered as a theme. Despite the limited research, the current evidence does suggest that stillbirth is stigmatising.^{7,10,12,14,19,30}

Bereaved parents commonly report stigmatising perceptions, attitudes, and feelings, with a multitude of articles reporting common experiences of blame, shame and guilt over their stillbirth.^{10,11,14,19,30,31} Even though Murphy's¹⁴ qualitative study of predominately mothers in the UK was not directly exploring stigma in stillbirth found that participants often spoke about the stigmatising effects, without the participants directly mentioning stigma. Examples include changing relationships and the attitudes of others being changed around them. They also experienced social isolation and avoidance, with some participants stating that members from their community would cross the road to avoid

them. Brierley-Jones et al.⁷ qualitative study of 162 bereaved mothers found that stillbirth was stigmatising as their status as a mother was questioned, and this impacted how they were treated within the hospital setting and their interactions with friends/family and others once they left the hospital. Their study reported experiences of mothers being excluded from their friendship group after their stillbirth, feeling like they were a 'leper,' being denied pain relief during labour and feeling unable to show memories of their stillborn baby to others.⁷ Furthermore, they reported how the stillborn baby was stigmatised, with examples of the baby being placed in a store cupboard or presented with a blanket over its head.

Stigmatisers could also be health care professionals which the bereaved parents interact with in the hospital and their aftercare. Frøen et al.¹⁹ study of health care professionals from around the world reported stigmatising attitudes, stereotypes, and beliefs about bereaved mothers, with 29% reporting a belief that she was at fault for the stillbirth. A further 20% believed that she failed as a spouse, and 13% responded the bereaved mother was impure or taboo. Frøen et al.¹⁹ study stops short of defining the type of stigma the participants experienced and therefore leaves the topic open to further exploration.

Little research has directly explored the experience of stigma after stillbirth. Therefore, this study sought to capture the experiences of stigma after stillbirth with bereaved parents from high-income countries.

2. Method

2.1. Development of the survey

This survey was part of the main authors PhD project. It was designed to capture the experiences of bereaved parents and was piloted in a smaller Australian sample (female: n=94; male: n=6) in 2017 via surveymonkey.com[®]. During development, there was end-used consultation with organisations who provide support (online and face to face) and awareness of stillbirth, and with individual bereaved parents advising on the appropriateness, readability, relevance, clarity, and completeness of the questions. Following a pilot, it was decided that recruitment would occur internationally. Consultation from researchers and bereaved parent groups within each targeted country- the United Kingdom, United States of America, and New Zealand was undertaken to ensure the questions were culturally appropriate and bereaved parents experiences in the different medical systems were appropriately captured. By using a snowballing recruitment strategy, other high-income countries were captured (mainly, Canada) and subsequently included within this study.

2.2. Data collection

The survey was available online via Survey Monkey[®] from May to September 2018. Participants were invited to complete the survey if they were over the age of 18 years old and had a stillbirth (20 weeks gestation and/or 400 g). The authors contacted multiple organisations which support bereaved parents in the United States of America, Australia, New Zealand and the United Kingdom. A snowball recruitment methodology was utilised, which meant that some other responses from non-targeted countries were received and included if they were from a high-income country (HIC). Organisations were asked to post the recruitment advertisement on pregnancy loss support or awareness, and Facebook pages, which were than shared. Participants consented to participate in the survey, by clicking 'I accept.' Participants were asked to respond to a series of psychometric scales- Multidimensional Scale of Perceived Social Support (MSPSS),³² Rosenberg Self-esteem Scale

(RSES),³³ Perinatal Grief Scale (PGS)³⁴ and a scale currently in development measuring stillbirth stigma (manuscript currently under preparation). Participants were then asked through open-ended responses (refer to Table 1) and closed questions their self-perception of stigma, silence, and their interaction with others, the findings from which are presented here.

2.3. Research ethics

This study was approved on the 5/12/2016 by the University of South Australia Human Research Ethics Committee. Protocol number 000036017.

2.4. Analysis

2.4.1. Quantitative data analysis

Many responses were expected with this survey due to the online and international methodology taken. Therefore, some closed questions were asked before certain open-ended responses to further inform the responses of the bereaved parents quickly. Descriptive statistics using Statistical Programming for Social Science (SPSS) was utilised.

2.4.2. Qualitative data analysis

We used the thematic approach developed by Braun and Clarke.³⁵ The main author (DP) familiarised herself with the data, generated codes, and searched for themes. JW checked DP's analysis and confirmed the generated codes. Once those themes were found, all authors reviewed the themes and agreed that the definitions and names were appropriate. Extracts of responses were also reviewed by all authors to determine that they adequately captured those agreed upon definitions.

