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Breaking the silence: Determining Prevalence and Understanding Stillbirth Stigma ☆,☆☆,★,★★,†

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ABSTRACT

Background: The 2011 and 2016 Stillbirth Lancet series made a call to action to identify mechanisms to reduce stillbirth stigma. This research answers that call, investigating the extent and dimensions of stillbirth stigma experienced by an international sample of mothers bereaved by stillbirth.

Objective: To determine the prevalence and type as well as explore explanatory variables associated with higher levels of stillbirth stigma with bereaved mothers in high-income countries (Australia, United Kingdom, The United States of America and New Zealand).

Method: An international survey of 889 bereaved mothers was conducted utilising the recently developed Stillbirth Stigma Scale to explore the extent and types of stigma experienced, as well as the association between stigma and self-esteem (Rosenberg Self- Esteem Scales), perinatal grief (Perinatal Grief Scale), and perceived social support (Perceived Social Support Scale). Demographic information (e.g. age, education, stillbirth history, sexual orientation and mental health) were collected to determine the association between individual demographic factors and stillbirth stigma.

Results: Results of the Stillbirth Stigma Scale indicated that a majority (54%) of bereaved mothers experienced stigma. Self-stigma was the predominant type of stigma experienced (80%), followed by perceived devaluation (64.9%). Bereaved mothers also experienced discrimination (29.1%) and issues with disclosing their stillbirth to their community (36.7%). Stillbirth stigma scores were higher in bereaved mothers who had experienced the loss of their first child. High scores were associated with the mother's mental health status (diagnoses prior to stillbirth, and/or after stillbirth ($p<.05$)).The other scales used indicated that higher stillbirth stigma scores were also associated with lower self-esteem ($r(877) = -.304$, $p<.001$), lower perceived social support ($r(871) = -.448$, $p<.001$) and higher levels of grief ($r(829) = .609$, $p<.001$).

Conclusion: The current research was the first to identify that 54% of bereaved mothers experienced stigma, with self-stigma being the most prominent. Bereaved mothers endured discriminating experiences and had trouble disclosing their stillbirth to others within their community. The first-time mother with a self- reported history of mental illnesses appears to be the most at-risk of higher levels of stigma. Future longitudinal research needs to

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be conducted to determine the direction of the explanatory variables i.e. mental health, self-esteem and social support and develop interventions, which support the bereaved mother and reduce stillbirth stigma.

Relevance: This study is the first to demonstrate the prevalence, extent, type and explanatory variables of stigma reported by bereaved mothers and the association between this and poorer outcomes including increased grief and decreased self-esteem. This study begins a dialogue about prevalence and explanatory variables of stillbirth stigma and its impact, to inform future prevention and support potential stigma reduction programs for community and bereaved mothers.

Introduction

Every year there are 2.6 million stillbirths (death of a baby in-utero after 28 weeks) (Blencowe et al, 2016), however, this definition varies between countries (20- 28 weeks gestation) (Blencowe et al, 2016). Bereaved parents experience high rates of depression, anxiety and Post Traumatic Stress Disorder (PTSD) (Heazell et al, 2016). These psychological sequalae are often exacerbated by feelings of shame, blame and frequently, reports of silence surrounding stillbirth (Burden et al, 2016). Furthermore, bereaved parents often report feeling silenced and stigmatised due to experiencing a stillbirth (Burden et al, 2016).

Stigma remains a complex social process (Mannarini and Rossi, 2019; Pescosolido and Martin, 2015). Goffman (1968) defines stigma as the devaluation of an individual's worthiness within society. Link and Phelan (2001), built upon the definition developed by Goffman (1968) and add that stigma is the convergence of labelling, stereotyping, separation, discrimination and status loss. Furthermore, several types of stigma have been identified in the literature (Sheehan, Nieweglowski and Corrigan, 2016). These types include self-stigma which is the internalization of the stereotypes and prejudice an individual experiences (Sheehan, Nieweglowski and Corrigan, 2016) and perceived devaluation stigma which aims to understand what the stigmatised perceive others to believe (Link, Yang, Phelan and Collins, 2004).

