

# Support after stillbirth: Findings from the Parent Voices Initiative Global Registry Project

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**Keywords:** *stillbirth, bereavement, respectful care*

## Implications for practice

- Major gaps in stillbirth parent support worldwide were identified with parents and communities most in need being most underserved.
- Our findings suggest that closing gaps in providing and receiving support, overcoming silence and stigma, and improving support for affected families requires an intentional and collaborative approach across disciplines and geographies. Including:
  - advocacy to governments and policymakers to overcome complex political and legal challenges faced by stillbirth support providers

- improving access to funding, international collaboration, networking, and partnerships amongst support providers
- development of bereavement and support-specific skills and knowledge through training and peer support or supervision, as well as better funding opportunities for training.

## Abstract

The need for respectful bereavement care following a stillbirth has been poorly recognised within global public health initiatives. To date, there has been no comprehensive cataloguing of providers that support parents after stillbirth, nor any review of the challenges they face. We aimed to identify providers (organisations and point persons) that support bereaved parents worldwide and to investigate the challenges they face.

A systematic global online search was done to identify providers of support after stillbirth. Subsets of providers were surveyed and interviewed. These were purposively sampled to achieve diversity in geography, organisation size and point person role. Challenges in providing support in six key areas – stigma, funding, reach, policy, workforce, and advocacy – were analysed thematically.

Overall, 621 providers from 75 countries were identified. No support providers were identified in 123 countries, and in the 6 countries that carry almost half of the global burden of stillbirths, only 8 support providers were found. Support providers faced challenges in accessing funding, reaching key populations, and training and retaining staff, while complex policies hampered bereavement care. Support providers were challenged by silence and stigma around stillbirth. Overcoming these challenges requires collaboration, effort, and political will at local and international scales.

## Background

Around two million women experience a stillborn baby every year (UN-IGCME, 2020). These stillbirths, and their accompanying burden of grief, are not distributed equally; the vast majority of stillbirths occur in low- and middle-income countries (LMIC) (UN-IGCME, 2020). Inequalities exist within countries, for example higher stillbirth rates are often observed in rural areas compared with urban areas (UN-IGCME, 2020). Parents of stillborn babies are often stigmatised and are more likely to experience adverse mental health outcomes such as anxiety, paranoia, depressive symptoms, relationship breakdown, and social isolation, compared with those who have a livebirth (Heazell *et al*, 2016). Stillbirths are a neglected global public health issue, absent from the Millennium Development Goals and the Sustainable Development Goals, and often invisible and underfinanced in policies and programming (UN-IGCME, 2020).

Respectful bereavement care following a stillbirth is also absent within global public health initiatives. The main global initiative addressing stillbirths, the Every Newborn Action Plan (World Health Organization, 2014), focuses primarily on reducing preventable stillbirths and not on alleviating the burden borne by parents and families following a stillbirth. International advocacy efforts to address this gap are emerging; for instance, the RESPECT study established eight evidence-based principles for bereavement care after stillbirth, including training for healthcare staff, reduction of stigma, physical and psychological support, and supporting informed choices for women and their families. While this initiative is being expanded to include parent voices, particularly from LMIC (Shakespeare *et al*, 2020), there has been no comprehensive cataloguing of organisations that provide bereavement support to families after stillbirth, nor any review of the challenges these organisations face.

The Finding Parent Voices project was created to address these gaps and, alongside the Raising Parent Voices project, was implemented within the Parent Voices Initiative (PVI), which was established in 2020 by the Stillbirth Advocacy Working Group of the International Stillbirth Alliance (<https://www.stillbirthalliance.org/advocacy-working-group/>) to address the absence of parent

voices in stillbirth action. Specifically, this project aimed to:

1. Identify organisations and individuals that provide support to families following a stillbirth,
2. Investigate key challenges related to support provision.
3. Identify potential ways to overcome those challenges.

This work contributed to the Finding Parent Voices Online Registry of Stillbirth Support (<https://www.stillbirthalliance.org/isa-registry-map/>), and sits alongside the Raising Parent Voices project, which aimed to develop a toolkit for stillbirth support providers.

## Methods

We identified and defined two types of stillbirth support providers.

- Parent support organisations: organisations that provided bereavement support to parents who have experienced a stillbirth. These include formal support organisations and networks, meet-up and community groups, Facebook pages, and online forums.
- Parent support point persons: individuals who, through their professional work as midwives, doctors, or counsellors, help to facilitate support activities for bereaved parents. Point persons may create formal or informal networks or support groups, but they have the explicit intent to support parents or offer informal support to parents.

### Identifying stillbirth support providers

A web-based and snowball search was done to identify and collate information on organisations and point persons that provide support to families following a stillbirth. First, we conducted a systematic online search on Google, Facebook, Meetup, and Reddit between July and September 2020 to identify organisations and point persons worldwide. Search terms included combinations of topic and location-specific words (see Appendix 1 in the supplementary file). A pilot search was completed by VPH in London, UK, and New Jersey, USA, to test the search terms and strategy, and results were checked by two study authors, HB and SL. The full search was conducted in Spanish for Spanish-speaking countries and in English for

all other countries. Publicly available data, including location, aims, support offered, target population(s), and contact details, were collected for each organisation and point persons identified using a data abstraction sheet. Only active organisations, defined as having had at least one form of online or face-to-face activity in the previous year, were included. Additional organisations were considered based on a snowball search via professional networks of the study authors. A PVI advisory group was set up to guide the overall PVI project and consisted of international experts working within the field of stillbirth research and parent support.

