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Review article

Understanding stillbirth stigma: A scoping literature review

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ABSTRACT

Background: The World Health Organization, and the 2011 and 2016 Lancet Stillbirth series as well as medical and scientific literature, have all called for stillbirth stigma to be reduced. However, few studies have explored or attempted to conceptualise the meaning of stigma in the context of stillbirth.
Aim: To explore the current knowledge surrounding stillbirth stigma, specifically the extent, type and experiences of bereaved parents.
Methods: A five-stage scoping review framework was utilised. A search of relevant databases (MedLine, EMBASE, PsychInfo, PsychArticles, and Ovid Emcare) was undertaken with several key words related to 'stillbirth' and 'stigma.' The reference lists of included studies were also searched.
Findings: A total of 23 resources met the inclusion criteria for this review. A thematic analysis regarding how stigma was conceptualised and/or experienced within results and/or discussion was employed on these studies. Five over-arching themes, with several sub-themes, were discovered: Type of stigma, identity, silence, bereaved mothers' experiences of stigma in low-income countries and transformation.
Discussion: Stillbirth stigma remains an under-researched topic. Few articles conceptualised the experiences of the bereaved parent within a stigma framework. However, examples of bereaved parents enduring stigma were found within the literature. Common stigmatising experiences included, bereaved parents' identities being challenged; and feelings of shame, guilt, and blame after their stillbirth. Stigmatising experiences could be different based on the bereaved parent's cultural background.
Conclusion: Further research which attempts to conceptualise stillbirth stigma and explores those experiences from a bereaved parent perspective is needed to help inform stigma reduction strategies.

Statement of significance

Problem or issue

Stillbirth stigma is considered a key barrier in supporting bereaved parents. However, little research has been conducted on stillbirth stigma.

What is already known

Bereaved parents report feeling isolated and removed from their community, silenced, shamed and blamed for the death of their baby.

What this paper adds

This scoping review conceptualises stillbirth stigma and has identified examples within the literature of stigmatising experiences. This review also highlights areas of future research, namely the need to develop instruments to measure the extent and type of stillbirth stigma and understand the father's stigma experiences.

1. Background

Worldwide, stillbirth is a largely ignored public health issue.[1] Every year, there are 2.6 million stillbirths (death of a baby occurring in-utero after 28 weeks of gestation and/or 1000 g birth weight) globally.[1] These figures are considered to be modest

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estimates as the definition of, and reporting rate of stillbirth varies between countries.[1] Irrespective of definitions and statistics, a ripple effect occurs following a stillbirth, impacting bereaved parents, their families, and the broader community.[2]

Research demonstrates that bereaved families often experience social and economic consequences, such as increased isolation, and employment difficulties.[2] For example, in a systematic review of literature describing the psychosocial impact of stillbirth, Burden et al.[2] report that bereaved parents endure higher rates of depression, anxiety and post-traumatic stress disorder (PTSD). Further, they also state that grief after stillbirth is often disenfranchised because parents feel they are unable to discuss their experience or baby with their family or members of their community. They indicate the consequences of stillbirth are long-lasting and not only impact subsequent pregnancies, but existing relationships and attachments with living children. They note that many bereaved parents report being blamed for the death of their baby which increased social isolation and even experiences of rejection from their spouse, extended families and communities. They add that stillbirth does not just impact the bereaved parent, but also the extended family such as grandparents. Each of these experiences so commonly described within the literature are probably said to be exacerbated by the stigma and social silence surrounding stillbirth.[2]

Stigma is a complex social process that is challenging to define.[3] The original description by Goffman[4] describes stigma as a phenomenon which turns an individual "from a whole and usual person to a tainted, discounted one" (p. 3). According to Link and Phelan's[5] theory, this is achieved through labelling and stereotyping individuals with stigmatising conditions which result in separation, status loss and discrimination for the stigmatised. Attitudes and perceptions by the community create negative labels and stereotypes which associates a condition with negative attributes, stereotypes and labels. Subsequently, these can be internalised by the stigmatised individual.[5] Consequences of stigma have been well-explored in other areas, such as mental health and HIV/AIDs and include lowered self-esteem,[6] social isolation[7] and reduced help-seeking, which can each exacerbate pre-existing conditions and result in higher rates of co-morbidities.[8]

Stigma has been identified as a critical obstacle to addressing stillbirth rates and supporting bereaved parents.[9,10] The 2011 and 2016 Lancet Stillbirth Series made a 'call to action' to identify mechanisms to reduce stillbirth stigma by 2020. While the literature is replete with suggestions that there is a 'stigma' associated with stillbirth,[10–19] these authors most often report that stigma has occurred because their participants report being 'silenced.' Whether used consciously or unconsciously, silencing is considered a social management tool that can reinforce the stigmatising relationship between the stigmatiser and stigmatized.[20] Silencing the stigmatised can result in control and power to oppress the stigmatised. Therefore, silence can be considered a significant component which reinforces stigma, while not being stigma itself.[17]

Feeling shamed and blamed and subsequently being socially isolated from their community are common stigmatising experiences especially because bereaved parents may feel limited in their ability to talk about their experience.[11,18] However, there is little evidence which directly explores the attitudes and perceptions of stillbirth, the bereaved mother and stillbirth baby from their respective community.

Furthermore, Health care providers (HCPs) may be compounding the effects of stigma. For example, an international survey of 2731 of HCPs reported that the mother, was considered a failure, the stillbirth was her fault, and that she was now considered impure or taboo by others within her community.[14] Undesirable attitudes towards the stillborn baby were also described by Frøen et al.'s[14] study where HCPs believed that the baby was also a taboo object. They also stated that HCPs believed that stillbirth was caused mostly due to medical causes, and mainly thought that the baby was never supposed to live, or it was 'bad luck'.[14]

Despite, these social consequences and attitudes which surround stillbirth identified within the literature, there has been little response to the 2011, and 2016 Lancet Stillbirth Series call to action to reduce stillbirth. Subsequently, research related to stillbirth stigma remains scarce.[21] The limited research which has been conducted suggests that stillbirth may be stigmatising. However, there remains no clear conceptual definition of the impact of stillbirth stigma which is in stark contrast to other areas, such as mental health,[22] and HIV/Aids.[3] There is limited knowledge regarding the extent and different types of stillbirth stigma and little understanding of the bereaved parents' experiences of stigma. The lack of empirical research on stillbirth stigma presents a key challenge in creating interventions to support bereaved parents. Therefore, in this scoping review of the literature, we sought to synthesise the limited literature available about stigma and stillbirth and to clarify crucial future research directions relating to stillbirth stigma.