A plethora of negative consequences of stigma has been identified in other areas such as mental health and HIV/Aids. Research in these fields often report individuals experiencing poorer access to quality health care, isolation, low self-esteem, and lower levels of perceived social support compared with non-stigmatised individuals (Corrigan, Druss and Perlick, 2014; Corrigan and Kleinlein, 2005; Link et al, 2001; Schomerus et al, 2018; Smith, Rossetto and Peterson, 2008). These consequences could be more felt by those that live with multiple stigmatising identities such as mental health and a disability (Sheehan, Nieweglowski and Corrigan, 2016). There is little evidence discussing stillbirth and stigma together (Pollock et al., 2020)

However, despite this little evidence in peer-review literature, the Lancet Stillbirth series in 2011 and in 2016 called for an examination of the mechanisms that lead to stillbirth stigma, with the view to instigating strategies to minimise the experience of stigma related to stillbirth. This repeated call has remained largely unanswered. Studies, which have explored stigma, mostly by employing qualitative approaches, have identified some of the likely emotional, psychological and social consequences of stillbirth stigma for the bereaved mother (Pollock et al., 2020). Bereaved mothers experience of stigma includes being discriminated by their workplace and health care provider. Furthermore, they experienced being stereotyped as 'weak,' 'broken' and 'fragile.' Self-blame and blaming by others was prominent in the literature (Pollock et al., 2020). Bereaved mothers reported feeling that they were too blame for their baby's death or were told directly by others that they were. Their identity as a mother were questioned by others and by themselves, as their baby was not physically with them. The experience and impact of stigma has been qualitatively explored, however to date there has been no quantitative tools allowing for assessment of the extent of experiences of stigma amongst bereaved mothers or evaluation of how stillbirth stigma experiences may relate to other extensively explored in other fields of stigma research such as self-esteem and perceived social support.

Determining the prevalence of stillbirth stigma is an important first step in understanding the scope of the issue. Only one study has taken a quantitative approach to "measuring" stigma (Pollock et al., 2020). This was an international survey of 817 bereaved parents, which reported that 38.3% (n=313) answered yes to the question: 'Do you feel since the stillbirth of your baby that you have been stigmatised?' This single dichotomous (yes/no) question was the first to identify the possibility of stigmatisation in a population of bereaved parents (Pollock et al., 2020).

Recently we developed the SSS to measure the extent and type of stillbirth stigma among bereaved parents (Pollock et al., 2019, 2020). In the current paper we demonstrate the utility of the scale, alongside other psychometric scales (Perinatal Grief Scale (PGS) (Toedter et al., 1988, 2001), Perceived Social Support Scale (PSSS) (Zimet et al., 1990) and the Rosenberg Self-esteem Scale (RSES) (Rosenberg, 1965). Furthermore, to identify the prevalence of stillbirth stigma, as well as its relationship between the extent of stigma experienced and other related constructs such as grief and self-esteem in an international sample of bereaved mothers. Therefore, the aims of the current study were:

(1) To identify the extent and types of stigma experienced by bereaved mothers;
(2) To determine norms for the SSS in order to identify those who may be considered at high-risk of experiencing stigma;
(3) To explore individual demographic factors associated with greater levels of self-reported stigma; and
(4) Examine the interrelationships between stillbirth stigma and grief, self-esteem, and perceived social support.

Methods

An online survey was hosted on surveymonkey.com from May to September 2018. The definition of stillbirth varies between the targeted countries identified for this survey. Therefore, it was decided that a broader and more inclusive definition would be utilised. Participants were invited to complete the survey if they had experienced a stillbirth (defined as 20 weeks gestation and /or 400g) and 18 years and over. An online snowball recruitment approach was adopted via organisations who provide stillbirth bereavement support, prevention and/or advocacy in America, Australia, New Zealand and the United Kingdom. The survey consisted of the following scales:

Stillbirth Stigma Scale (SSS)