3. Findings

3.1. Participants

A total of 817 participants (n = 796 female; n = 17 male) aged 18 years or over who had experienced a stillbirth (20 weeks gestation or more) participated in this survey. Participants were recruited from high-income countries, which have varying definitions of stillbirth. To be more inclusive and allow for the bereaved parent's voice to be heard, the lower definition (20 weeks gestation and/or 400 g gestational weight) was applied. Women were excluded if they had a medical termination. Bereaved parents from Australia represented 44% (n = 359) of the sample, and there was also a large proportion of participants (36.1%, n = 294) from the United States of America. Participants were mostly Caucasian (90.5%; n = 739), with a range of other ethnicities, such as South Asian (1.5%, n = 12); Hispanic (1.3%; n = 11) and Aboriginal Australians (.7%; n = 6) represented within the sample. There were 13 (1.6%) participants who stated that they were from multiple ethnicities. Over 24% (n = 198) of participants held a bachelor's degree, 17.3% (n = 141)

Table 2
Demographic characteristics of participants.

	N	%
Residing Country		
Australia	359	43.9
United States of America	294	36.0
United Kingdom of Great Britain and Northern Ireland	73	9
New Zealand	50	6.1
Canada	25	3.1
Ireland	7	.9
*Other	7	.9
Ethnicity		
Caucasian	739	90.5
South Asian	12	1.5
Latin American	11	1.3
Aboriginal Australian	7	.8
Maori	5	.6
East Asian	4	.5
Caribbean	3	.4
African	2	.2
African American	2	.2
Native American	1	.1
Multiple ethnicities	13	1.6
Did not identify	13	1.6
Other	5	.6
Education level		
Some high school	49	6.0
Graduated from high school	141	17.3
GED (General Education Development)	10	1.2
Non-University trade certificate/degree	121	14.8
Associates degree	41	5.0
Bachelor's degree	198	24.3
Bachelor's degree (Honours)	44	5.4
Graduate certificate	23	2.8
Graduate diploma	50	6.1
Masters	113	13.9
Doctorate	25	3.1

graduated from high school, and a further 13.8% (n = 113) had obtained at least a master's degree. Refer to Table 2, for further details of the participant's demographic characteristics.

Over 79% (n = 648) of participants were married, 11.7% (n = 96) identified as being in a defacto/common law marriage and 7.2% (n = 59) were single. At the time of completing the survey, 14.6% (n = 119) participants identified as being pregnant. There were 376 (46.1%) participants who had a living child before their stillbirth. Details on the participant's stillbirth history can be seen in Table 3. There were 46 (5.6%) participants who had multiple stillbirths, 32 (3.6%) participants had two stillbirths, six (.7%) participants had three stillbirths, and one participant had four stillbirths.

3.2. Quantitative data findings

Approximately one-third of the sample 38.3% (n = 313) directly reported feeling stigmatised following their stillbirth. Almost all bereaved parents endorsed the feeling that silence surrounding

Table 1
Open-ended questions within SurveyMonkey®.

Questions	N = 817
Do you feel since the stillbirth of your baby that you have been stigmatised? Please elaborate.	219
Do you feel that there is a silence surrounding stillbirth? Please elaborate	428
Have you noticed since your stillbirth that you are perceived differently by others? Please provide examples.	263
What is it like to be a mother or father to your stillborn baby?	611
Are you able to talk about your stillborn baby with friends and family?	337
How have comments from others about your stillbirth made you feel?	576
How has your stillbirth affected your ability to interact with others?	600
How has this experience affected your relationship with others (Friends/family/workplace/partner)?	584

Table 3
Stillbirth history of participants.

	1st stillbirth	2nd stillbirth	3rd stillbirth	4th stillbirth
N = participants	816	39	6	1
Year of participants last stillbirth				
2018	112	2	–	–
2017	185	7	1	–
2016	88	3	–	–
2015	88	8	–	–
2014	54	–	–	–
2009–2013	143	9	1	–
2000–2008	82	6	2	–
1970–1999	65	4	2	1
Gestation				
20–24	129	23	4	1
25–28	94	6	1	–
29–36	233	4	1	–
37–40	184	1	–	–
40+	100	–	–	–
Missing	77	–	–	–

stillbirth existed, (96.1%; n = 785). However, most bereaved parents felt able to speak to their family and friends about their stillborn baby (85.9%; n = 702). Furthermore, 57.5% (n = 470) stated that after their stillbirth they were perceived differently by others (Table 4).