2. Method

A scoping review was determined to be an appropriate method to examine existing literature as it seeks to identify research gaps, by rapidly mapping the key concepts within a research area. The review utilised the five-stage approach outlined by Arksey and O'Malley.[23] The five stages are (1) identify a research question (2) identify the relevant studies through a search strategy (3) select the included articles (4) charting the data and (5) collating, summarising and reporting the results. Following on from this framework; stage one developed a research question, which is: What is known about stillbirth stigma within the literature?

We aimed to discover and explore the full range of literature and to canvass the broadest range of literature available. We examined all papers regardless of study design, which explored 'stigma', and 'silence' and stillbirth.

2.1. Stage two: identify relevant studies- search strategy

An online search between August and October 2018 of the electronic databases MedLine, EMBASE, PsychInfo, PsychArticles, and Ovid Emcare was conducted using the following keyword search terms: stillborn or stillbirth or FDU or IUFD or intrauterine death or intra-uterine death or IUD or IUFD or f?etal death* or f?etal loss*or f?etal demise* or perinatal death* or pregnancy demise* AND Stigma or Silence.

The search was restricted to studies published in English and to those relating to human subjects. A secondary search of the references cited in the selected articles was undertaken, and Google Scholar was utilised to access these sources. All articles were exported to and managed in Endnote™.

2.2. Stage three: article selection inclusion and exclusion criteria

The inclusion criteria for articles were; (1) written in English; (2) focused on stillbirth (3) the abstract or title included the words stigma OR silence. For this review, no set definition of a stillbirth was adopted as there is still no consensual definition between countries. To ensure a comprehensive mapping of the relevant literature no time range was placed on resources, however, articles not published at the time of this scoping review being submitted for publication (October 2018) were not included.

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The initial search identified relevant articles, and duplicates were excluded (see Fig. 1). Each abstract was reviewed by DP to determine if the article met the inclusion criteria, with JW confirming each result. The Prisma chart (Fig. 1) shows the study selection flow. The initial search retrieved 191 results, including articles, editorials, discussion papers, and theses. After the removal of 82 duplicates, 109 abstracts were reviewed, and after screening the title and abstract, 70 were excluded. A further 19 studies were excluded after the full-text review. Arksey and O'Malley[23] suggest a consultation be undertaken with other researchers, and, a further three articles[12,19,24] were identified and included within the scoping review. There were 23 articles included in this review

2.3. Stage four: charting the data

Each article was reviewed and the data charted with following details: source (author, year, country); journal; study design/method; sampling; if stigma was discussed and defined.

The earliest study was published in 1995, the latest in July 2018. There has been a small rise in the number of articles which discussed stillbirth stigma since the call for more research made in the Lancet in 2011 (n = 8, vs. n = 15 in the years 1995–2011). However, there has yet to be another rise after a similar recall was made in 2016. Of the 23 articles identified, there were 15 research reports, three discussion papers, three practice papers, and two commentaries. Methodologically, most (n = 13) of the 15 research articles used a qualitative method; of the remaining two, one was quantitative and the other a mixed-methods design. Data collection was mainly via interviews (n = 11), surveys (n = 3) and focus groups (n = 1), made up the remainder. A dominant western perspective was noted, with most (n = 18) originating in high-income countries (HICs). Within this sample, the United Kingdom (n = 6), the United States of America (n = 6), and Australia (n = 3) were the most prominent locations. There were three studies each from the African continent. The Asian continent had one article, from Nepal. Two articles represented research from more than one country; one focused solely on high-income countries (HIC) the other on one, both HIC and one LIC.

All research articles within this scoping review included bereaved mothers. There were no studies which solely focused on bereaved fathers. Six research articles included both fathers and mothers; however, due to the low number's fathers were still poorly represented in the findings. Furthermore, out of the 15 research articles, only Kelley and Trinidad[25] research of bereaved mothers, fathers and health care professionals via focus groups discussed how the father's voice was not being represented within the literature. Please refer to Table 1, for a full chart of the included resources within this scoping review.

2.4. Stage five: collating, summarising and reporting results

Braun and Clarke's[26] six-phase thematic analysis approach was utilised. Thematic analysis was employed to search the findings and/or discussion sections of each paper for themes related to stigma. The method included (1) familiarising ourselves with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing of themes, (5) defining and naming themes and finally (6) producing the report. DP first read the included articles to become familiar with the content. As she did not have pre-set codes, an open coding technique was utilised which allowed for flexibility throughout the coding process. Once the initial list of codes was generated, they were organised into broad themes and sub-themes. During stages three to five, JW cross-checked each code to ensure the themes identified were appropriate. All authors included in this paper then confirmed that the themes made theoretical sense and were appropriate.

Stigma has been variously reported and defined, or indeed not defined at all. This lack of consistency was evident in our review. Only one article organised their findings under Goffman[4] theoretical framework.[13] Two articles noted Goffman's[4] definition of stigma.[11,12] Even though the word stigma was used repeatedly, it was only reported as an outcome in eight manuscripts [11–14,16,17,19,25]. Stigma was most often used as contextual information by authors whose intentions were to capture the general experiences of bereaved parents.

The term mother/father and/or parent are used interchangeably throughout this scoping review. Times, when the term mother is used, are articles which only had women within their sample. Parents are used when the articles had both men and women as participants unless the author of those papers stated that the findings were specific to the mother or father experience.

3. Findings

Within the 23 articles identified in this scoping review, we identified five key themes: type of stigma, impact on identity, silence, bereaved mothers' experiences in LIC and transformation. Due to the volume of research and complexity in types of stigma, identity, and silence, these three themes were further divided into sub-theme of similarities. Table 2 provides an understanding of the context of each theme with the inclusion of an exemplary quote found from the qualitative resources included within this scoping review.