The items in the SSS was developed from literature (Pollock et al., 2019, 2020), consultation with bereaved parents and Still Aware (an Australian stillbirth awareness and advocacy organisation), and adapting stigma scales from other fields. The SSS contains 20-items across four subscales - perceived devaluation (6 items), discrimination (7 items), self-stigma (4 items) and disclosure (3 items) and was created to measure the extent and dimensions of stillbirth stigma experienced by bereaved parents. Participants respond to each item on a 5-point Likert scale ranging from 1= strongly agree to 5 = strongly disagree, to questions such as: 'I blamed myself after my stillbirth' and 'Most people will avoid discussing your stillbirth or stillborn child.' Negatively worded items are reverse coded prior to analysis, yielding a total possible scale

score between 20-100, with higher scores indicating a higher level of stigma experienced. The scale underwent initial pilot testing with bereaved parents from Australia, and further validity and reliability analysis with an international population of bereaved parents. The Cronbach's α of the total scale was α= .89, indicating a good internal consistency. Reliability of the scale was assessed through the Pearson correlation of test-retest during the pilot stage and was deemed satisfactory (r=.90 for total scale). The individual sub-scales of the SSS had higher correlations to the total stillbirth stigma scale, rather than each other, indicating they are distinct but related aspects of stigma. The SSS was associated in the expected direction with self-esteem, indicating the scale had convergent validity (constructs associated in the expected way). These results indicate that the SSS has construct validity. For further information about the process of developing, and the reliability and validity of the SSS please see self-cite et al (2019) and self-cite et al (2020).

Perceived Social Support Scale

The PSSS contains 12 items and three sub-scales which identify the source of the social support - family, friends, and significant other (Zimet et al, 1990). In This scale has good internal consistency (α=.88) and consistency (r=.85) and has been successfully utilised with a wide variety of samples in subsequent research (Osman et al, 2013; Smith et al, 2008; Zimet et al, 1990).

Rosenberg Self-Esteem Scale

The RSES contains 10-items and measures global self-worth (Rosenberg, 1965). It has been consistently found to have good reliability (r=82 to r=.88) and internal consistency (α= .77 to α= .88) and has been applied to several different populations, for example, adolescents (Supple and Plunkett, 2011), older adults (Mullen, Gothe and McAuley, 2013) and those who live with a mental illness (Winter et al, 2018).

Perinatal Grief Scale

The PGS is a 33-item scale, with three sub-scales: active grief, difficulty coping and despair (Toedter, Lasker and Alhadeff, 1988). It has high internal consistency (α= .95), across diverse population diverse populations including miscarriage, stillbirths, and newborn loss (Toedter, Lasker and Janssen, 2001). This scale has been validated for all pregnancy loss and high-income countries (Lasker and Toedter, 2000; Toedter et al, 2001).

Research ethics

This study was approved on the 5/12/2016 by the (Removal of identifying information) Human Research Ethics Committee. Protocol number 0000036017.

Findings

Participants

There were 1318 participants who responded to the survey; however, 108 responses were removed because the participant did not meet the inclusion criteria (n=1 was not over 18; n=107 stated that their most recent stillbirth was a medical termination). A further n=195 participants did not sufficiently complete the SSS and n=106 did not fully complete the other psychometric scales used within the survey (PGS, PSSS and RSES) and therefore missing data were excluded from the analysis. Males were also invited to participate in this study; however, despite targeted recruitment efforts through bereaved father support pages, only 20 bereaved fathers completed the survey. Due to these low numbers, they were not included in the analysis. Therefore, responses from 889 bereaved mothers were analysed. Most were from Australia (n=389; 43.6%), and the United States of America (n=318; 35.7%), most identified as being Caucasian (n=804; 91.4%) and married (n=711; 80.9%). Participants were generally highly educated (n=501; 56.3% had a bachelor's degree or above). Further demographic information is provided in Table 1.

Table 1
Demographic information.

	n	%
Residing country		
Australia	389	43.6
United States of America	318	35.7
United Kingdom & Northern Ireland	83	9.3
New Zealand	56	6.3
Canada	26	2.9
Other	19	2.1
Ethnic Background		
European Caucasian	804	91.4
Mixed Ethnicity	15	1.7
South Asian	14	1.6
Latin American	13	1.5
Australian Aboriginal/Torres Strait Islander	8	.91
East Asian	5	.6
Maori	5	.6
Other	16	1.8
Education		
Some high school	56	6.3
Graduated from high school	162	18.2
Trade certificate	125	14.1
Associate Degree	44	4.9
Bachelor's degree	268	30.2
Post-graduate degree	233	26.2
Relationship status		
Married	711	80.9
Partnered	102	11.6
Single	65	7.4
Widowed	1	.1

Table 2
Perinatal demographics of participants.