3.3. Qualitative results

After analysing the open-ended responses thematically, six themes were discovered. The original intention was not to organise the themes within Link and Phelan²³ stigma theory, however, once analysed the responses matched well within this theory, especially, the stigma domains: Labelling, stereotyping, separation, status loss and discrimination, and power. One more theme outside of these known stigma domains was also found namely- bereaved parents as agents of change. As described within Link and Phelan,²³ these domains are inter-related, as is the nature of stigma. Therefore, some of these responses could have fit within many of the themes.

3.3.1. Labelling

It is within human nature to recognise differences between individuals using labels; however, generally, these differences have minimal effect on lives.²³ Labelling tends to be an oversimplification, such as 'black,' 'white,' and fails to recognise the broad spectrum of distinguishing characteristics.²³ However, when that label carries social significance or falls between the clearly defined label negative consequences, such as social isolation and social awkwardness can occur.³⁶ Furthermore, labelling can create stereotypes.²³ The label 'mother' is a socially important and clearly defined role, usually characterised with the presence of the child. However, after stillbirth, this label is no longer clear-cut. For first time mothers within this study, they experienced a limbo of starting a transition to motherhood, but it is abruptly cut short.

Table 4
Closed-ended questions within the survey.

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 38.3%	477 58.4%	27 3.3%
Do you feel that there is a silence surrounding stillbirth?	816	785 96.1%	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%

Those with children before their loss may already have held the 'mother' label, however, still experienced awkwardness when discussing their motherhood in the context of their stillborn baby. Furthermore, they also may gain a 'bereaved mother' label which could either elicit negative or positive social interactions. Within this study, the label of 'mother' did not resonate with participants for three reasons listed below with exemplar quotes:

- 1) Bereaved parents did not feel like a mother: "I am a failure to be around. Mothers who lose children are not mothers at all. The child does not exist."
- 2) Individuals surrounding the bereaved parents told them that they were not a mother: "They say you are not a mother because you do not have physical children."
- 3) Bereaved parents felt awkward/uncertain about answering the question "how many children do you have?":

"When people ask the question 'How many kids do you have? The fast-paced thoughts of 'do I say I have six children or five? Or should I say that I have five living one in heaven? Should I just lie completely and say I have five and quickly change the subject! It's alot to try and figure out if the person who has asked the question is ready for the REAL answer!'"

Bereaved fathers may also feel that their fatherhood identity is questioned, one bereaved father stated:

"Some people do not think I am a father because my daughter is not alive!"

A loss of identity after stillbirth also occurred for some participants: "I feel when I talk to people that know I have lost a baby they see me as the girl whose baby was stillborn not the person in Accounts or worked for the company for ten years!" As this

participant suggested, after stillbirth they lost any other identity they may have previously held, and society solely labelled them as a 'bereaved parent,' and nothing else.

3.3.2. Stereotyping

Stereotyping can be a consequence of labelling²³ as mothers and fathers who no longer fit into a clearly defined label are subject to stereotypes. Mothers expressed many stereotypes within their responses; examples include being described as 'weak,' 'broken,' 'fragile.' However, two main stereotypes were discovered- the first, the mother must have done something wrong to cause her stillbirth. The second was that the bereaved mothers were somehow contagious after their stillbirth.

3.3.2.1. The bereaved mother must have done something 'wrong.' Participants commonly reported that their family, friends, colleagues and even strangers suggested that they must have done something wrong to cause the death of their baby.

"... I feel people assume I am to blame, or I did something wrong, that I'm too old or may have eaten something wrong or not slept on my side. I feel I have been branded as a failure and as a bad mother even before I got to experience motherhood."

"Most people do not understand stillbirth and think it only happens to people who use drugs/alcohol, etc. So many people assume that is what happened in my case. When in reality his cord was tangled. So, you feel as if people are judging you as though you did this to your child."

The mothers within this study often added how they did nothing wrong in their pregnancy and followed the rules such as maintaining a healthy lifestyle avoiding smoking, drinking or eating the wrong thing. This type of social management technique was probably used to protect their identity and try to establish that the cause of their stillbirth was not their fault and they were indeed a 'moral' mother¹⁴ who did not deserve this experience and should not be stereotyped. According to Spencer et al.³⁷ this behaviour could be due to the stereotype threat, which comes from a fear of being judged for their actions.

"... Another friend wrote a Facebook post sharing ways to prevent stillbirth, writing that she did not want it to happen to any of her friends! – Implying our daughters' death was something I could've prevented during my pregnancy. However, I'm a highly educated mother of two living boys, slept on my left side in every single pregnancy, was extremely vigilant re listeria/foods to avoid, etc. & we eventually determined our baby passed away during labour as a result of GBS-a case of medical negligence . . ."