3.1. Types of stigma

While there are several different types of stigma defined elsewhere,[27] only two types of stigma were identified in this review- public and self-stigma. Public stigma explains the external stigmatising experiences of the individual (in this case the bereaved parent) and the community of the stigmatised individual.[28] Such experiences can include the bereaved parent being discriminated against, being treated unkindly, being avoided, or even mocked for their stillbirth experience. This experience often arises from a community that is ignorant of the condition (i.e., stillbirth).[29] Self-stigma is the internalisation of stereotypes associated with the condition.[30] It can lead to sequelae of poor outcomes including self-blame, lower self-esteem, isolation and social withdrawal.[6,7] Self-stigma is associated with an individual's fear of experiencing public stigma[31] and may deter stigmatised individuals seeking help.[8]

3.1.1. Bereaved parents experienced 'public stigma'

Six studies found examples of bereaved parents experiencing public stigma.[11–14,16,17] The most identified examples of public stigma were minimisation, loss of friendships and family support and silencing when wanting to discuss their stillborn baby.[3,11,12,14,16,17] However, there were more apparent examples of public stigma. Murphy's[11] qualitative study of 10 couples and 12 bereaved mothers in the United Kingdom reported that bereaved parents struggled socially after the death of their baby. However, one example from a bereaved mother in Murphy's[11] study stated that neighbours would cross the road to avoid talking to her. Murphy[11] also reported that two mothers were blamed for their baby's death by members of their family. HCPs were also identified as a potential source of public stigma. Brierley-Jones et al.'s[13] qualitative survey of 162 bereaved mothers recounted examples of poor care experiences, examples include mothers being left to labour by themselves and having no access to pain medication. Two further articles qualitatively explored the perception and experiences of stillbirth through focus groups and interviews of bereaved mothers, elders and community members in Tanzania

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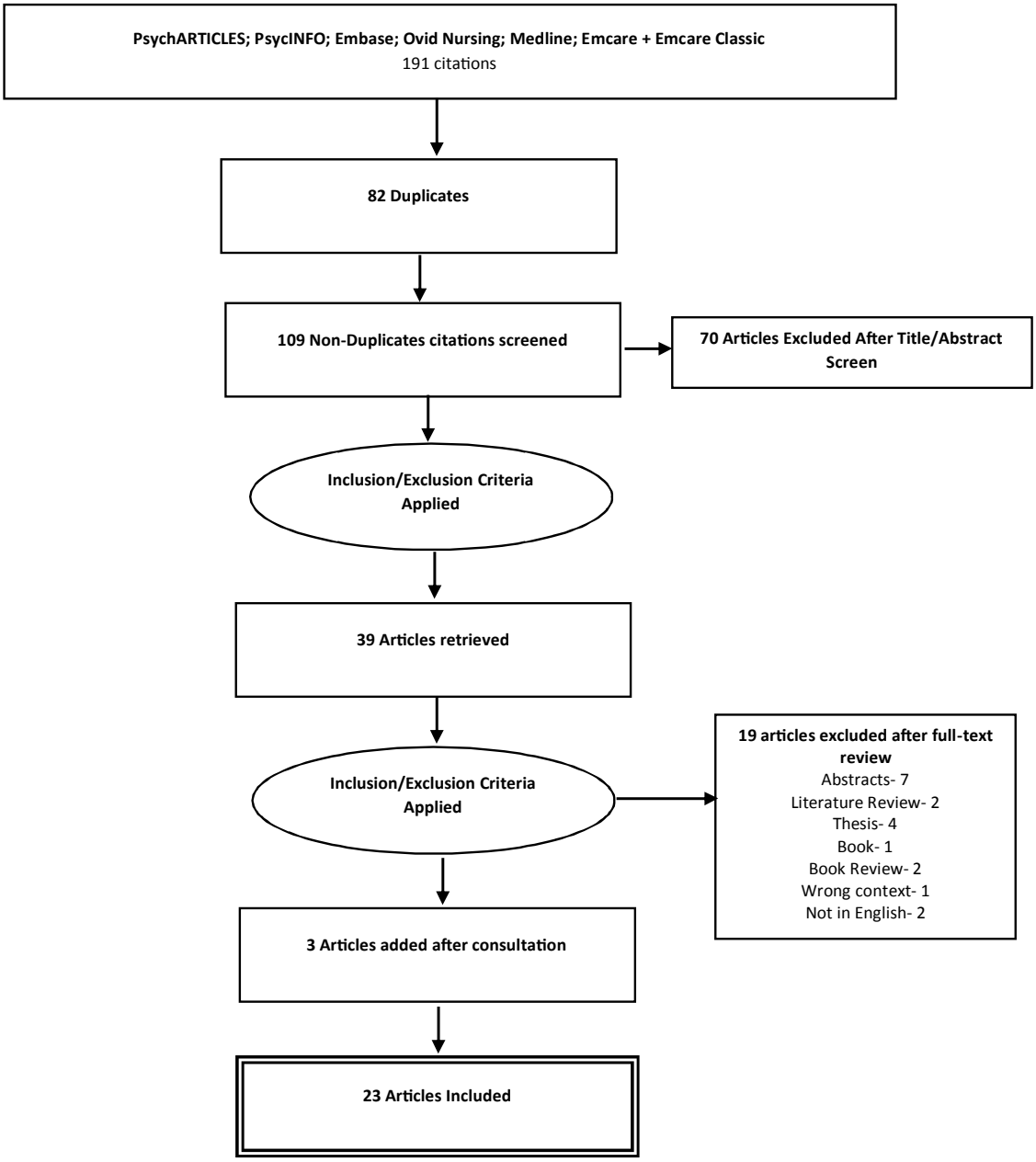

Fig. 1. PRISMA chart of scoping review.

and Uganda, stated bereaved women were accused of aborting their baby, even though this was not true.[16,17]

3.1.2. Bereaved parents experienced self-stigma

Eight articles described the self-stigma experiences of bereaved parents.[11,12,14,16,18,25,32,33] Three articles explored the perceptions of bereaved parents from their community.[14,16,17] Frøen et al.'s[14] international (135 countries) survey of 2731 bereaved parents and HCPs reported several negative attributes associated with stillbirth, such as, the baby is impure and taboo, the baby was never supposed to live, and the mother should try and forget and have another child. Most concerning, Froen's study highlighted that 29% believe that it was the mother's sins or fault which caused the death of her baby, and 20% believed she has failed as a mother.[14] Those studies which explored the perceptions of the community did not mention if bereaved fathers experience the same perceived attributes that mothers endure. Bereaved mothers could internalise these perceptions, even if they have not been directly told that they were at fault and blame themselves for the death of their baby.