	N	%
Are you currently pregnant?		
Yes	124	14.0
No	761	86.0
Prior children before stillbirth:		
Yes	409	46.2
No	477	53.8
Year of most recent stillbirth		
2016-2018	412	46.4
2010-2015	295	33.2
2000-2009	115	13.0
1990s	32	3.6
1980s	26	2.9
1970s	8	.9
Number of stillbirths		
1	845	95.1
2	38	4.3
3	5	.6
4	1	.1

The participant's obstetric history is outlined in Table 2. Most stillbirths had occurred within two years of taking the survey (2016-2018) (n= 412; 46.4%), however the earliest stillbirth occurred in 1970. There were 46.2% (n=409) who had a previous baby before their stillbirth. A further 14% (n= 124) were pregnant at the time of undertaking the survey.

Participants were also asked whether they identified as belonging to other minority groups which have previously been associated with stigma experiences, such as LGBTIQ+ or having a disability and/or mental health condition. Participants mostly identified as heterosexual

Table 3
Further demographics of participants.

	N	%
Sexual orientation		
Heterosexual	856	95.9
Homosexual	11	1.2
Bisexual	16	1.8
Prefer not to answer	8	.89
Do you identify as having a disability?		
Yes	23	2.6
No	860	96.7
Prefer not to answer	6	.7
Mental illnesses status (before stillbirth)		
Yes	222	25.0
No	654	73.6
Prefer not to answer	11	1.2
Mental illnesses status (after stillbirth)		
Yes	167	18.8
No	665	74.8
Prefer not to answer	17	1.9

(n=856; 95.9%) and were living without a disability (n=860; 96.7%). Participants mental health history was reported, by asking participants if they had a diagnosed mental illness prior to their stillbirth occurring (yes: n=222; 25%); and, if they were diagnosed with a mental illness after their stillbirth (yes: n=167; 18.8%). Further details can be seen in Table 3.

In order to identify the extent and types of stigma experienced by bereaved mothers, descriptive statistics were calculated for the sample on the Stigma Scale total and each of the four sub-scales (Table 4). The mean score on the SSS was 61.91 out of a possible score of 100 however, there was substantial individual variation. Consistent with methods employed by Ritsher and Phelan (2004) and Fadipe et al, (2018) for the internalised stigma of mental illness (ISMI), an item mean score was calculated by dividing the scale (or subscale) total by the number of items. An item mean score above the mid-point (defined as 3.01 or greater) was used to identify those experiencing stigma on each of the subscales and the overall scale. Using this methodology, 54.6% of the overall sample reported that they had experienced stigma, with Self-Stigma being the most prominent dimension of stigma (80.5%), followed by Perceived Devaluation (64.9%).

Item-level analysis of the individual items in the SSS *(refer to supplementary information 1)* found that 80.1% of bereaved parents agreed with the statement that most people would avoid discussing their stillbirth and stillborn child (Perceived Devaluation). Nearly half (45.2%) of bereaved mothers agreed that others held the belief that you were not a mother/father if you had experienced a stillbirth (Perceived Devaluation). Item level analysis of the Discrimination sub-scale revealed that bereaved mothers had experienced discrimination from family (39.7%), friends (32.3%) and health care professionals (16.7%). Bereaved mothers identified with having high levels of self-blame after their stillbirth (80%), and 54.5% agreed to the statement that they felt blemished for having had a stillbirth (Self- stigma). Furthermore, 57.2% of bereaved mothers agreed to the statement: 'I find it hard telling people I have had a stillbirth' (Disclosure).

To identify bereaved mothers who may be at greater risk of adverse outcomes (low self-esteem, higher levels of grief) due to high levels of stigma, norms were established for this sample and the relationship between total stigma scores based of the SSS and self-reported stigma responses was explored. As anticipated, scores on the SSS were associated with participant responses to the single-item question 'do you feel since the birth of your baby you have been stigmatised'? Those who self-identified as having experienced stigma via the single item, scored higher on the Self-Stigma Scale (M= 70.99, scale item mean = 3.54, SE= 0.64) than those who did not self-identify as having experienced stigma (M= 55.87, scale item mean= 2.79, SE= 0.55). This difference was statistically significant t (761)= 17.65, p<.001, and represents a large effect size (Cohen's d= 1.32). The top quartile within the sample had an item mean for the total SSS between 3.6-5. The 75th percentile for the subscales were Perceived Devaluation (4.00), Discrimination (3.14), Self-Stigma (4.50), and Disclosure (3.33).