### Online survey

Survey questions were developed in collaboration with the PVI advisory group and included questions on location and aims, challenges in providing stillbirth parent support and ways to overcome those challenges (see Appendix 2 in the supplementary file). The survey was piloted with two organisations and three point persons known to the PVI advisory group. The final online survey was sent between October and December 2020 via email or social media to those organisations and point persons identified above who had contact information available. Two reminders were sent over a period of three months before an organisation or point person was designated non-responsive. The survey was administered in English.

### Interviews

A subset of online survey respondents was contacted for interview. Purposive sampling was used with the aim of achieving diversity of geographic location, organisation size and, in the case of point persons, role. Selected participants were approached via email to participate in semi-structured interviews over Zoom. Two reminders were sent over two months before an organisation or point person was designated as a non-responder. Interview guides were developed by the study authors, and semi-structured interviews lasting up to one hour were conducted by VPH and recorded via Zoom between January and March 2020 (see appendices 3a,b in the supplementary file). Participants were provided with their previously completed survey answers and a brief guide to the interview process, aims, and themes. Participants were asked questions based on their survey answers

and were then probed and prompted for further information within each pre-defined theme. Two interviews were conducted in Spanish by VPH and later translated into English by AB. Interviewees were asked about challenges and how to overcome them, as well as their successes in providing care. Further information can be found in Appendices 4 and 5 in the supplementary file.

### Analysis

The web search results were analysed descriptively by the Sustainable Development Goals regional classification (United Nations, 2020). Results from the online survey and interviews were analysed according to a framework including seven key thematic areas (Table 1) (Gale *et al*, 2013). Six areas – stigma, funding, reach, policy, workforce, and advocacy – were identified beforehand based on expert opinion from the study authors and the PVI

advisory group. A seventh, understanding of loss, was added to the framework during analysis as a major emergent theme.

Quantitative online survey data was analysed descriptively by VPH. Interview transcripts were coded independently by VPH, AB and SM. Content was analysed according to the thematic framework described above. VPH and AB agreed the final results. Quantitative and qualitative data was analysed in Microsoft Excel. Results were reported in accordance with COREQ (Consolidated criteria for Reporting Qualitative research) guidance (Tong *et al*, 2007) (see Appendix 6 in the supplementary file).

### Ethical approval

This study was approved by the London School of Hygiene & Tropical Medicine Observational/

**Table 1 Description of seven key thematic areas used as a framework for analysing qualitative data**

Key area	Example content
Understanding of loss	What it means to lose a child; parenthood following a stillbirth; ways of grieving and understanding grief after a stillbirth; loss felt by the wider family and community.
Stigma	Prevalence of stillbirth-related stigma; challenges in supporting parents and families stemming from stigma; types and recipients of stillbirth-related stigma at local and national levels; ways of overcoming challenges, either already completed or possible.
Funding	Awareness of funding sources; access to funding sources; challenges in accessing different types and levels of funding; challenges stemming from lack of funding or inability to access relevant funding; ways of overcoming challenges, either already completed or possible.
Reach	Challenges in reaching parents and families physically and/or online; challenges in reaching different populations, eg men, rural populations; capacity to develop support in order to reach more parents and families; ways of overcoming challenges, either already completed or possible.
Policy	Awareness of international, national, and local level policies that influence capacity to support parents and families impacted by stillbirth; understanding of different policies and contributions to policy-making; ways of overcoming challenges, either already completed or possible.
Workforce	Workforce size and skills; capacity of workforce to serve population in need of support; challenges in developing, training, and retaining workforces; ways of overcoming challenges, either already completed or possible.
Participation in advocacy	Understanding of stillbirth-related advocacy; activities undertaken to participate in advocacy; challenges to participating in advocacy; ways of overcoming challenges, either already completed or possible.  Stillbirth advocacy was defined in this study as: 'any activity that is aimed at influencing people who make decisions that could help prevent stillbirths and support bereaved families. This might include people who work on or make decisions on health budgets, health policies, or healthcare services. Examples of activities that would fall within 'stillbirth advocacy' include responding to a request for public input to a local or national health plan, giving a radio interview, teaching or training healthcare professionals, or speaking at an event to explain stillbirth to the public. This is also sometimes called 'lobbying'.'

Interventions Ethics Committee (reference 22591). Written and verbal informed consent was gathered by all survey and interview participants prior to participation.