3.3.2.2. Feelings of being 'contagious.'

The other stereotype discovered in the data was participant's responses which stated that they felt their family, friends, particularly those who were pregnant believed that stillbirth was contagious. According to Kurzban and Leary³⁸ having a "contagious" status allows for others to justify classifying the person (in this case, bereaved parents) as potentially dangerous and subsequently exclude them to protect 'non-contagious' members of society. One participant stated: "People who have not had a stillbirth act as if being my friend means one of their children will randomly die. Like I have a contagious disease." Participants also discussed the consequence of this stereotype, which often resulted in isolation:

"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 . . ."

3.3.3. Separation

Separation allows for the societal perpetuation of the 'us' vs. 'them' mentality.²³ In which, distinguishing attributes, characteristics have been identified and subsequently labelled then stereotyped. From an evolutionary perspective, this can be understood as a means of protecting the community, by isolating those who were perceived as different (them) from those who are normal (us) from the threat.³⁸ Subsequently, the stigmatised tend to separate from their social community when they have either felt devalued and disrespected or anticipate that they will. Being blamed or shunned due to their experiences are common elements of separation³⁶ although bereaved parents did mention examples where they were supported, included and assured that they were not to blame for the death of their baby. The more common experiences discovered in the data were largely negative where the bereaved mothers and fathers were socially isolated either consciously or unconsciously by either friends, family or strangers.

3.3.3.1. Isolation. Bereaved parents indicated they isolated themselves, this was due to various reasons, such as avoiding 'awkward' encounters, not having enough energy to participate in social situations or being worried about reactions from others.

"It took me over two years to invite anyone to our house again. I went from entertainer extraordinaire to recluse and not answering the front door. This was even the way after returning to work and being 'ok' out and about. The day to day just drained me, just holding it together in public took it out of me. I needed my space to feel secure and gain the energy for 'tomorrow.' I doubt anyone in my circle even realised this except my husband. I think he was a bit the same."

"I have lost lots of confidence. I am fairly shy in larger groups, and that has increased now. I feel like no one wants to hear about my daughter I see the way they look at me with pity. I am generally retreating into myself more and more. Currently, I'm unsure if this is me becoming depressed or if it is just a fact that this life-changing experience is putting a barrier between me and the world, I once felt I had a place in."

Isolation was not always self-imposed, with many bereaved parents purposely excluded from events, and who wrote they had friends no longer talk to them after their stillbirth.

"Perhaps stigmatised is too strong of a word, but I do not think so. People have avoided me and excluded me while others have reached out in ways that they never had before. Generally, it feels like people are simply ignorant and insensitive rather than malicious. However, there is absolutely a feeling or removal from society, from events, and of being in too much pain to have around."

Participants felt that because their 'label' as mothers was ambiguous, they were then excluded from events primarily focused on mothers interacting, as stated by one participant: "Anything having to do with mothers, I am excluded from, not even thought of. I am seen as a delicate with all things related to babies or children . . . sometimes excluded entirely from hanging out with friends who have children."

Participants within this survey understood that it was uncomfortable to bring up their child:

"I know when I bring up my baby, people around me are sad. Feeling sad is uncomfortable, being depressed is uncomfortable, my baby dying is uncomfortable. It is easier for people to pretend these uncomfortable and terrible things do not exist. It is scary to face that we live in a world where tragic things happen. Many will choose to ignore it to protect themselves, and the result is that those of us that experience it ends up feeling very alone."

Subsequently, the bereaved parents isolated themselves as they felt that their experience would scare others: "I do this (isolate)

myself. I avoid pregnant people as I do not want to scare them. I do not want people to see how it broke our family. We represent people's worst fear their child dying for no reason, with no warning."

3.3.3.2. Blame. Blame can also be a powerful source of social separation.³⁶ The extent to which the attribute is deemed as deliberate can determine the extent of the social distance. Many participants said they experienced being blamed by others. One example of blame, was others questioning the bereaved parent about how they did not notice that there was a change in movement, as one participant stated: "People always ask, 'didn't you feel the baby not moving?' 'and always makes me feel like it was my fault like I should have known and feel so shamed and blamed.'" Other participants endured blame from their familiar relationships, which caused social distance and marital difficulties with their partner.

"Friends- some went some came. The husband became distant- then after the birth of rainbow I have twins prematurely- he left me and physically assaulted me. However, in truth losing [name] was the beginning of the end of our marriage. He has blamed me and called me a murderer in front of his other children and to his friends."

"My mother-in-law went out of her way several times in the year after my stillbirth to say, "I just don't know why she had to eat those turkey sandwiches' either to me, within my earshot, or to my mother. Even though my daughter died of a likely cord accident and there was zero evidence of Listeria, this made me feel like she felt it was my fault, which only magnified the feelings of failure and self-blame I was already struggling with!"