Skewness and Kurtosis of the SSS was high 1.158 and SE=.081; kurtosis: -.226 and SE=.163 thus violating the assumption of normality. Therefore, in order to explore individual demographic factors associated with the outcome variable of greater levels of stigma, multiple regression analyses with bootstrapping (1000 samples) were utilised (Hancock and Liu, 2012). Education level was dummy coded (Chen, 2010) into high school, trade, undergraduate or post-graduate studies; country of residence as Australian (majority of sample) vs other; relationship status at the time of the stillbirth as single vs partner; and sexual orientation as heterosexual vs LGBTIQ+. Two mental health variables were included to represent a diagnosis prior to experiencing the stillbirth and a diagnosis following the stillbirth in comparison to no mental health condition. As the purposes of this regression was an exploratory analysis to determine potential demographic explanatory variables, all potential explanatory variables (demographics) were entered into the regression model.

The regression model was statistically significant F (14, 780) = 4.93, p<.001, with an adjusted R2= .066. Statistically significant explanatory variables included years since the last stillbirth (such that stillbirth stigma scores were higher for those who had more recently experienced their stillbirth); whether mothers had a living child prior to their stillbirth (having no living children was associated with higher stillbirth stigma scores); and mental health status (both having a self-reported mental health condition prior to the stillbirth and being diagnosed following the stillbirth were associated with higher stillbirth stigma scores). Sexual identity, age, education level, country of origin, and relationship status were not significantly related to stillbirth stigma (refer to Table 5).

A Pearson's correlation was utilised to determine the relationship between stillbirth stigma and other theoretically related constructs, including grief, self-esteem, and perceived social support. A significant relationship, with a large effect size, between stillbirth stigma and perinatal grief, r(829)=.609, p<.001, such that higher stillbirth stigma scores were associated with higher perinatal grief was found. A significant negative relationship with a moderate effect size between stillbirth stigma and self-esteem, r(877)=-.304, p<.001, such that higher stillbirth stigma scores were associated with lower self-esteem was also identified. There was also a significant negative relationship between stillbirth stigma and perceived social support (moderate-large effect size), such that higher stillbirth stigma scores were associated with lower perceived social support, r (871) =-.448, p<.001.

Table 4
Descriptive statistics for Stillbirth Stigma Scale and Sub-Scale Scores.

	N	Min	Max	Possible Range	Mean (SD)	Item mean	% with scores above scale mid-point
Total Stigma	879	20.00	99.00	20-100	61.91 (13.77)	3.10	54.6%
Perceived Devaluation	887		30.00	6-30	20.41 (5.19)	3.40	64.9%
Discrimination	887	7.00	35.00	7-35	17.61 (6.49)	2.51	29.1%
Self-Stigma	883	4.00	20.00	4-20	15.53 (3.58)	3.88	80.5%
Disclosure	889	3.00	15.00	3-15	8.39 (2.94)	2.80	36.7%

Table 5
Multiple regression model outputs for prediction of higher stigma levels in bereaved mothers.

Source	*B*	*SE B*	*95% CI Lower*	*95% CI Upper*
Constant	73.34	8.99		
Education Level High School vs Trade	-.61	1.41	-3.67	2.22
High School vs Undergrad	-.64	1.29	-3.22	1.96
High School vs Post Grad	1.28	1.63	-2.32	4.58
Mental Health				
Never vs previous	5.77	1.13	3.48	8.36
Never vs following	9.31	2.32	5.02	14.06
Age	.01	.10	-.19	.21
Country of residence (other vs Australia)	-.82	1.01	-2.97	1.18
Relationship status (single vs partner)	-1.52	1.86	-5.29	2.30
Sexual Orientation (heterosexual vs LGBTIQ)	-3.35	2.83	-9.29	2.58
Disability (yes vs no)	-6.22	3.09	-12.45	.04
Currently pregnant	.83	1.40	-1.76	3.38
Did you have any living children prior to stillbirth	2.20	0.99	.32	4.04
How many stillbirths?	2.11	1.89	-1.67	5.78
Years since last stillbirth	-.26	.10	-.46	-.07

Discussion

In this paper we answer the previous calls to action arising from the Stillbirth Lancet series to find mechanisms to reduce stigma by quantifying the prevalence of stigma experienced as well as identifying the distinct types of stigma (self-stigma, perceived devaluation, discrimination, disclosure) experienced by bereaved mothers. Furthermore, this paper found potential explanatory variables associated with higher stigma, such as being a first-time mother which could help identify bereaved mothers most 'at risk'.