A common experience reported within the literature reviewed was parents conveying feelings of self-blame, shame and guilt. Even though being blamed by others may be a form of 'public stigma' bereaved parents commonly blamed themselves for the death of their baby. St John et al.'s[18] interviews of three bereaved mothers suggested that self-blame was often linked with feeling like they did not do enough to 'save' their baby. The bereaved mothers suggested that they should have known that something was wrong and sought help before their stillbirth.[12,18] Kelley and Trinidad's[25] qualitative study suggested that HCPs could address self-blame, by normalising the experience and helping the bereaved parents to understand they were not at fault through providing information about common causes of and rate of stillbirth.

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Table 1
Results of Literature Review.

Author	Title	Year	Journal	Place of research	Type of Research	Methodology	Tool	Type of pregnancy loss	Participants	Stigma an outcome?
Bakhbakhi D.; Burden C.; Storey C.; Siassakos D.	Care following stillbirth in high-resource settings: Latest evidence, guidelines, and best practice points	2017	*Seminars in Fetal and Neonatal Medicine*	United Kingdom	Practice paper	N/A	N/A	Stillbirth	N/A	N/A
Brierley-Jones L.; Crawley R.; Lomax S.; Ayers S.	Stillbirth and stigma: the spoiling and repair of multiple social identities	2015	*Omega*	United Kingdom	Original Article	Qualitative	Survey; Making and Sharing Memories Questionnaire; DASS-21; PTSSS; Open-ended questions	Stillbirth	162 women	Yes
Flenady V.; Boyle F.; Koopmans L.; Wilson T.; Stones W.; Cacciatore J.	Meeting the needs of parents after a stillbirth or neonatal death	2014	*BJOG: an international journal of obstetrics and gynaecology*	Australia	Discussion	N/A	N/A	Stillbirth or Neonatal death	N/A	No
Flenady V.; Wojcieszek A.M.; Middleton P.; Ellwood D.; Erwich J.J.; Coory M.; Khong T.Y.; Silver R.M.; Smith G.C.S.; Boyle F.M.; Lawn J.E.; Blencowe H.; Leisher S.H.; Gross M.M.; Horey D.; Farrales L.; Bloomfield F.; McCowan L.; Brown S.J.; Joseph K.S.; Zeitlin J.; Reinebrant H.E.; Ravaldi C.; Vannacci A.; Cassidy J.; Cassidy P.; Farquhar C.; Wallace E.; Siassakos D.; Heazell A.E.P.; Storey C.; Sadler L.; Petersen S.; Froen J.F.; Goldenberg R.L.	Stillbirths: Recall to action in high-income countries	2016	*The Lancet*	World-wide	Original Article	Mixed methods	Survey	Stillbirth	6636 responses	No
Froen J.F.; Cacciatore J.; McClure E.M.; Kuti O.; Jokhio A.H.; Islam M.; Shiffman J.	Stillbirths: Why they matter	2011	*The Lancet*	World-wide	Original Article	Quantitative	Survey	Stillbirth	2731 responses from HCP; 1127 Parents (95% women)	Yes
Glasgow, C	Midwives' reflections and coping strategies around neonatal death	2017	*MIDIRS Midwifery Digest*	Australia	Discussion	N/A	N/A	N/A		No
Haws R.A.; Mashasi I.; Mrisho M.; Schellenberg J.A.; Darmstadt G.L.; Winch P.J.	"These are not good things for other people to know": How rural Tanzanian women's experiences of pregnancy loss and early neonatal death may impact survey data quality	2010	*Social Science and Medicine*	Tanzania	Original Article	Qualitative	Interviews	All types of pregnancy loss; infertility	50 bereaved mothers; 31 new mothers and elders	Yes
Hazen, Mary Ann	Societal and workplace	2003	*Human Relations*	United States	Original Article	Qualitative	Interviews		14 women	No

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Table 1 (*Continued*)

Author	Title	Year	Journal	Place of research	Type of Research	Methodology	Tool	Type of pregnancy loss	Participants	Stigma an outcome?
	responses to perinatal loss: Disenfranchised grief or healing connection.							All types of pregnancy loss		
Heazell A.E.P.	Stillbirth - a challenge for the 21st century	2016	*BMC Pregnancy and Childbirth*	United Kingdom	Commentary	N/A	N/A			
Kelley M.C.; Trinidad S.B.	Silent loss and the clinical encounter: Parents' and physicians' experiences of stillbirth-a qualitative analysis	2012	*BMC Pregnancy and Childbirth*	United States	Original Article	Qualitative	Focus groups	Stillbirth	9 bereaved mothers; 8 parents of stillborn babies; 3 mothers of stillborn babies thatwere also health professional; 8 OB/GYN/ Academics	Yes
Kiguli J.; Namusoko S.; Kerber K.; Peterson S.; Waiswa P	Weeping in silence: community experiences of stillbirths in rural eastern Uganda	2015	*Global health action*	Eastern Uganda	Original Article	Qualitative	Interviews	Stillbirth	14 bereaved mothers; 6 men whose wives had at least one stillbirth; 4 grandmothers; 1 grandfather; 4 traditional birth attendant	Yes
Layne L.L.	Motherhood lost: Cultural dimensions of miscarriage and stillbirth in America	1990	*Women and Health*	United States	Discussion	N/A	N/A	Miscarriage and stillbirth	N/A	No
Murphy S.	Reclaiming a moral identity: stillbirth, stigma and 'moral mothers'	2012	*Midwifery*	United Kingdom	Original Article	Qualitative	Interviews	Stillbirth	10 bereaved couples; 12 mothers	Yes
Murphy, S. L	Finding the positive in loss: stillbirth and its potential for parental empowerment	2012	*Bereavement Care*	United Kingdom	Original Article	Qualitative	Interviews	Stillbirth	10 bereaved couples; 12 mothers	Yes
Osman H.M.; Egal J.A.; Kiruja J.; Osman F.; Byrskog U.; Erlandsson K.	Women's experiences of stillbirth in Somaliland: A phenomenological description	2012	*Sexual and Reproductive Healthcare*	Somaliland	Original Article	Qualitative	Interviews	Intrapartum stillbirth at 28 weeks and beyond	10 bereaved mothers	No
Price S.K.	Women and reproductive loss: Client-worker dialogues designed to break the silence	2008	*Social Work*	United States	Practice paper	N/A	N/A	All pregnancy loss	N/A	No
Paudel, M; Javaparast, S; Dasvarma, G; Newman, L	Religio-cultural factors contributing to perinatal mortality and morbidity in mountain villages of Nepal: Implications for future healthcare provision	2018	*PLoS ONE*	Nepal	Original Article	Qualitative	Interviews	Stillbirth and Newborn death	42 women of childbearing age and their family members; 15 HCP; 5 stakeholders	No
Radestad I.; Malm M.-C.; Lindgren H.; Pettersson K.; Larsson L.-L.F.	Being alone in silence - mothers' experiences upon confirmation of their baby's death in utero	2014	*Midwifery*	Sweden	Original Article	Qualitative	Interviews	Stillbirth	23 bereaved mothers	No
Scott J.		2011	*The Lancet*		Commentary	N/A	N/A	Stillbirth	N/A	No