## Results

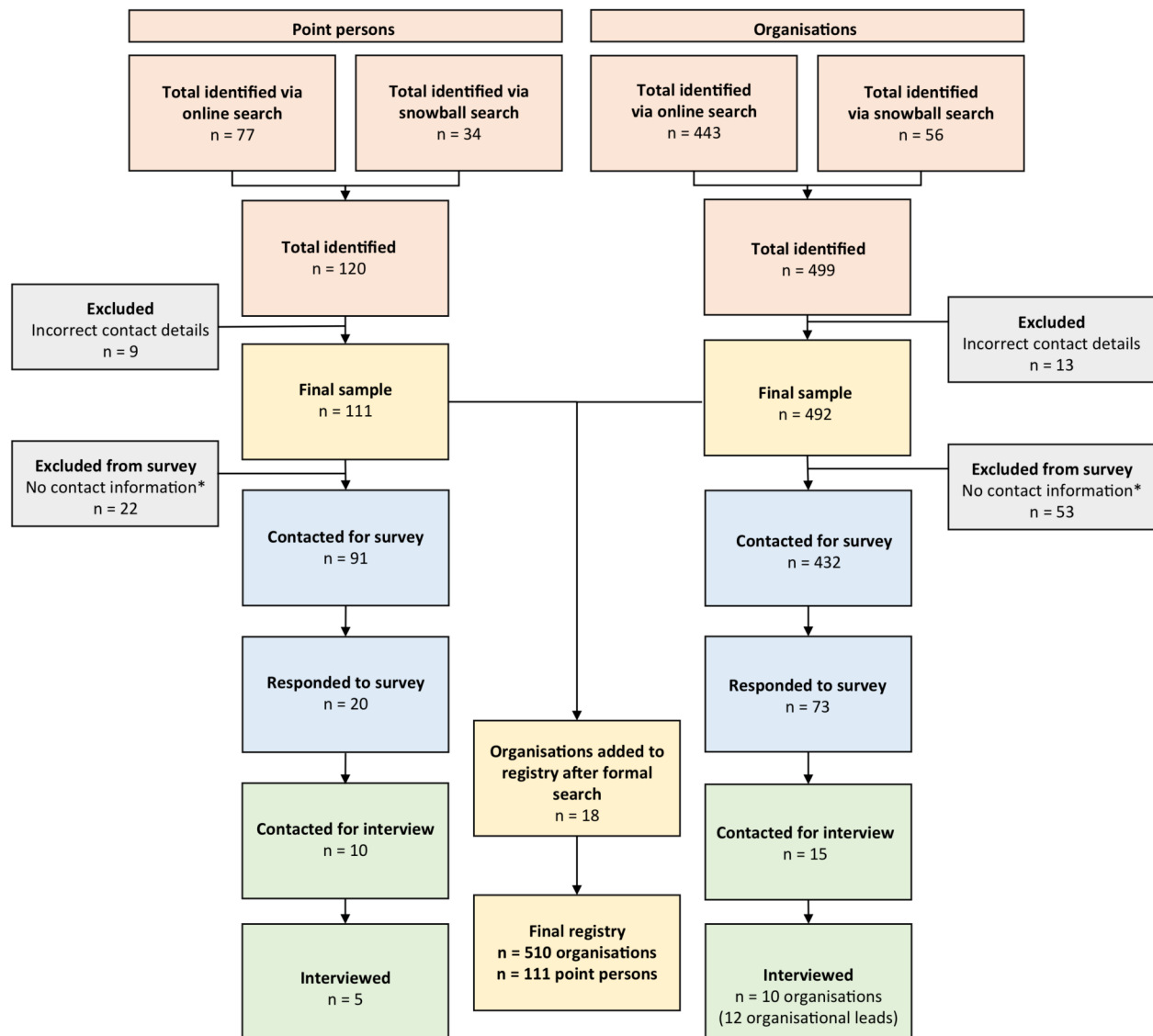
### Web search results for stillbirth support organisations

In total, we identified 619 organisations and 120 point persons. Our final sample included those with available contact details: 510 organisations (485 organisations from 63 countries plus 25 organisations from unknown locations), and 111

point persons from 47 countries, totalling 621 support organisations or point persons from 75 countries (see Figure 1 and Table 2).

Overall, 60% of organisations were located in Northern America and Europe (see Table 2). We found no organisations or point persons in ‘Oceania excluding Australia and New Zealand’, and no point persons in ‘North Africa and Western Asia’. In all other regions, we identified at least one organisation and one point person. In the six countries with the largest number of stillbirths, we only identified eight support organisations: six in India, two in Nigeria and none in China, Ethiopia, Pakistan or the DRC. In 123 (63.7%) countries, we identified no support providers.

Figure 1 Flowchart of participants included at each step of data collection and analysis



**Table 2 Organisations and point persons identified via an online and snowball search, by region**

SDG Region	Countries (n)	Point persons		Organisations		Total	
		n	%	n	%	n	%
Australia and New Zealand	2	0	0.0%	49	9.6%	49	7.9%
Central Asia and Southern Asia	14	16	14.4%	12	2.4%	28	4.5%
Eastern Asia and South-eastern Asia	16	13	11.7%	14	2.7%	27	4.3%
Latin America and the Caribbean	33	28	25.2%	24	4.7%	52	8.4%
Northern America and Europe	45	28	25.2%	340	66.7%	368	59.3%
Oceania (excl Australia and New Zealand)	14	0	0.0%	0	0.0%	0	0.0%
Sub-Saharan Africa	48	17	15.3%	33	6.5%	50	8.1%
Western Asia and Northern Africa	24	9	8.1%	13	2.4%	22	3.5%
Unknown location	-	0	0.0%	25	4.9%	25	4.0%
<b>Total</b>	<b>196</b>	<b>111</b>	<b>100.0%</b>	<b>510</b>	<b>100.0%</b>	<b>621</b>	<b>100.0%</b>

There was a diversity of organisation types, including established organisations, informal groups, online blogs, and social media pages. Over 90% (n=463) of organisations used English as their primary working language; 47 organisations used a language other than English, including 27 (5.3%) Spanish, 6 (1.2%) German, and 2 (0.4%) Catalan. Other languages included Bulgarian, Finnish, Hindi, Irish, Italian, Japanese, Malay, Norwegian, Russian, Swedish, Turkish and Ukrainian.

### Survey and interview results

Results from both surveys and interviews are presented here. In total, 432 organisations and 91 point persons identified via the web search were invited to participate in the online survey; 73 organisations and 20 point persons responded (21.9% of point persons and 16.9% of organisations, with some regional variation) (see Figure 1 and Table 3). Of those, 10 point persons and 15 organisational leads were contacted for interview; 5 point persons and 12 organisational leads from 10 organisations responded and were interviewed (see Figure 1 and Appendix 7 in the supplementary file). Notably, none of the 48 organisations in any Asian or Northern African regions, or whose region was unknown, responded to the online survey.

### Understanding of grief and stillbirth

Both point persons and organisational leads identified a lack of understanding of grief and stillbirth among families, communities and

healthcare workers as a major challenge to supporting parents following a stillbirth. Not normalising or accepting trauma and grief after the death of a baby meant that support was viewed as unnecessary by the community, creating a barrier against those providing support as well as those in need. Trauma and grief were compounded for parents by an expectation that grief would disappear with the birth of a subsequent child, a lack of understanding that a stillbirth is not an abstract loss but the loss of a child and person, and perceived inadequate medical care.