3.3.3.3. Shame. Feelings of shame were also common with bereaved parents, which some felt was exacerbated with the silence they felt surrounding the topic of stillbirth, as one participant stated: "No one talks about it until it happens to you. I have heard so many stories from family and friends since my daughter was stillborn. People are not talking about stillbirth just adds to the shameful feelings." Other, bereaved mothers indicated that they felt ashamed that their body failed them and did not meet up to the expectation of bringing home a baby: "Not from 'outside sources.' I feel shame from the inside . . . that my body could not do what it should have, produce live babies . . ."

Bereaved parents also felt shame when people thought they have been grieving too long, one participant stated: "It has been two years since my baby died. Whenever I try and talk about her, I get accused of being stuck and not moving on. People make me feel ashamed that I'm still struggling with her death."

3.3.3.4. Concealment of stillbirth. Concealing is a social management tool used to protect one's status in society to avoid being stereotyped and subsequently separated from their community.³⁹ It was once thought that being able to conceal a stigmatised identity meant less adverse outcomes, such as experiencing prejudice and discriminations.^{39,40} However, research now suggests that having to hide your stigma adds to stressors and impact a stigmatised individual's sense of belonging and increase social rejection.⁴⁰ Participants stated how they often had to decide whether to conceal if they were a bereaved parent "It is hard when people see me out with my kids and ask: 'how many do you have now.' I always ask myself 'do I want to tell people the whole truth or part of the truth.' Most people are very kind when I tell them about my daughter, but there is always the uncomfortable feeling that settles over the conversation."

However, this concealment sometimes elicited further guilt as it made them feel like they denied their stillborn baby, a participant stated: ". . . I have to decide if I want to correct a

wrong assumption and tell the world about the son I lost or if I would like to feel the internal guilt for letting incorrect assumptions slide." Furthermore, concealing also meant that some participants lived in fear of being found out: "You fear as though you are carrying a secret around. Except you do not want our child whom you love to be a secret." Concealing and living in fear meant social ramifications for bereaved parents, with many stating that is affected their ability to interact with others, for example: "I am at times scared to make contact with others and hide if I do not think they are aware of my loss."

3.3.4. Status loss and discrimination

The consequences of negative labelling and stereotyping are potentially discrediting the individual status within their social hierarchy, which ultimately could mean that bereaved parents face discrimination.²³

3.3.4.1. Status loss for the baby and the parent occurred after stillbirth. Responses suggested that participants lost their status as a mother on an individual level: ". . . I am less than them because I could not keep my baby alive . . ." There were multiple quotes by participants who expressed that their baby was not recognised as a person by others or their baby's loss was often minimised with the medical terminology they used to describe the baby, for example: ". . . Referring to my baby as 'stillborn' rather than my daughter is painful. She is not what happened to her; she is my baby girl." The word 'fetus' was also used with members of the bereaved parent's community, as seen in the following quote: "he was referred to as 'just a fetus' despite being four days off full term." Unfortunately, bereaved parents and stillborn babies were also subjected to crueler terms, as seen in the following quote: "I have had my son referred to as the unfortunate incident by an obstetrician at a teaching hospital . . ." By using words such as 'stillborn' or 'fetus,' this subsequently reduces the status of the baby within society.

Participants also reported that their status as parents was not acknowledged by their respective government, as seen in the following quote: ". . . Medical and legislative support recognising the stillborn baby as a baby that existed, and the parents as actual parents is virtually non-existent in America." When a baby's status is not recognised legislative, this meant parents are not able to, "file taxes, I cannot claim my daughter even once as I am told she was never born alive therefore she does not qualify as a child. This implies that I am not a mother."

3.3.4.2. Discrimination of bereaved parents. Discrimination can occur at an individual or structural level, in which opportunities are not available or been removed due to a stigmatised identity.²³ Bereaved parents suggested they were discriminated in two scenarios- by health care providers after their stillbirth, and from their workplace.

Bereaved parents felt that health care professionals treated them differently after their stillbirth, as one participant stated: "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."

Participants also experienced discrimination when returning to work with several bereaved parents either being fired or redundant, for example: "Lost my permanent job! Was made to forgo my five years unpaid parental leave. Either resign or return to work full time. I was physically unable to return, so I was forced to resign." Furthermore, some participants were made to feel like they were not coping in their role due to their loss, as seen in the following quote: "My work position was altered after my stillbirth as my employer felt I was not coping. I was no longer allowed to work alone."