Prevalence of stillbirth stigma

Over half (54%) of the bereaved mothers who participated in this study reported stigma due to their stillbirth. Self-stigma, which is the internalisation of the negative labels and stereotypes seen within the community, was the most prevalent dimension of stigma, with 80% of bereaved mothers reporting feelings of shame and blame. This is not surprising given the copious literature documenting examples of self-stigmatisation within bereaved parents after stillbirth (Brierley-Jones et al, 2015; Burden et al, 2016; Murphy, 2012; Self-cite et al, 2019a). However, prior to the SSS, these examples were qualitative, as there had been no tool, which could quantify this experience.

Evidence from other fields using stigma scales, have also reported self-stigma, although at lower levels. For example, research in mental illnesses reports 36% of sufferers report self- stigmatising experiences (West et al, 2011) and 23.9% in HIV/Aids patients (Radcliffe et al, 2015). The higher the extent of self-stigma reported in a bereaved mother population compared to these other areas could reflect the high value placed on motherhood in our society (Murphy, 2012). When a baby dies it directly violates two highly valued societal assumptions: The first, is that babies in HIC no longer die before they draw breath; and the second, the mother is somehow to blame because she should have kept her baby safe (Self-cite et al, 2019a). These findings suggest that many bereaved mothers internalise blame for their baby's death. While this assumption has been reported extensively within qualitative literature (Burden et al, 2016; Haws et al, 2010; Hazen, 2003; Kelley and Trinidad, 2012; Murphy, 2012; Murphy, 2013; St John, Cooke and Goopy, 2006) this paper is the first to confirm this using a psychometric scale. Further research can now explore protective influences and strategies to reduce self-stigma and mechanisms to ameliorate factors placing women at risk.

While Self-Stigma was the dimension most commonly reported among this sample, another concerning finding of this study was the prevalence of discrimination experienced by bereaved mothers. Almost one in three participants felt discriminated against because of their stillbirth. In the item-level descriptives (*included in the supplementary material*), bereaved mothers identified that they were discriminated by family (39.7%), friends (32.3%) and health care professionals (16.7%). This highlights that stillbirth stigma permeates macro (government) and micro (inter-personal relationships) levels. This is not dissimilar from other areas of stigma research, such as mental health (Corrigan, Markowitz and Watson, 2004; Holder et al, 2019). Health care providers may play a crucial role in reducing stillbirth stigma. A portion of our participants (16.7%) identified that their health care provider discriminated them based on their stillbirth. Experiences of discrimination by health care providers were previously reported in Self-cite et al, (2019a), in that bereaved mothers felt that their health concerns after stillbirth were dismissed due to 'stress from losing the baby.' As found in mental health stigma research, motivation to seek and access quality health care becomes a barrier due to their prior stigmatising and discriminatory interactions with health care professionals. Bereaved mothers could also be enduring the same experience, which eventually could influence the quality of their emotional, psychological and physical well-being.

Furthermore, if some health care providers are in fact, stigmatising (consciously or unconsciously), this could theoretically influence the information shared and provided to expectant mothers and subsequently perpetuate the silence and stigma surrounding stillbirth during antenatal care. It has been reported that health care providers can struggle to discuss stillbirth especially if they are concerned it may create unnecessary anxiety for the woman (Self-cite, 2015). Consequently, woman might not receive the necessary health messages (i.e. the importance of monitoring baby's movements to protect her baby (Frøen et al, 2011; Mangesi and Hofmeyr, 2007; Saastad et al, 2011; Tveit et al, 2010). Further research is needed to understand why health care providers may be consciously or unconsciously perpetuating stillbirth stigma to enable an informed discussion and development of stigma-reduction programs can occur. However, as seen in HIV research, by reducing the stigma held by health care providers, can not only reduce the stigma felt by bereaved parents, but also ensure the quality of care does not diminish for those living with a stigmatising condition (Nyblade et al, 2019).