‘One of the biggest issues is most people forget, you know, we never forget because it’s our children. But outside our own families, people don’t really, they’ve moved on. They don’t even remember that we had a stillbirth or a miscarriage or whatever, let alone when.’

**Organisational lead 9, Northern America & Europe**

‘What is keeping them away from the help that they need...it’s that silence.’

**Point person 4, Northern America & Europe**

Overcoming the challenges involved with understanding the loss and grief associated with stillbirth affects not just parents, but the wider family and community as well. The importance of providing bereavement support to grandparents after a stillbirth was emphasised.

‘The grandparents are grieving twice aren’t they, they’re grieving for the loss of the child,

**Table 3 Response rates of point persons and organisations contacted for participation in the survey**

SDG Region	Point persons		Organisations		Total	
	Contacted	Responded	Contacted	Responded	Contacted	Responded
	n	(%)	n	%	n	%
Australia and New Zealand	0	-	43	8 (18.6%)	43	8 (18.6%)
Central Asia and Southern Asia	16	5 (31.3%)	7	0 (0%)	23	5 (21.7%)
Eastern Asia and South-eastern Asia	12	2 (16.7%)	10	0 (0%)	22	2 (9.1%)
Latin America and the Caribbean	18	3 (16.7%)	22	2 (9.1%)	40	5 (12.5%)
Northern America and Europe	25	7 (28.0%)	294	56 (19.0%)	319	63 (19.7%)
Oceania (excl Australia and New Zealand)	0	-	0	-	0	-
Sub-Saharan Africa	11	2 (18.2%)	25	7 (28%)	36	9 (25%)
Western Asia and Northern Africa	9	1 (11.1%)	11	0 (0%)	20	1 (5%)
Unknown	0	-	20	0 (0%)	20	0 (0%)
<b>Total</b>	<b>91</b>	<b>20 (21.9%)</b>	<b>432</b>	<b>73 (16.9%)</b>	<b>523</b>	<b>93 (17.8%)</b>

but also for their own child who has lost their child, so you know, there's generational sort of grieving.'

**Organisational lead 7, Australia & New Zealand**

Societal expectations around what grief should look like acted as a major barrier to providing support. Stillbirth was minimised within the family and community and was not viewed as deserving of grief.

'Overall [grieving is] not something that people are encouraged to share and talk about, but more to be tough and strong and move on.'

**Organisational lead 2, Sub-Saharan Africa**

'[they say] how, two weeks after your baby died, are you still crying?'

**Organisational lead 1, Latin America and the Caribbean**

Several participants noted that gendered expectations about how men did not need to grieve presented a barrier to providing men with the support they required.

'Men...their main focus is on, how's my partner and how is she doing, and everyone is worried about her. They don't always ask about him and sometimes I feel like they are really expected to be brave and move on

quickly, and you know, they grieve as well... sometimes they don't get the support they need, and I do think there is this natural stigma that a man shouldn't cry, and we all know that it's totally okay for men to cry and it's you know, a really manly thing to do, to show emotion.'

**Point person 5, North America and Europe**

'Men... it's like they have no right to cry. They don't have a right to just stop, and grieve, and this has a greater impact because the man...doesn't even have time to be able to go to his counselling sessions.'

**Organisational lead 1, Latin America and Caribbean**

Although many participants spoke about similar perceptions of grief following a stillbirth, one participant from Southeast Asia noted the differences between Western rituals and practices and those in their country.

'...in [the UK], you remember the baby on the day of their birth, that way you celebrate that, but it is not like that here...if some adult dies, we have so many rituals after 13 days, every month, then every year, then every four years, but for stillbirth, I don't think we have such kind of rituals.'

**Point person 2, South East Asia**

Organisational leads spoke about a general societal discomfort or taboo around death, and emphasised that this contributed to feelings of shame, silence, and stigma around stillbirth.

‘In Western society where we’re uncomfortable with grieving in general, grieving for babies is ... even more difficult... so until we kind of give people alternatives and ways to think about that differently, it’s going to be difficult.’

**Organisational lead 3, Australia and New Zealand**

‘For families, it is very difficult to find help, it is a cultural challenge. And in Latin American countries? Losing a baby feels shameful in many cases and it generates fear, to tell others that your child has died. Because whoever listens does not know how to support you. Therefore, it is best to remain silent and not look for help.’

**Organisational lead 1, Latin America and the Caribbean**

These understandings of loss underpinned findings within other major themes, reported below.

## Stigma

Across all regions in this study, stigma was identified as a major challenge to providing parent support. Organisations and point persons reported stigmatisation coming from many directions including wider society (66.4%, n=48 organisations; 65.0%, 13 point persons), family members (58.2%, n=43 organisations; 55.0%, 11 point persons), and healthcare workers (36.3%, n=26 organisations; 45%, 9 point persons). Stigma compounded the trauma of stillbirth, and created and amplified silence around it.

‘People suffer in silence, because of what the society will think about them and when they suffer in silence, they’re unable to get the relevant support from [an] organisation or even within the community.’

**Organisational lead 6, Sub-Saharan Africa**

Participants spoke about stigma being rooted in a lack of education, poverty, religious institutions, and the media. They cited a pervasive lack of awareness and knowledge of stillbirth and general reproductive health, which contributed to stigma and silence and built barriers to support.

‘Stigma is not the root cause of the root problem, but the root problem is poverty. Poverty in terms of education... People are not being educated. So definitely for us to work around stigma, we need to do a lot of education.’