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Table 1 (*Continued*)

Author	Title	Year	Journal	Place of research	Type of Research	Methodology	Tool	Type of pregnancy loss	Participants	Stigma an outcome?
	Stillbirths: Breaking the silence of a hidden grief			United Kingdom						
St John A.; Cooke M.; Goopy S.	Shrouds of silence: three women's stories of prenatal loss	2006	*The Australian Journal of advanced nursing: a quarterly publication of the Royal Australian Nursing Federation*	Australia	Original Article	Qualitative	Interviews	All pregnancy loss	3 bereaved mothers	No
Trulsson O.; Radestad I.	The silent child - Mothers' experiences before, during, and after stillbirth	2004	*Birth*	Sweden	Original article	Qualitative	Interviews	Stillbirth	12 bereaved mothers	No
Van P.	Breaking the silence of African American women: healing after pregnancy loss	2001	*Health care for women international*	United States	Original article	Qualitative	Interviews	All pregnancy loss	10 bereaved mothers	No
Zeidenstein, L	Breaking the silence. Finding a voice for loss.	1995	*Journal of nurse-midwifery*	United States	Discussion	N/A				

3.2. Stillbirth challenges the 'identities' of the bereaved parent

Stigma according to Goffman[4] is the spoiling of an individual's identities. Stigma serves to discredit the individual because they possess an attribute that is against the social norms.[4] Brierley-Jones et al.'s[13] survey of 162 bereaved mothers suggested within the open-text responses that stillbirth stigma has the potential to challenge several identities. These included the motherhood, patient, full citizen, and the identity of the baby.

3.2.1. Motherhood identity

The challenging of the motherhood identity starts from the time a stillbirth is confirmed.[13] Seven articles provided examples of how the motherhood identity was challenged after stillbirth.[11,13,14,16,25,34,35]

Being able to participate in acts, such as holding, washing and dressing their stillborn baby after birth may be an essential factor in determining a bereaved mother's identity. For example, in a mixed methods survey study of 162 bereaved mothers, Brierley-Jones et al. [13] identified that the motherhood identity intertwined with the mother's ability to not only partake in memory making activities with her baby but also to then share these memories with others. They also reported that when mothers were denied the ability to share their memories, they questioned their own identity as a mother.[13] Furthermore, questioning of one's motherhood was further exacerbated when their baby was not officially recognised with a birth certificate.[13] To be denied acknowledgment from friends, families and their government meant that bereaved parents felt that their identity as a mother[25] and father[12] was not recognised.

The ramifications of motherhood status loss in a collectivist culture, where there is a strong emphasis on being accepted and living within the community norms, such as in Tanzania and Uganda appeared to be even more prominent.[16,17] For example, a study of qualitative interviews conducted in Uganda reported husbands of bereaved mothers being told to separate from and reject their wives due to their stillbirth.[17] Losing one's status as a mother can be a precarious position for a woman to be in especially if she lives within a community where she relies solely on a husband for support.[16]

Furthermore, mothers in one qualitative study were quick to justify their 'moral' behaviour (i.e., "I didn't do anything wrong") that they were not responsible for their baby's death to protect their motherhood identity.[11]

The identity of fathers was only mentioned once within the literature involved in this scoping review. Murphy's[11] qualitative study interviewed bereaved couples and reported fathers did not feel that they had to justify their behaviour, unlike their partners. However, they took on a stereotypical 'protective' role- for example, protecting the mothers 'moral identity',[11] i.e. "she did not do anything wrong".

3.2.2. The patient identity

Once a stillbirth has been confirmed by health care professionals (HCPs) and admitted to the hospital, the mother initiates a 'patient' identity.[13] Four qualitative studies explored the experiences of the bereaved parent from confirmation of stillbirth, their stay, and experiences within the hospital, to leaving after birth.[13,25,36,37] Three of these studies took place in Europe (the United Kingdom and Sweden),[13,36,37] while Kelley and Trinidad's[25] qualitative study of focus groups focused on bereaved parents and HCPs experience in America. However, Brierley-Jones et al.' s[13] study was the only one to directly relate to how these hospital experiences by HCPs was stigmatising for the bereaved parent. The further three studies provided examples of how the patient identity changed once stillbirth was confirmed. Trulsson and Rådestad's[37] study of 12 bereaved mothers reported through interviews that communication between the HCP and mother often ceased during the ultrasound to confirm the absence of a fetal heartbeat. Three articles further described how bereaved parents were treated during their labour.[13,25,37] Although, there were

Table 2
Summary of themes found within scoping literature review.