Together this suggests that, any intervention aimed at reducing stillbirth stigma should incorporate a multi-layered approach which focuses on the interpersonal relationships between friends and families, interprofessional relationships between parent and health care provider and structural issues such as hospital practices which each may perpetuate the stigma of stillbirth.

Explanatory variables of stillbirth stigma

Individual level factors explored in this study accounted for 6.6% of the total variance in stillbirth stigma scores. This exploratory study only included personal-level factors in the regression model, the low total

variance observed highlights the complexity of understanding stigma, and the many different potential influences associated with it. The results suggest stigma is highest in the immediate years following the stillbirth and if the mother had no prior living child. This supports existing literature, which discusses the loss of identity first-time mothers commonly feel after stillbirth (Brierley-Jones et al, 2015).

Additionally, the authors (xx, xx,) years of lived experience as bereaved mothers confirms that mothers who endure the loss of their first baby often find that their community struggles to identify them as mothers until they have a child who lives. This loss of identity could also explain the levels of perceived devaluation (64.5%) we found, in which participants endorsed questions that people would "accept their child as one of theirs", and that "most people" would believe they are not a mother/father if they have had a stillbirth. In future, researchers need to assess if the first-time mother requires additional support following their stillbirth to potentially minimise the impact of this kind of stigma.

A diagnosis of a mental illness prior to a stillbirth, or after a stillbirth were also related to higher levels of stigma. Furthermore, the disability status of a bereaved mother was also noted as nearing statistical significance p=.053, however, with only a small sample identifying as living with a disability this may be a purely cursory finding that warrants future research. However, considering the plethora of research which strongly suggests that a mental illness status and disability are both highly stigmatising conditions in their own right (Ali et al, 2012; Buljevac, Majdak and Leutar, 2012; Corrigan and Rao, 2012; Wang et al, 2018).

With mental health and disability each potentially playing a role in higher stigma scores of bereaved parents, future research should consider utilising an intersectional framework.

Intersectionality describes the phenomenon of an individual experiencing multiple stigmatising identities (Turan et al, 2019) which traditionally have been race and gender identities. However, other health related intersections are emerging within the literature, such as mental health, sexuality and disability (Turan et al, 2019). Furthermore, future research is needed to assess whether those already enduring a previous stigmatising condition are compounding the existing stigma by experiencing a stillbirth, or enduring a completely different type of stigma. Those individuals, who live with multiple stigmatising identities such as having had a stillbirth and living with a mental illness, are potentially at increased risk of not receiving the appropriate care and support (Turan et al, 2019). Without considering the possibility of individuals living with multiple stigmas, interventions and care, which only address one-type of stigma, may have limited success (Turan et al, 2019). Understanding individual level factors, such as demographics, mental illness and disability status helps researchers, policymakers, public health officials and clinicians, to better understand individuals who may be at risk and/or benefit from additional support; particularly those who experience the stillbirth of their first child or those with a pre-existing mental health condition (or disability). The association between stillbirth stigma scores and a mental health issue diagnosed following their baby's death is also worthy of further consideration.

The current study also explored stigma and its association with grief, perceived social support and self-esteem. We found a relationship between grief and stigma, that may be impacted by time since loss and if the stillbirth was the first child for the bereaved mother. Perhaps unsurprisingly we report a strong relationship with a large effect size between grief and stigma (.609) N= 831, p<.001). Qualitative research also often indicates that grief after stillbirth is disenfranchised, meaning that it lacks the recognition of the community (Golan and Leichtentritt, 2016; Lang et al, 2011). Prior to the development of the SSS there had been no means to assess the relationship between grief and stigma. Higher levels of grief have been associated with adverse mental health issues, such as depression and anxiety (Gravensteen et al, 2018). Therefore, it is imperative that further research explore the role of stigma in its relationship to grief, to assess if it is increasing poorer adverse psychological outcome and/or exacerbating the disenfranchisement of stillbirth.

