Ending preventable stillbirths 3

Stillbirths: economic and psychosocial consequences

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Despite the frequency of stillbirths, the subsequent implications are overlooked and underappreciated. We present findings from comprehensive, systematic literature reviews, and new analyses of published and unpublished data, to establish the effect of stillbirth on parents, families, health-care providers, and societies worldwide. Data for direct effects of this event are sparse but suggest that a stillbirth needs more resources than a livebirth, both in the perinatal period and in additional surveillance during subsequent pregnancies. Indirect and intangible costs of stillbirth are extensive and are usually met by families alone. This issue is particularly onerous for those with few resources. Negative effects, particularly on parental mental health, might be moderated by empathic attitudes of care providers and tailored interventions. The value of the baby, as well as the associated costs for parents, families, care providers, communities, and society, should be considered to prevent stillbirths and reduce associated morbidity.

Introduction

Despite the 2·6 million stillbirths worldwide,1 the costs of stillbirth are largely unknown and therefore unappreciated by contrast with other adverse pregnancy outcomes.2–5 For the most part, health metrics, such as quality-adjusted life-years (QALYs) and disability-adjusted life-years (DALYs), have neglected stillbirth. No value is generally given for the loss of life or the loss to parents and families. Most economic analyses have focused on the cost of stillbirth prevention.6,7 In low-income and middle-income countries (LMICs), costs vary from US$4781 to $10 571 per stillbirth averted (in 2013 prices).6,8 In high-income countries (HICs) with lower stillbirth rates, prevention costs are greater than they are in LMICs—eg, smoking cessation costs $125 961 per stillbirth averted.9 If stillbirths are included in analyses of the effect of antenatal and intrapartum care on maternal and newborn deaths, the cost per death averted reduces substantially from $27 551 to $2143 (panel 1).10 However, to accurately assess whether these programmes are cost effective, a better appreciation of the costs of stillbirth is needed and so far, no comprehensive estimates have been made.

In this Series paper, the costs associated with stillbirths are described as direct (including the cost of medical care) or indirect (such as welfare payments) financial costs. Outcomes are divided into psychological and social effects on bereaved parents and families,10 and overall effects on health professionals. We identify these costs and outcomes through systematic reviews and new analyses of published and unpublished data (panel 2).

We also evaluate interventions to reduce negative effects, such as parental support by peers or professionals. To address the cost-effectiveness of these interventions and those to prevent stillbirth, we consider the effects of different methods used to value the loss of fetal life. Most studies included in the systematic reviews were undertaken in HICs (n=177), with fewer studies in LMICs (n=26; appendix p 68).

Direct financial costs of stillbirth

Three studies describing direct costs, including investigations into the cause of death, ranged from $1450,11 and £19511 to $8067.12 Care costs for stillbirths were 10–70% greater than with a livebirth.7,13 Direct costs of health-care provision were typically met by government or insurance...
companies, although in some cases this expenditure was passed on to parents; 14% of respondents from HICs and 32% from middle-income countries (MICs) had medical costs to meet during and after the birth. Where reported, parents paid between $397–3093 for investigations to identify the cause of stillbirth and $118–20000 in hospital fees for additional medical care (appendix pp 75, 76).

No direct reports of the cost of care in subsequent pregnancy exist, although three papers,21–23 all from HICs, recommended additional fetal monitoring in pregnancies after a stillbirth. By use of these recommendations to derive models of care, we estimated costs from £3499 after a stillbirth of a non-recurrent cause to £4057 for a stillbirth of unknown cause.11 A pregnancy after stillbirth costs £558–1735 more than if the previous pregnancy ended in an uncomplicated livebirth. Additionally, if care included more intensive surveillance with cardiotocography, costs rose to £4654–5616.1415 Thus, the costs of subsequent pregnancy care add to the health-care costs associated with stillbirths in HICs; this situation will extend to MICs as these countries scale-up more intensive antenatal monitoring and care.