Themes	Articles	Exemplar Quotes
Theme 1: Type of Stigma		
Sub-theme 1: Public Stigma	Brierley-Jones et al.[13]; Froen et al.[14]; Haws et al.[16]; Kiguli et al.[17]; Murphy[11];	*"Fiona: 'I had a lady, a neighbour, literally cross the road and went in the other direction, which was very hurtful.'* (Murphy[12])
Sub-theme 2: Self-stigma	Frøen et al.,[14]; Haws et al.[16]; Hazen[32]; Kelley & Trinidad[25]; Murphy[11]; Price[33]; St. John et al.[18]; Murphy[12]	*"There is heaps of self-blame - I should have done this, and I should have done that..' How could I have headed this off?"* (St. John et al.[18] pg. 10)
Theme 2: Identity		
Sub-theme 1: Motherhood	Brierley-Jones et al.[13]; Frøen et al.[14]; Haws et al.[16]; Kelley & Trinidad[25]; Layne[35]; Murphy[11]; Osman et al., 2012	*"I am a mom, but you don't get that recognition. (. . .) Just the birth certificate- I was really fixated. I want a piece of paper to say that my child existed."* (Kelley & Trinidad[25] pg. 10)
Sub-theme 2: Patient	Brierley-Jones et al.[13]; Kelley & Trinidad[25]; Rådestad et al.[36]; Trulsson & Rådestad[37];	*"The only thing I'm a bit critical about is what happened before the delivery. I just don't think they got to grips with the situation. I felt like a thing, an object that got moved around. I got pushed out of the way like I wasn't important. As long as you had a dead baby inside you, you weren't important and just got pushed to one side. 'Out of the way, out of the way,' and nobody wanted to be responsible or talk to you."* (Trulsson & Rådestad[37], pg. 191).
Sub-theme 3: Full Citizen	Brierley-Jones et al.[13]; Frøen et al.[14]; Haws et al.[16]; Kiguli et al.[17]; St. John et al.[18];	*"You are some kind of freak."* (St. John et al.[18], pg. 10)
Sub-theme 4: The stillborn baby's identity	Brierley-Jones et al.[13]; Frøen et al.[14]; Kiguli et al.[17]; Layne[35]; Trulsson & Rådestad[37]; Haws et al.[16]	*"Although the midwife who supported me during* labor *was wonderful, the midwife who replaced her at the birth was awful, cold, and distant. She did not encourage me to bond with my baby. She brought my baby to our room with a blanket over his head."* (Brierley-Jones et al.[13], pg. 151)
Theme 3: Silence		
Sub-theme 2: Silence upon confirmation of stillbirth and within the hospital system	Brierley-Jones et al.[13]; Kelley & Trinidad[25]; Rådestad et al.[36]; Trulsson & Rådestad[37]	*"They didn't say anything. Everybody was totally silent, and we asked, 'What's going on, what's happening?' They didn't say anything, so I thought it was . . . . First, there was a midwife, then a doctor came in, and then a gynaecologist, and they were all talking to each other but not to us"* (Trulsson & Rådestad[37], pg. 190).
Sub-theme 3: Bereaved parents entering a silent reality	Brierley-Jones et al.[13]; Flenady et al.[15]; Hazen[32]; Haws et al. [16]; Kelley & Trinidad[25]; Kiguli et al.[17]; Layne[35]; Murphy,[11]	*"As a society, we really haven't given it a place, so if somebody did have that experience it was very quiet . . . There isn't an appropriate way to grieve a child that is stillborn, especially when people have never seen it. The only people I have met that have their own ways of grieving and celebrating are in support groups or around a community of people that have experienced the same thing. Outside of that community there is just this void, nothing.* (Kelley & Trinidad[25] pg. 9).
Sub-theme 4: HCPs silence in antenatal care and professional education.	Glasgow[24]; Kelley & Trinidad[25]; Price[33]; Bakhbakhi[41]; Flenady et al.[40]; Zeidenstein[39]	*"They never taught me that birth and death could be a breath apart. Perhaps as a midwifery student in Australia I missed it, but I do not think so. They never taught me that one day I would stand in a midwives' station, beside a cot, with my hand resting on the chest of a recently born girl, dressed impeccably, wrapped in a* pink *blanket, long eyelashes resting on cheeks but with no gentle rising and falling of breath . . . The air and light around us was palpable with silence."* (Glasgow[24])
Theme 4: Bereaved mothers in LIC experiences of stigma	Frøen et al.[14]; Haws et al.[16]; Kiguli et al.[17]; Paudel et al.[19]	*"My grandmother had 10 births (Sutkas—childbirths). All of her babies died.. . ., after 12 years she delivered my father and his three sisters. My father says,' you are young, you can bear babies, you haven't lost anything'. My father-in-law is also the only surviving son in his family."* (Paudel et al.[19], pg. 22–23).
Theme 5: Transformation	St. John et al.,[18]; Murphy,[11]; Van[42]	*"I deal with it in a way that you know, to crusade, to campaign, to make sure things change, to try and take the positives as much as you can out of the whole situation rather than dwell on, you know, the terrible things that have happened because, you know, you can't change what's happened unfortunately in the past. What you can do is change things for the future, so I'm always . . . glass half full."* (Murphy[11], pg. 101)

positive experiences mentioned where bereaved parents felt supported.[37] Most labour experiences were negative and included by being left alone, hearing 'live' babies cry, and HCPs coming in and not being aware that the baby had died which reinforced the loss of patient identity.[13,25,37]

3.2.3. The full citizen

Stigma has not only the potential to rob the parents of their parenting and patient identity but also their sense of citizenship and status within their community.[13] Five articles discussed stillbirth and subsequent loss of full citizenship, and all focused on the mother's experience.[13,14,16–18] Bereaved mothers are deeply affected by the death of their baby but are often expected to go back to normality soon after or 'move on'. Brierley-Jones et al.'s[13] study stated that stillbirth could continue to affect everyday interactions for bereaved mothers in the years following the event. Examples reported within Brierley-Jones et al.'s[13] survey study suggested that discussion of their stillbirth was avoided and treated as a 'non-event'.

Furthermore, one bereaved mother stated that she felt like a '*leper*' (pg. 153), especially to pregnant friends. These interactions often meant even after a subsequent child; bereaved mothers felt unable to attend play groups as they were unable to discuss their deceased baby.[13] St John et al.,[18] also found in their small qualitative study of three bereaved mothers that they described themselves as being on the outside looking in, no longer able to find a place within society or even the healthcare system. As a result, there was a perception of isolation by bereaved mothers due to their experience.

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3.2.4. The stillborn baby identity

Six articles discussed how the baby was perceived by health care professionals based on the perceptions of the bereaved parent.[13,14,16,17,35,37] Stigma potentially plays a role in how the baby is viewed, Brierley-Jones et al.[13] reported that bereaved mothers felt if the HCPs reacted negatively towards the stillborn baby, it impacted upon their 'motherhood' identity and made them question if they were truly a mother. Even though there were positive examples of the baby being respected and valued by medical professionals,[13,37] the most common experience discovered within these articles were mostly negative. Examples within the literature include, the baby being hidden and often in inappropriate locations such as cupboards, the baby being objectified or even viewed as 'monstrous' by health care professionals.[13,14,16,17,35,37] There were also examples of mothers feeling the need to seek permission from HCPs to view their child and the baby being inappropriately presented to them, for example, being shown that their baby was in a store cupboard, or the baby is given to the mother with a blanket over its head.[13]

Frøen et al.'s,[14] worldwide survey of 2731 healthcare professionals from 138 countries, confirmed that staff can consider the baby as taboo with 24% responding 'always or often' that the stillborn baby is seen as a taboo object. In Uganda the stillborn baby is referred to as an 'empuna', which translates as 'thing', consequently, they were often denied burial as they were not considered a 'child'.[17] Haws et al.'s,[16] qualitative study in Tanzania of bereaved mothers, and members of the community also reported evidence that stillborn babies were either labelled as 'complete' or 'immature', the latter generally reserved for babies with macerated skin. Where the baby was considered 'immature', the mother was not allowed to talk about it.[16]

3.3. Silence

The discussion of silence was identified across the literature reviewed, with 11 articles discussing how it impacts bereaved parents.[13,15,17–19,24,25,32,35,37–39] The silence was seen in three different facets of the stillbirth experiences- bereaved parents within the hospital system; bereaved parents entering a silent reality and HCPs silence in antenatal care and professional education.