3.3.5. Power

A power imbalance is described as an essential component of stigma.^{23, 24} Conscious awareness of power imbalances generally occurs but is often dismissed as it can be subtle.^{23, 24} However, if a stigmatised group does not have the social, economic, or political power to challenge the labels, and stereotypes associated with their group, then there is a power imbalance.^{23,24} Furthermore, those who can stigmatise have the power to control access to resources which could inform the community about the issue. In the experience of stillbirth, mothers stated that they were not informed about the possibility of stillbirth occurring by their health care provider. By not informing pregnant women about stillbirth during their antenatal care, this creates a power imbalance, in which the health care provider is using their power to consciously or unconsciously withhold information. However, the consequences of health care providers not informing pregnant women about the possibility of stillbirth, meant that the bereaved parent felt it was not an acceptable topic to discuss within their respective communities, subsequently, silencing them further.

“Definitely! Never heard about stillbirth until it happened to me! Then to find out six babies are stillborn [every day] and it is a very common occurrence not only here in Australia but all over the world . . . This needs to be a widespread topic that is mentioned on the very first visit for a pregnancy. I would have preferred to have readily available information and having a little fear in me and knowing about the warning signs and maybe just maybe many parents wouldn't have to walk from a birthing suite empty arms, heart aching, and having to prepare a funeral for their baby . . . when the information is there but not being shared I think that is a let down from the government for bereaved parents alone.”

“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 sights (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 because it is never talked about.”

3.3.6. Bereaved parents as Agents of Change

One of the key criticisms within stigma research is the perpetuation that stigmatised groups are helpless victims.²³ Despite the multitude of challenges that bereaved parents endured within their experiences of stillbirth in the hospital and within their community, there were also numerous responses of advocacy, hope, and love. These responses show that despite facing a stigmatising environment, they are actively resisting the negative labels, stereotypes and power imbalance.

One of the greatest assets to the bereaved parent were others who had experienced a stillbirth. This support provided them with comfort in knowing that they were not alone and were accepted.

“Doctors do not even tell patients that stillbirth can even happen. When I found out that there was no heartbeat, I felt like I was transported to Victorian times and felt so alone. That is don't happen and only happen to me. I was then welcomed into the undergrounds world of other loss parents. The only people that allow me to speak my daughter's name without fear and judgment.”

Some mothers found that by themselves being open about their stillbirth, it empowered other bereaved parents to open up, essentially breaking the silence, for example:

“Only after my loss did, I realise I was surrounded in my community by old and young mothers who had experienced stillbirth, and you can see that pain is still there 50 years later, but I only found out after I was so public with my own sons' death.

Discussing their stillbirth, some participants felt they had allowed others who had never divulged able to start grieving for their stillbirth: *“...When I open up, it gives others permission to share their pain, and that is when the healing begins.”* Furthermore, when women divulged their experience, they felt it helped challenged the taboo surrounding stillbirth: *“Before I even had a stillbirth myself, it was like a dirty word for me. So, I understand. But I try to change that in other people by being so open about my son.”*

“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.

Some mothers have used this opportunity to advocate for further funding to reduce stillbirth rates.

“...When we announced that we had lost our first-born daughter to family and friends. There was an overwhelming response of love, support, and condolences not just here in Australia but all of our friends around the world. To demonstrate this, we raised 4k+ for stillbirth foundation Australia in the month we lost her.”

4. Discussion

The current study has found evidence that bereaved parents who have endured a stillbirth, experience stigma. The current study is the first to quantify and describe the extent of stillbirth stigma and silence amongst bereaved parents, based on self-perception of stigma, 38% of bereaved parents felt that they have directly been stigmatised due to their stillbirth, and 96.1% felt that there was a broader silence surrounding stillbirth. The results suggest that bereaved parents experience all the dimensions of stigma as suggested by Link and Phelan,²³ labelling, stereotyping, separation, status loss, and discrimination and power. Another theme was also found within this study; bereaved parents as “agents of change.”

The current research supports the numerous studies which have explored the experiences of the bereaved parent.^{4,41} Common experiences found within the literature have been feelings of blame, shame, isolation⁴¹ and questioning of motherhood.⁷ However, this is one of the few studies which has applied these experiences under a previously described stigma framework.²³ Research which has addressed stillbirth stigma have often relied on Goffman's²¹ work.^{7,14} Although useful in understanding stigma, Goffman's work has been criticised for following a micro-level approach, essentially placing the onus on the stigmatised.²³ It also fails to recognise the structural societal issues that could be creating a stigma for a population.²³ Therefore, structural discrimination, i.e., baby not receiving a birth certificate, from bereaved parents has not been thoroughly explored within the context of stigma. By drawing these experiences under the stigma framework, it has created a knowledge base where the focus is not just on the micro level interactions of the bereaved parent and inter-personal interactions but allows for an exploration into the macro level interactions, such as government policies, care provider practices and access to information about stillbirth.