The role and relationship of perceived social support and self-esteem exists in the stigma literature (Kleiman and Riskind, 2012; Marshall et al, 2013), however, has not previously been specifically measured in bereaved mothers after stillbirth. Nevertheless, literature does support the notion that bereaved mothers are at increased risk of experiencing lower levels of self-esteem (Wonch Hill et al, 2017) and our findings suggest that higher levels of stigma could potentially negatively influence self-esteem. The cross-sectional design of this study does limit further recommendations on self-esteem. However, the current research highlights the need for further investigation to explore the direction of self-esteem and stigma, and whether reducing stigma could potentially serve to protect bereaved mothers' self-esteem.

Family social support after stillbirth has been well-associated with bereaved mothers experiencing lower levels of depression and anxiety (Cacciatore, Schnebly and Froen, 2009; Surkan et al, 2009). However, what makes someone receive or give social support after stillbirth has not been well explored. Our findings addfurther insight and suggests that perceived social support and stigma are interrelated, with social support protective against the level of stigma experienced. Establishing whether low perceived social support is a driver of stigma, results from stigma, or potentially shares some conceptual overlap is needed in order to understand how best to support and protect parents from suffering stigmatisation following stillbirth.

Limitations and strengths of the current study and future research

A strength of this study is the international sample and sample size which recruited participants from Australia, New Zealand, the United Kingdom and the United States of America. However, representation in this study was restricted, with most participants identifying as European Caucasian (91.4%) and educated (over 60% of participants had some college education). Therefore, this study may not be generalised to other contexts with different ethnicities, and/or low- and middle-income countries. Furthermore, it is increasingly recognised that stigma experiences differ between each cultural group, this study due to its lack of representation from culturally and linguistically diverse (CALD) groups was unable to capture this, therefore, the SSS needs to also be validated in these communities prior to use in such settings.

Due to the correlational design utilised within this study, the direction of the relationships between stigma, grief, perceived social support, self-esteem and the factors included within the regression analysis are unable to be ascertained. For example, it was not possible to determine whether stigma increases the likelihood of a subsequent mental illness or whether a mental illness increases perceptions of stigma or whether the relationship may be bidirectional. Further longitudinal research is needed to explore the relationships between these constructs across time and to further elucidate direction of causality. Furthermore, mental health has been self-reported in this study. As previously reported in this study, mental health is an established stigmatising condition (Corrigan et al, 2019). Therefore, this could have led to under-reporting of mental illnesses in this study and need to be considered in future research.

Future research, which explores the direction and offered more insight on how stillbirth stigma infiltrates at a macro level such as health care providers and government should be conducted to ensure that any future intervention is informed from an in-depth understanding and evidence. Conclusion

This is the first study to measure the prevalence of stillbirth stigma using the SSS, with findings indicating over half of the bereaved mothers in this research were stigmatised. Of concern, was the high prevalence of bereaved mothers who self-stigmatised and internalised blame often associated with stillbirth, as well as the discrimination reported by nearly a third of bereaved mothers. The findings suggest higher levels of stigmatisation are experienced by first-time mothers; those with a mental health diagnosis prior to, or following, their stillbirth; and that stigma is highest in the years immediately following the loss. This has important

implications for providing targeted support services to groups identified as being at greater risk. Furthermore, this research demonstrates that higher stillbirth stigma is associated with adverse outcomes for bereaved mothers including greater perinatal grief and reduced self-esteem, while social support may be a protective factor. The current study takes the necessary first step in answering the 2011 and 2016 stillbirth Lancet series call to find mechanisms to reduce stigma and will provide a baseline and basis for subsequent stigma reduction interventions and evaluations across time for researchers, policymakers, government officials and non-government organisations. Now that stillbirth stigma can be measured, we call for further research to reduce stigma. It is time to respond and answer the call by the 2011 and 2016 Stillbirth Lancet Series to reduce stillbirth stigma, so bereaved parents no longer have to live in silence.

DP was responsible for the conceptualization. All authors conceived the study and were responsible for the interpretation of results, drafting and editing of this project. JW, TZ, EP & MC supervised DP. DP was responsible for the conceptualization, recruitment and original draft preparation. DP and EP performed the analysis and all authors have seen and approved the final version of the entire article and abstract.

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Supplementary materials

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