3.3.1. Silence upon confirmation of stillbirth and within the hospital system

Four articles discussed the silence felt by bereaved parents within the hospital.[13,25,36,37] Two qualitative articles from Sweden explored the experience of the bereaved mothers when waiting for confirmation of their stillbirth.[36,37] Three qualitative articles discussed the hospital experience during labour and directly after birth, and explored the perceptions by the bereaved parent on how the HCP communicated with them during their time in the hospital.[13,25,37] Three articles noted good examples of communication between HCPs and bereaved parents and how that helped them feel supported, and subsequently made the hospital room feel less silent.[25,36,37]

Kelley and Trinidad[25] was the only article to interview Obstetrician/Gynecology (OB/GYN)/ Academics (n = 8) and health professionals who were also bereaved mothers (n = 3). This article presented conflicting views of the experience between the bereaved parents and the HCP after a stillbirth occurred. Many bereaved parents felt a silence by OB/GYNs, but the HCPs thought that they tried to break the silence by giving as many answers as possible.[25]

3.3.2. Bereaved parents entering a silent reality

Following stillbirth, the silence continues, with eight papers reporting examples of silencing within bereaved populations, their social networks, workplace and community.[11,13,15–17,25,32,35] The silence was also shown to be associated with the actions of those surrounding the parents.[11] Examples of silencing included family members avoiding talking to bereaved parents, not acknowledging the existence of their baby, and never saying their baby's name.[12] Acts of silencing were also overt with bereaved parents describing examples of people they knew walking to the other side of the road to avoid talking to them.[12]

Flenady et al.'s,[15] international survey, reported that one in two parents felt that their community believed parents should not talk about their stillborn baby as it made people feel uncomfortable. Kelley and Trinidad[25] gave a variety of silencing examples from bereaved parents in their qualitative research which included the person looking away when the baby was discussed, a quick and deliberate change of conversation, or simply just not acknowledging the deceased baby. The use of minimisation techniques, such as the use of clichés including "at least you can have a child",' "your baby is in a better place", and "you are young, you can have another" were common and illustrative of both silencing and disenfranchisement.[25]

3.3.3. HCPs silence in antenatal care and professional education

Four articles explored the silence of stillbirth and how it impacted on all facets of professional practice and extended to the education HCPs received regarding stillbirth.[24,25,33,39] HCPs felt silenced in their ability to discuss perinatal death because they feared their colleagues might question their professional competency.[39] In Kelley and Trinidad's[25] focus groups study, OB/GYNS and Academics stated they did not want to get blamed for a stillbirth by the woman, due to the potential for a malpractice suit. Ultimately, this has led to an environment where HCPs cannot easily debrief or seek further support for their own experiences.

Two articles discussed an antenatal silence about stillbirth by HCPs.[15,25] Kelley and Trinidad[25] stated in their qualitative study of bereaved mothers that they felt blindsided by their stillbirth particularly as they had never been informed about stillbirth by their HCP. Furthermore, one world-wide article of bereaved parents, care providers and general community members (n = 6636) which explored HICs, reported that more than a third of bereaved parents perceived that HCPs minimised their concerns before and after their stillbirth.[15]

Two articles specifically focused on informing HCPs of the appropriate practice to help bereaved parents during their hospital admission and avoid potential adverse outcomes, such as stigma.[40,41] Both articles reiterate the need for bereaved parents to create memories, be supported throughout their care, and the need for HCPs to receive continual formal education in confirming stillbirth and assisting bereaved parents throughout their hospital stay.[41]

3.4. Bereaved mothers in LIC experiences of stigma

Three articles included in this scoping review was conducted in LIC- Tanzania, Uganda, Nepal,[16,17,19] with one study including multiple LIC's.[14] Kiguli et al.,[17] found clear examples of the impact of stigma on a bereaved mother due to her baby's stillbirth. These examples appeared to be more socially destructive for the mother such as women being removed from their communities, divorced and even experiencing domestic abuse.[17]

Frøen et al.'s,[14] international study reported strong fatalistic attitudes towards stillbirth around the world by HCPs. Within this survey, 29% of HCPs responded with 'always or often' when asked if the stillborn baby was never supposed to live. Furthermore, three qualitative interview studies[16,17,19] support Frøen et al.'s,[14] results. Paudel et al.,[19] suggested that fatalistic attitudes in a Nepalese community created an attitude that stillbirths were unpreventable

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and therefore there was a need to count every stillbirth. Haws et al.,[16] and Kiguli et al.,[17] studies also suggested that there was a fatalistic attitude in their respective communities towards stillbirth.

Surprisingly, the impact of fatalism on the bereaved mother may not always be damaging, but it appears within the qualitative studies of Haws et al.,[16] and Paudel et al.,[19] protective. Paudel et al.'s[19] of Nepalese mothers, birth attendants, and health care workers reported no discernible stigma attached to bereaved mothers due to how common stillbirth was within their community, and a strong belief that it was God's will. However, bereaved mothers needed to follow the social rules of remaining silent about their pregnancy and not discussing it openly, especially if the baby appeared macerated or immature. Remaining silent protected the women from stigma as her value in the community was then not questioned.[17]

3.5. Experiencing a stillbirth could be transformative

While most of the literature focused on the harmful components of stigma, three of the selected texts indicated that bereaved parents could be empowered by their stillbirth experiences.[12,18,42]. Van's[42] qualitative study on 10 African American bereaved mothers reported that after their loss, women found a 'higher' purpose. St John et al.'s,[18] qualitative interviews of three bereaved mothers suggested that in subsequent pregnancies after a loss, women researched heavily and became informed about how to keep their baby safe in their next pregnancy. Advocacy after stillbirth allowed bereaved parents to find the strength to protect their baby's memory.[12,18] Murphy's[12] qualitative study of 10 bereaved couples and 12 bereaved mothers expressed how bereaved parents, in particular, bereaved mothers, utilised their experience to advocate and challenge the current perceptions, policies, and procedures surrounding stillbirth, or indeed use their experience as a catalyst for changing their lives for the better.[12,18]