Furthermore it recognises that bereaved parents could also be suffering from discrimination. The current study highlighted that bereaved parents could be enduring workplace discrimination.

Notably, mothers losing employment, or being deemed as unfit to continue within their current position. With this knowledge, the call to action to reduce stigma can finally be addressed, and stigma-reduction interventions can start to be developed.

Link and Phelan²³ proposed that for the stigma to occur, there must be a power imbalance between the stigmatised, and the stigmatisers. In the current study, the stillbirth experiences of bereaved parents were captured from those living in high-income countries. The component of power may not be as visual within this setting; however, the experiences suggest that even though in some cases resources were there, bereaved parents struggled to access them, and within their antenatal care, information about stillbirth prevention during pregnancy may have been withheld by their care provider. The power imbalance between those who have experienced a stillbirth and are already marginalised or reside in low-income countries is more apparent.¹ The rates of stillbirth are significantly higher in low-income countries,¹ marginalised populations⁸ or those with lower educational levels.⁸ Pregnant women in these settings often do not have access to the resources to be able to challenge the stigmatisers effectively which subsequently makes their status within society further devalued and precarious.^{10,12} Understanding the power imbalances associated with stillbirth and even the information and resources which pregnant women receive in their antenatal care is imperative. As Link and Phelan²³ believe that by understanding the power imbalance within the relationship between the stigmatised and stigmatiser than more targeted stigma reduction interventions can be created.

One further theme was discovered within the current study, bereaved parents as agents of change. Bereaved parents became advocates and challenged the system that was stigmatising them. The current study found bereaved parents using their experiences to challenge the silence surrounding stillbirth by talking about their baby, even when knowing that it would make others uncomfortable. By talking about their baby, it permitted other bereaved parents to share their experiences. Some bereaved mothers shared that they had changed careers and became counsellors to help others who had experienced a stillbirth. Advocacy and empowerment after stillbirth are not well-researched, with the dominant narrative within the research mostly negative and focusing on the negative impact on the bereaved parent. Murphy's¹⁴ interviews with bereaved mothers and fathers highlighted that bereaved parents could be empowered and move into the role of advocate to create change within their community and health care system and the current study also supports this. Stigma theory has long been criticised for its continual victimisation of people who are already being stigmatised.²³ However, this theme reminds both researchers, governments, policy-makers and the communities that bereaved parents are strong, resilient and they can fight against stigma.

Furthermore, this theme shows that bereaved parents can resist more powerful forces of stigmatisation that might attempt to devalue and stereotype them. Link and Phelan's²³ original definition was that when labelling, stereotyping, separation, status loss, and discrimination co-occur with the presence of a power imbalance, stigma occurs. A bereaved parent does not need to be an agent of change to be stigmatised; it was more a response that many made to what was commonly described as a stigmatising environment. Within grey literature, and even within this study, many bereaved parents indicated that they did have support, either from friends, or family, just maybe not both. Some bereaved parents can look around their community and see many friends who are supporting them and advocating for change without having had experienced a stillbirth. So, therefore, one could argue that being an agent of change is not part of the Link and Phelan²³ stigma theory but acts as a necessary reminder to avoid further disenfranchisement of a community already being stigmatised.

4.1. The health care provider, bereaved parents, and stigma

Inadvertently, health care providers could be a source of stigma for a bereaved parent by perpetuating the silence of stillbirth. The current study found evidence that bereaved parents were not informed about the possibility of stillbirth in their antenatal care, and subsequently, this exacerbated the feeling of silence and blame. Warland and Glover's⁴² intervention study of 109 midwives suggest that health care providers are anxious about discussing stillbirth with pregnant women. Whether this anxiety, is caused by the stigma of stillbirth is yet to be researched. However, what is currently known suggests that stigma is not just impacting the bereaved parent, but how health care professionals talk with pregnant women and/or how they disseminate and distribute stillbirth awareness resources.

Furthermore, Frøen et al.¹⁹ international study of 2490 health care providers found concerning perceptions regarding the mother and baby; 20% of their respondents believed that she failed as a mother; 29% believed the stillbirth was her fault or due to her sins. Furthermore, 25% of health care providers within the survey responded 'always' that the baby is seen as a taboo object by 25% of health care professionals. These concerning perceptions are all symptoms of stigma and mirror the current study's stereotype experience from the bereaved parent.¹⁹ However, further research regarding whether health care professionals are a source of stigma for the bereaved parent, and the implications of this needs to be conducted. Nevertheless, in other areas of stigma research, when the health care provider is a source of stigma, it becomes a barrier for help-seeking for the stigmatised.⁴³

4.2. Clinical implications

Clinical implications of this study cannot yet be drawn as there is a need for further evidence. However, bereaved parents felt that pregnant women, in particular, should be informed about the possibility of stillbirth. As found within the current study, the silence from health care providers during their antenatal care could have possibly exacerbated feelings of silence and blame after their stillbirth. Bereaved parents felt shocked that they were not informed about the possibility of stillbirth. Therefore, health care providers need to take an active role in educating pregnant women about the possibility of stillbirth, alongside tools (fetal movement, sleeping on your side education and trusting your intuition) which empower pregnant women to act if they have concerns. Research could now shift towards how health care providers can best inform pregnant women about stillbirth within their antenatal care.