**Organisational lead 12, Sub-Saharan Africa**

‘Media outlets wanting to put trigger warnings on stories related to stillbirth... you know, I understand why, but until we’re willing to have a conversation without things like that then we’re actually never going to change people’s awareness and until people are aware... the stigma is not going to reduce.’

**Organisational lead 3, Australia and New Zealand**

Bereaved mothers were recognised as most stigmatised: by their families, the media, healthcare workers, society, and older generations. Stillbirth was perceived as a bodily failure, and participants stated that often bereaved mothers were not recognised as mothers, with negative implications for accessing not only emotional support but also support at work. Policy that was developed from the cultural viewpoint that stillbirth is something that people should get over quickly prolonged parents’ grief and deepened stigma associated with stillbirth.

‘I think there’s a lot of feeling of failure and there’s something wrong with my body, there’s something wrong with me.’

**Point person 5, North America and Europe**

‘The parents feel that they don’t have the right to be supported. Many don’t ask for help even when they need it, because in their family and at work, they have been told that at two weeks, they have to be ok.’

**Organisational lead 1, Latin America and the Caribbean**

Though stigma around stillbirth is complex, most participants mentioned that an effective way to overcome it was to talk more openly about stillbirth. Being open about grief and bereavement with family members, the community, and at work was seen as a direct way of reducing stigma related to stillbirth. Several participants spoke about the positive impact that celebrities or high profile individuals can have on reducing stigma by speaking openly about their own stillbirth or baby/pregnancy loss. Providing more opportunities for education around stillbirth and associated grief, whether at home, school, or work was identified as key.



## Funding

Across all regions, most organisations (70.5%, n=12) did not receive any funding, except in Northern America and Europe, where nearly half received funding (46.4%, n=26 vs 41.1%, n=23). For those that did, annual funding over the previous year (2019–2020) ranged from US\$350 to US\$1 million.

The lack of specific funding opportunities for stillbirth research, action, and advocacy was noted by point persons and organisational leads across all regions as a barrier to providing evidence-based support to parents. In many settings, participants noted that stillbirth support was not integrated into the healthcare system, and participants spoke about difficulties finding funding to provide support outside the healthcare system.

‘We used to say...nobody like really wants to open up their wallets, whether they’re individual or institutional, and like, give money for sad mums.’

**Point person 4, Northern America & Europe**

‘So we haven’t been able to get any funding... people are like, this is just a small thing, just get other babies.’

**Organisational lead 11, Sub-Saharan Africa**

Organisational eligibility criteria attached to funding proposals was a barrier for smaller organisations, particularly in LMIC, and a lack of opportunities to network and develop partnerships with larger organisations in other regions further contributed to an inability to access funding. Several organisations faced difficulties in knowing where and how to apply for funding.

‘It is not about...good ideas to get funding, it’s more about the relationships that we have.’

**Organisational lead 12, Sub-Saharan Africa**

Participants felt that linking and collaborating with others working in the same field would provide better chances of successfully applying for funding opportunities and allow them to be better informed of such opportunities. Training on how to find and apply for funding would additionally help to overcome these challenges.

## Reach

The survey found that bereaved parents, families, and healthcare workers were the primary recipients

of parent support, and almost all organisations reached their recipients online (94.5%, n=69), by social media (90.4%, n=66), or by word of mouth (87.6%, n=64). In general, organisations reached substantially more people than point persons, with an average of 473 people reached in the last year by organisations compared with 46 people by point persons.

Physically reaching parents was a commonly reported challenge. A lack of funding and resources such as internet, phones, and vehicles created practical barriers to communicating with parents. Support providers were often one of the only, or the only, provider within a large area, posing difficulties in reaching everyone who needed support.

‘We reach people by word of mouth. For example, right now I am supporting a woman in a very small place in [this country], very, very, very far away, and we do it by telephone because she does not have internet. This is a huge challenge. Many do not even know we exist.’

**Organisational lead 1, Latin America and the Caribbean**

‘A lot of our people, our families that we serve, do not live close to us, so that’s a challenge for them to come, they might live an hour or two away.’

**Organisational lead 2, North America and Europe**

Organisational leads discussed how reach-related challenges were linked to difficulties maintaining contact with local hospitals and healthcare providers. The lack of a coordinated referral system through which support providers could reach parents in healthcare settings posed challenges.

‘There are, I’d say, probably a dozen major hospitals in the area and then all the private ones. And to try and maintain contacts at all of those is very, very difficult.’

**Organisational lead 9, North America and Europe**

Reach was affected by barriers relating to cultural background and social class, and point persons and organisational leads alike spoke about difficulties adapting their services for different groups.

‘Most people here speak English, but we have a lot of Spanish-speaking patients. And so it’s been a challenge trying...you know, we don’t want for anyone to feel that they can’t be

supported, just because they speak a language that's not you know, a language that we speak.'

**Point Person 5, North America and Europe**

'The topic of stillbirth, it cuts across women of all social classes, but hits the poorest homes hardest, and then this issue of how to reach them, how to support them? How to support this group...that is becoming more and more the majority of women?'

**Point person 1, Latin America and the Caribbean**

Maintaining contact with bereaved parents and families with complex needs, such as those experiencing mental health issues or domestic violence, was another challenge.

'Imagine when somebody is in that situation of domestic violence...the chances of having a stillbirth are very high, and most people would just be looking at the physical person, but not the emotional person when they deal with these domestic cases of violence.'

**Organisational lead 12, Sub-Saharan Africa**

'We are also seeing significant increases in the complexity of cases...five years ago, somebody would be ringing or joining a group and the focus would very much be on their grief. Now, you know, other mental health issues, family, other family crises all of those things are coming in, as well, so the skills that volunteers need to have and paid staff, and particularly our counsellors need to have is broader and needs to broaden out and so that capacity for people to risk assess everything from being able to undertake a suicide assessment, to be able to sensitively explore issues of family violence, things that are really, really present and have to be factored into services now.'