4. Discussion

This scoping review has synthesised content from 23 resources examining stillbirth stigma experiences of bereaved parents. To our knowledge, this is the first scoping review to focus solely on stigma and stillbirth. We have identified two types of stigma experienced by bereaved parents – public and self. We have also explained the common stigma experiences bereaved parents have endured, including feelings of shame, blame and guilt as well as being silenced. However, suprisingly, the literature also indicates that bereaved parents can be empowered after their stillbirth by advocating for positive perceptions of stillbirth within their community and clinical change within the health care system. This scoping review suprisingly found some evidence to suggest that there may be a difference of stigma experiences for bereaved mothers in LIC, with two qualitative articles suggesting that fatalistic attitudes towards stillbirth are potentially protective against stigma.

The literature within this review was western dominant, and therefore further research exploring the stillbirth stigma experience in LIC needs to be undertaken. The findings of this scoping review highlight key gaps within the literature and therefore future foci for researchers and clinicians surrounding stillbirth stigma and its impact.

A critical methodological gap within the current literature is a lack of theoretical framework when discussing stigma. Goffman's[4] stigma theory was addressed in three articles[11–13]; however, this theory is criticised for placing the onus of stigma on the stigmatised. Consequently, it does not recognise the macro interactions which influence stigma. Using a standardised framework, such as Link and Phelan's,[5] would enable clarity and examples within concepts such as labelling, status loss and discrimination, separation and stereoping. Also, Link and Phelan's[5] framework address both the micro and macro level interactions in the presence of power, which is relevant to their cultural context.

A significant amount of qualitative literature (n = 18) addressing stillbirth stigma creates something of a methodological limitation to all the studies reviewed. Baum[43] argues that in public health topics, such as pregnancy loss, a balanced approach of research methods is needed to understand the complexity of the issue. Qualitative research provides detailed insights into the experiences of bereaved parents. However, it cannot effectively utilise measurement. Thus, while some experiences of stigma have been reported, the extent and type of stigma in pregnancy loss literature have not yet been adequately measured or described. Without this knowledge, any interventions created to reduce stillbirth stigma may be ineffective.

A well-known limitation and critique of pregnancy loss literature is its tendency to be mother-dominated.[44] Only six of the papers included fathers' views and experiences.[11,12,14,15,17,25] No studies in this review primarily focused on fathers. However, the father's voice is essential, particularly as they are often the person who provides support to the mother, rather than being an equal partner that has also just lost their child.[44] Thus, it should not be assumed that the experiences of stigma in bereaved fathers are the same as bereaved mothers and therefore, the results of this scoping review cannot be generalised to the father's experience. However, such a focus is essential for future research.

5. Future research

Our review has highlighted that there are apparent gaps in the literature related to stigma and stillbirth and future research is needed. As seen within this scoping review, there is a lack of conceptualisation of stillbirth stigma, with only one article organising their findings under a stigma framework, and a further two articles just providing a definition. Furthermore, no articles addressed the differing types of stigma bereaved parents maybe experiencing after stigma. In well-explored areas of stigma, the types of stigma have different outcomes and specific interventions in attempting to reduce it. Therefore, it is important to understand what type of stigma bereaved parents are enduring to ensure more refined attempts at reducing it. Furthermore, methodologically, there was a significant amount of qualitative research (13/15 research articles) and only one quantitative, and one mixed-methods which means that stillbirth stigma has not yet been quantified within knowledge. By providing a measurement to determine the extent of stigma may, in turn, allow an exploration of the impact of stigma on low self-esteem, mental illnesses such as depression and anxiety which are common variables associated with stigma in other areas.

The father's voice is under-represented in stillbirth research, and this scoping review again highlighted this problem. The grief and experiences of the bereaved father are distinct but equal to the mother's, and therefore should be explored further. Finally, the attitudes and perception of society on stillbirth should also be explored. Frøen et al.'s[14] international study offers some insight into the negative perceptions surrounding stillbirth. However, this may need further exploration to be more specific to each country. As seen in other areas where understanding stigma is well-established, such research may provide an opportunity to create interventions which influence public views, perceptions and stigma surrounding stillbirth and perhaps even influence the impact that stigma has on stillbirth rates. Without this information, the operationalisation of interventions targeting stigma reduction so often called for will likely remain inadequate.

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6. Strengths and limitations of this scoping review

All efforts have been undertaken to reduce the limitations of this review. Following Arksey and O'Malley's[23] approach, multiple databases, hand searching of reference lists, the inclusion of grey literature and consultation with other researchers for any other articles was undertaken. Despite this extensive search process, there may have been articles missed. The exclusion of non-English article could have prevented the voice of those with the highest stillbirth rates from being heard. However, this scoping review, for the first time, presents a critical analysis stigma about stillbirth.

7. Conclusion

This scoping review sought to describe stillbirth stigma as experienced by bereaved parents by using the Arksey and O'Malley's[23] five-stage framework. Findings from the literature reviewed suggest that bereaved parents are stigmatised due to their stillbirth. Two types of stigma experienced by bereaved parents were identified – public and self. The collective experience of stillbirth stigma includes feelings of shame, blame, guilt and silence. These experiences challenge the identities of a bereaved mother by questioning her motherhood, her status within her community and how she is seen within the hospital setting. Losing a baby and experiencing stigma could also be transformative and empowering for the bereaved parent. As such, an individual's culture could play a mediating factor in the experiences, extent, and type of stigma felt. There are significant gaps in the literature regarding the bereaved parent's experience of stigma. Also, a clear indication in other fields that stigma has the potential to negatively impact the emotional, psychosocial and physical well-being of the individual. Therefore, further investigations of stillbirth stigma are warranted with a focus on developing instruments to measure the extent and type of stillbirth stigma and understanding the father's stigma experiences.

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Ethical statement

The authors declare that no ethics application was needed as no human or animal participants were included within this study.

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Author contributions

Danielle Pollock: Conceptualisation, data collection of literature and analysis, writing of the original paper and editing. Jane Warland: Supervision of Danielle, data analysis and editing. Tahereh Ziaian, Megan Cooper and Elissa Pearson: Supervision of Danielle, reviewing of the themes and editing.

Conflict of interest

None declared.

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