4.3. Strengths and limitations

A strength of the survey methodology was that it provided an opportunity for a larger number of bereaved parents to give voice to their experiences, and the relatively private nature of the instrument may also have increased comfort and participation. The limitation of this approach is that there was less opportunity to capture the depth and complexity of stillbirth stigma. Future research would benefit from exploring this through alternate methodologies such as in-depth interviews or focus groups.

To allow for an inclusive survey, which respected the experiences of all bereaved parents, there was no limitation on how long ago the stillbirth occurred. Subsequently, there were 65 participants who had experienced their stillbirth over 20 years ago and could be subjected to recall bias.

DP attempted to contact many bereaved parent organisations which solely support bereaved fathers, however, the current study has not been able to capture the bereaved fathers' voices. Furthermore, despite the wide recruiting strategy, most of the

bereaved parents identified as Caucasian. Therefore, we have not captured the voice of the culturally and linguistically diverse (CALD) population,⁴⁴ who have higher rates of stillbirth and therefore are in the most need of having their voice heard. Furthermore, due to the time limitations associated with a Ph.D. study, low-income countries, who have the majority of these stillbirths¹ were not included in the recruitment strategy, and therefore no responses were recorded from these countries. As the current study has not captured these experiences, these results might not be generalisable to these groups.

4.3.1. Further research

This study attempted to capture the stigma experiences of bereaved fathers, however, despite targeted recruitment strategies specifically targeting father organisations and due to time limitations associated with a Ph.D., recruitment was limited, and only 17 bereaved fathers were included within this study. Further research needs to be undertaken exploring the bereaved father's stigma experience. As the team working on this study were all women, there was no access to the specific bereaved father's support pages, and often, requests asking to advertise were not answered. Therefore, specific strategies aiming to involve more fathers within research should be developed. However, this can only be achieved by including bereaved father organisations, or, utilising a bereaved father 'spokesperson' to advocate for the promotion of research within these organisations.

Within stigma research, the voice of both the stigmatised and the stigmatiser (general population and health care providers) should be heard, in order to understand the complexity of the issue. Frøen et al.¹⁹ has provided some insight into the perceptions of stillbirth by health care providers and the bereaved parent. However, this was not presented under a stigma framework. Research on the perceptions of stillbirth should also be extended to the general population to create a well-developed understanding of stigma to help in the creation of an evidence-based stigma reduction intervention.

5. Conclusion

Our findings suggest that the bereaved parents of stillborn children endure stigma. Bereaved mothers face negative labelling, which contributes to stereotyping. Bereaved mothers were made to feel like they were not a 'real' mother. Two stereotypes emerged from this study- mothers must have done something wrong to cause their stillbirth, and subsequently deemed contagious. Consequences of these labels and stereotypes for the bereaved parents were a sense of separation through feelings of shame, blame, and isolation. Furthermore, bereaved parents faced discrimination, particularly in their workplace with many mothers losing employment. The current study also found that health care providers could be a potential source of stillbirth stigma by restricting the dissemination and distribution of resources. However, the current study also serves to remind the community, that despite the plethora of negative consequences of stillbirth stigma, bereaved parents became agents of change, were proud of their babies and felt a need to advocate and share their stories with others. The current study has provided insight into stigma experiences of the bereaved parents. However, stillbirth stigma remains a complex topic, with no easy solution or understanding and requires more attention in order to produce a stigma reduction intervention to alleviate the suffering bereaved parents endure after stillbirth.

Author Contributions

Danielle Pollock: Conceptualisation, data collection and analysis, writing of the original paper and editing. Jane Warland:

Supervision of Danielle, conceptualisation of the survey, data analysis and editing. Tahereh Ziaian, Megan Cooper and Elissa Pearson: Supervision of Danielle, reviewing of the themes and editing. Claire Foord provided end-user support through consultation in the conceptualisation of the survey, recruitment of participants and editing of the final draft.

Conflicts of interest

None declared.

Ethical statement

The authors declare that the research presented in the manuscript was approved by the University of South Australia's Human Research Ethics Committee on the 5/12/2016. Protocol number 0000036017.

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