**Organisational lead 3, Australia and New Zealand**

The need for integration of bereavement care and support into the healthcare system was emphasised by participants, and many spoke about the positive impact that better collaboration and communication between hospitals and support providers could have. This would enable services to scale up and reach more parents and families across larger areas. Similarly, many participants spoke about the importance of working with the government to reach more communities.

In the context of the Covid-19 pandemic, many organisations and point persons reported using online services more than usual which caused some technological difficulties but also provided a chance to expand their reach. Many participants spoke about the opportunities of providing online support; it enabled them to reach further out into communities, in particular fathers and other male family members, who may not have accessed support previously. Several participants noted that, to improve reach and inclusivity, support needed to engage with the whole family, particularly grandparents.

## Policy

A third of organisations (35.6%, n=26) and half of all point persons (50%, n=10) were not aware of any local or national policies or laws relevant to stillbirth in their country or area. The most commonly reported political or legal challenge was the lack of registration or certification of stillborn babies. This was most common in LMIC.

'I am not sure I've heard of any mother who has received a birth certificate for their baby who was born silent.'

**Organisational lead 11, Sub-Saharan Africa**

Many political and legal challenges stemmed from a lack of awareness of stillbirth at policy levels, which had consequences for policy and protocol development, as well as parent empowerment.

'There is no public policy at national level, neither for perinatal grief nor perinatal death. This topic does not exist, it is not written in public policy... and this also means that there are no protocols in hospitals.'

**Organisational lead 1, Latin America and the Caribbean**

'Our clients do not get to know about their rights, they do not get to be empowered.'

**Organisational lead 6, Sub-Saharan Africa**

Large variations in policies and protocols around the definition of stillbirth, burial of stillborn babies, parental leave, birth and death certification, mandated bereavement care, foetal autopsy and investigation, and recognition for stillborn babies and their parents, presented challenges to service providers. In particular, small organisations had limited capacity to keep up-to-date with relevant legal and political changes.

‘We don’t have any medical background; we don’t have any legal background. And as things become more complicated, it’s getting more and more difficult for us to just be able to encompass all these parents that need our support.’

**Organisational lead 9, North America and Europe**

‘The care we offer is so diverse... some people have quite good support and a lot of different opportunities and groups and lots of contacts with the hospital if they want to but in other parts of [this country], there’s actually nothing, they [are] just sent home afterwards.’

**Point person 3, North America and Europe**

Similarly, complex laws around stillbirth made it difficult to provide and access support. One organisational lead described how an organisation reneged on its commitment to providing paid parental leave following a stillbirth. Another discussed how bereavement leave did not apply in the event of a stillbirth, as parents were not deemed parents until a live baby was born.

‘The administrators of the program said, you’re no longer parents so you’re cut off as of today... so while they’re trying to grieve and plan funerals and recover, they’ve got this government program saying, sorry, we need our money back.’

**Organisational lead 10, North America and Europe**

‘There are five days [leave] for any type of death, it could be if your father dies. But normally, they don’t even give you the 5 days because as the baby didn’t exist in any way, there is nothing that gives you the right, you were not anyone’s father.’

**Organisational lead 1, Latin America and the Caribbean**

Lastly, some point persons reported fear that legal action could be taken in the case of a stillbirth which diminished the quality of care and support received by parents.

‘... in our profession if something bad happens litigations are there. People will start fighting with you, it’s very difficult for doctors also... Definitely parents should raise their voice, but we have to make them understand also that things can go wrong at any time, it is not that simple... it is not in our hands.’

**Point person 2, Southeast Asia**

The importance of government or state involvement in stillbirth support and care was emphasised as pivotal by both point persons and organisations. Many political and legal challenges were thought to be amenable to decision-making and resolution at those levels only; for example, support providers felt unable to influence decisions around provision of parental leave for stillbirth. Formalised procedures for registration, certification and burial of stillborn babies, and consistent implementation of these procedures, were also seen as crucial. Participants suggested that better training and education for healthcare workers on these procedures would improve care.

## Workforce

Almost half of all organisations (46.2%, n=43) paid their employees; this was similar across regions except for Sub-Saharan Africa, where almost 90% (n=7) paid their employees. The majority of point persons (66.7%, n=14) provided support as part of their usual job (ie they did not receive additional funding outside their usual pay) while some (38.1%, n=8) volunteered their support in addition to their usual job.

Participants reported feeling overburdened and overwhelmed. The emotional burden of providing stillbirth support was commonly raised as a major challenge to providing respectful and consistent care, both within and outside healthcare settings.

‘I try to understand how much I can help and how much I can contribute, how I can ease the pain and how I can help them get through this, but sometimes it’s overwhelming.’

**Point person 5, North America and Europe**

Peer support and supervision were raised as important for overcoming these challenges. Having a space where staff could talk and work through their own emotions, with peers and/or a trained supervisor or counsellor, would help to offload some of the emotional burden that comes with working with stillbirth, and was seen to improve motivation and staff retention as well as the quality of parent support.

Several participants reported that suboptimal healthcare compounds parents’ trauma, leading them to require more bereavement support later on. Inconsistencies in care in healthcare settings had consequences for supporting parents when they arrived at a support organisation.

‘It’s unfortunate to go through loss, but why do you have to allow them to be burdened by other traumatic experiences, by how you’re treating them.’

**Organisational lead 6, Sub-Saharan Africa**

Several solutions to improving the support given to parents in healthcare settings were proposed, including having training sessions for healthcare workers on how to deal with grief, loss and bereavement and the need for a dedicated, coordinated approach to perinatal bereavement care. In addition, the presence of a designated person or team who could respond to stillbirth and bereavement within a hospital or a healthcare system would enable consistent care for all parents and families, and improve parents’ continuation of care between the healthcare system and bereavement services. An intersectoral approach to bereavement care that included the medical and social work communities was highlighted as crucial.

## Advocacy

The majority of organisations and point persons (61.6%, n=45) had engaged in some form of stillbirth-related advocacy. This included contributing to media articles and interviews, participating in relevant discussions or events, lobbying politicians and parliament, providing evidence to governmental reviews, leading training, organising and participating in sponsored and community events, and contributing to national and/or international stillbirth-related groups, networks, or societies. However, difficulties reaching the right audience and a lack of opportunities to participate were reported, as was a lack of interest in stillbirth and stillbirth advocacy from the media and politicians.

‘You keep writing letters and letters and nobody responds.’

**Organisational lead 11, Sub-Saharan Africa**

‘We feel like there’s little impact, or nothing can be seen...sometimes it becomes overwhelming to keep on talking about this.’

**Organisational lead 6, Sub-Saharan Africa**

A lack of resources to participate in advocacy was also reported, and participants spoke about the lack of people power, skills, training, funding, and time as a major challenge.

‘I might be able to talk to the social workers and staff at one particular hospital, and that hospital may greatly improve how they’re dealing with the whole situation surrounding birth and loss, but what about the other eleven in the area?’

**Organisational lead 9, North America and Europe**

‘We have been on the television, on the radio...but what happens is that there is still no money.’

**Organisational lead 1, Latin America and the Caribbean**

Language barriers were also reported as a challenge to participation in international stillbirth-related advocacy by some participants in non-English-speaking countries.

‘If [international] organisations want to have more people participate and more people that are interested in the problem, there have to be channels of dialogue also in Spanish or in Portuguese... there has to be something, dialogue channels, they have to be opened up, the message has to be spread, and they have to allow many people to express themselves and exchange ideas...I think the language issue is a limitation for many people.’

**Point person 1, Latin America and the Caribbean**

Partnerships and connections with other organisations working in stillbirth parent support or related areas, as well as with government and with religious and cultural institutions, would help participants to participate more actively in stillbirth-related advocacy. Advocacy training was also highlighted as a potential way to overcome some advocacy-related challenges and increase skills in order to build capacity across organisations.

## Discussion

In total, 621 support providers across 75 countries were identified. This points to diverse support available to parents and families in some contexts; however, large gaps in support provision remain with no support identified in over 60% of countries. In the six countries with the highest burden of stillbirth, only eight support providers were identified; six of these were in India and two in Nigeria, with none identified in China, Ethiopia, the DRC, or Pakistan. While this may be in part due to lack of an online presence of some support

providers, or an online presence in a language other than English, it is also probably indicative of vast inequities in provision of support and invokes the concept of the ‘inverse care law’ where those most in need are least likely to receive care (Cookson *et al*, 2021; Tudor Hart, 1971). While this study did not explore patterns of burden and support provision within countries, it is likely that this holds in many contexts, so that those most in need in any country are least likely to be able to access bereavement support after stillbirth (Boerma *et al*, 2018; Kingdon *et al*, 2019).

Inequality of access to stillbirth support was highlighted in this study. Interview participants were often one of few support providers, or the only one, in vast geographical areas. Reaching populations in need was difficult, due to challenges such as poor internet or telephone signal, as well as cultural, social, and language barriers. Those most in need may present with complex backgrounds including, for example, exposure to domestic violence, which need additional separate skills to manage. The ability to reach and support historically-deprived indigenous and migrant populations was also highlighted as challenging due to differences in language and culture. Similar inequities have been documented elsewhere (Auger *et al*, 2020; Callander *et al*, 2021; Gamlin & Holmes, 2018). As part of the Raising Parent Voices project, a toolkit for stillbirth support specifically within indigenous populations in Australia is planned.

Stigma also played a part in restricting reach to some populations. Stigma linked to stillbirth is well-documented (Burden *et al*, 2016; UN-IGCME, 2020), and, similar to other studies, we found that stigma was seen to come from all sectors of society and contributed to a silence around stillbirth, limiting reach and impact of bereavement care (Mills *et al*, 2021). Both survey and interview respondents reported that stigma and understanding of grief and loss was often gendered, with far fewer men able to access support or to grieve openly and women perceived to be more commonly apportioned blame for stillbirth; this is also documented elsewhere, highlighting the need for more inclusive respectful bereavement care (Burden *et al*, 2016; Jones *et al*, 2019). Moreover, as Murphy (2013) noted, parents bereaved by stillbirth are often not recognised as parents, especially when it is their first child, which compounds their distress. However, in some

contexts, progress had been made in reducing this stigma, for example via celebrities speaking openly about their own stillbirth. Feasey (2021) has noted that celebrities talking about their own pregnancy losses might ‘go some way towards helping, not the pain or grief per se, but the shame, silencing, guilt and loneliness that is often said to follow the experience’.

Inequalities in support provision were often underpinned by difficulties in accessing and navigating stillbirth-specific funding opportunities, especially for smaller organisations. Eligibility criteria attached to larger international grants presented a barrier to accessing funding, as smaller organisations without a history of handling large funds could often not even apply for them. Lack of access to international arenas, where partnerships and collaborations could be built across organisations fed into this, further limiting capacity to provide support to parents. This was highlighted particularly by participants in Sub-Saharan Africa and Latin America. Global inequalities in access to funding have previously been highlighted in other areas of maternal, newborn and child health (Arregoces *et al*, 2019; Greco *et al*, 2008; Powell-Jackson *et al*, 2006).

Similarly, complex policies and laws around stillbirth affected support providers’ ability to reach and support key populations. Geographical differences in policies relating to, for example, certification, registration, and burial of stillborn babies, created a complicated policy landscape that was difficult to navigate for both parents and support providers. Changes between neighbouring hospitals, localities, and countries in level and type of care provided again feeds into inequalities in support provision, with implications for outcomes (Arroyave *et al*, 2021). In many contexts, this was perceived to be underpinned by a lack of prioritisation of stillbirth at policy levels, and a lack of sustainable policy implementation (Ssegujja, 2021).

All of these issues underpinned challenges in maintaining skilled and motivated staff for stillbirth parent support. Staff were reported to be overwhelmed and overburdened, and in most contexts were providing support to a large number of parents and families. A lack of funding for opportunities for training and development, as well as for basic pay, resulted in high staff turnover. Similar issues have been documented in other areas of healthcare (Haines *et al*, 2007; Hermann *et al*,

2009). Additionally, many participants in this study working in healthcare settings pointed to a lack of peer support or supervision, which contributed to diminished motivation; correspondingly, some point persons in higher income healthcare settings spoke about the positive impact that supervision at work had on their ability to provide consistent and high-quality care to parents and families. The benefits of peer support and supervision are well-documented (Hermann *et al*, 2009; Yousafzai *et al*, 2014) and learnings should be transferred to stillbirth support.

Overcoming these challenges is complex, and many potential solutions were proposed by participants in this study. While there is not room here to address all solutions, some were consistently raised across regions. Formalised policies and laws relating to stillbirth were seen as critical to providing respectful care to parents. Participants across all contexts emphasised the need for a coordinated and collaborative approach to stillbirth parent support. Development of a coordinated referral pathway, by which parents could be referred from healthcare settings to support providers, could form part of a more systematic approach to equitable stillbirth bereavement care, particularly for parents and families who require more comprehensive support. This has been highlighted elsewhere; Siassakos *et al* (2018) highlighted an urgent need for training and a national pathway for stillbirth care in the UK. Indeed, Boyle *et al* (2020) noted that stillbirth was not only a challenging area of practice but also that guidelines were tricky to produce due to a 'sparse and disparate evidence base'. Notwithstanding this, the Perinatal Society of Australia and New Zealand/Stillbirth Centre of Research Excellence has recently updated its guidelines to improve the care given to bereaved women by antenatal providers and associated services.

In the absence of more immediate funding for stillbirth parent support, the improvement of existing networks and development of new ones to link smaller organisations with others in the same area may help to overcome some of the challenges discussed above. Sharing knowledge and learning about the practicalities of successfully applying for funding would help to enable smaller organisations to grow. Similarly, the development of more inclusive networks would be welcome; the sole use of English within global health research and

advocacy is increasingly highlighted as an equity issue (Pakenham-Walsh, 2018) and development of more diverse groups and networks would enable further collaborations for stillbirth-related research, practice, and advocacy.

## Strengths and limitations

This research constitutes the first global review of stillbirth parent support. Organisations of all sizes as well as point persons, who largely work independently and so may be less visible than larger support organisations, were included in this review. This diversity allows for exploration of challenges faced by support providers across contexts.

There are some limitations to this research. Some organisations and point persons, particularly smaller groups and point persons who may provide support on a small-scale or ad hoc basis, may be difficult to find online and, whilst the snowball search may have helped to close this gap, many may be missing from this analysis. Smaller support organisations, for example, informal social media groups, may be less well-established than larger organisations and some identified in the web search may no longer be active, whilst others will have been created in the period since data collection. The web search was undertaken in English and Spanish only, therefore organisations and point persons working in settings or with target audiences that are not primarily English- or Spanish-speaking were missed. For example, in the United Arab Emirates (UAE), seven English-speaking organisations were identified while no organisations with Arabic as a primary language were identified. Demographic information about study participants and their employees or volunteers, for example gender and age, was not captured. This could have further added to our understanding of who supports parents after a stillbirth.

## Conclusions

The Finding Parent Voices project set out to understand what support is available to parents following a stillbirth and what challenges exist to support those affected by a stillbirth. The mapping of stillbirth support revealed large gaps, and, critically, support was largely missing in the highest burden countries. We primarily identified stillbirth

support in North America and Europe, with a range of types of support offered. Key challenges in providing this support included an array of issues linked to understanding of loss, stigma, funding, reach, policy, workforce, and advocacy. Overcoming these challenges will require multidisciplinary and collaborative efforts. The development of a coordinated approach to stillbirth bereavement care at local, national, and international policy levels could help to address some of these challenges, while better access to funding and networks could improve availability of support in the highest burden countries.

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**Funding statement:** This project was funded by a grant from the Partnership for Maternal, Newborn and Child Health (PMNCH), Geneva, Switzerland.

**Acknowledgements:** We would like to thank Davis Faigao and the August99 team for registry design, formatting, and publication. We thank those who piloted the study materials: Debbie Haine (2 Degrees Foundation), Clea Harmer (Sands UK), Sowmya Thota (Fernandez Hospital), Daisy Goodman (Dartmouth Hitchcock Medical Center), Sue Steen (Bethel University), Sheetal Samson (Hyderabad). Finally, we would like to thank all of the participants in our study, without whom this research would not have been possible.

**Author contributions:** Technical oversight of this project was led by SL, HB and CS. Quantitative data collection, management, and analysis, and qualitative data collection and management, were undertaken by VPH. Qualitative data were analysed by VPH, AB and SM. VPH and AB transcribed interviews from audio/visual recordings; AB translated two transcriptions from Spanish to English. The first draft of the paper was undertaken by VPH, with specific contributions from SL, HB, CS, AB, AD, SM. All authors reviewed and commented on the final text.