**Indirect financial costs of stillbirth**

The most frequent indirect costs for parents after stillbirth were for the funeral and burial or cremation of their baby (appendix). For some, this cost was mitigated by health insurance, government payments, or grants. Parents’ free text responses in the International Stillbirth Alliance (ISA) survey (appendix pp 22, 23) show the substantial financial burden of this group, magnifying the effect of these parents’ loss (panel 3).

Although some parents did not have to pay, others reported costs for funerals ranging from $460–11719, extending to $1179–11605 for burial plots and $1410–4605 for memorials (appendix pp 75, 76). The theme that occurred most frequently in the free text responses was the long-term financial effect on families. For many parents, stillbirth was associated with reduced earnings from employment or an inability to return to paid employment. Meeting the continuing costs of counselling and medical care in further pregnancies was also mentioned.

The experience of stillbirth also affected parents’ employment, with 10% of bereaved parents remaining off work for 6 months, and 38% of mothers and 21% of partners reducing their working hours (panel 3). Even after parents return to work, productivity was greatly reduced with estimates of 26% of normal work after 30 days, increasing to 63% after 6 months. Searches of the International Labour Organization database showed that only 12 of 170 countries with maternity benefit policies included specific provision for stillbirths; an average of 11 days leave for mothers (range 28–84 days) and an average of 1 day off for fathers (range 1–5 days). Even in the few countries with this leave provision, bereaved parents seem to have little option to delay their return to work. Policies relating to stillbirth or miscarriage were identified from five (10%) of 51 African countries, five (18%) of 28 countries in Asia, three (6%) of 47 countries in Europe, and four (12%) of 34 in the Americas (appendix pp 78–81). Governments might incur costs in countries that extend maternity rights to the parents of a stillborn child.

**Panel 1: Modelled scenario—the effect and cost of 90% coverage for quality antenatal and intrapartum care**

We used Lives Saved Tool (LiST) (version 5.28) to model the results of effective proven interventions on stillbirths and maternal and neonatal deaths. We modelled the potential effect of introducing selected interventions within health systems of the 75 high-burden Countdown countries (which account for 99% of all deaths).1 For each of the 75 Countdown countries, baseline scenarios were created that represent the most up-to-date details about the health status of these countries, including mortality, cause of death structure, and present coverage of interventions. The base year was set as 2015 and coverage of selected interventions was scaled up linearly to reach 90% by 2030. The modelled interventions were grouped into four packages along the continuum of care.

- **Basic antenatal care:** prevention of malaria with insecticide-treated bednets or intermittent preventive treatment with antimarial drugs, syphilis detection and treatment, and tetanus toxoid immunisation. Intermittent preventive treatment was scaled up only in countries where malaria is endemic and the effect would apply only to the proportion of women exposed to malaria.

- **Advanced antenatal care:** detection and management of hypertensive disorders of pregnancy, including treatment with magnesium sulphate and hospital care or caesarean section if needed, detection and management of diabetes in pregnancy, detection and management of fetal growth restriction, identification, and induction of mothers at 41 weeks of gestation or more.

- **Childbirth care:** skilled birth attendance, antenatal steroids for preterm labour, antibiotics for preterm premature rupture of the membranes, active management of the third stage of labour, neonatal resuscitation, immediate assessment, and stimulation of the newborn baby.

For costing, we used the LiST costing submodule to assess the running costs of the interventions for which we used an ingredients-based approach, identifying and valuing every resource. The costing submodule draws its assumptions about staffing, drugs, and need for services from the UN’s OneHealth Tool database. We have included only running costs and that was divided in four components: capital costs, drug and supply costs, labour costs, and other recurrent costs.

The results suggest that scaling up these proven antenatal and intrapartum interventions in the 75 high-burden countries can prevent 823 000 stillbirths, 1 145 000 neonatal deaths, and 166 000 maternal deaths annually by the year 2030 (appendix p24) at an additional annual running cost of US$4·6 billion or $2143 for each life saved (including stillbirth, maternal, and neonatal deaths; appendix p24). The analysis suggests that interventions in the preconception, basic, and advanced antenatal care packages are crucial, but most of the deaths including stillbirths and maternal and neonatal deaths are prevented by intervening in the intrapartum period alone and with a lower estimated cost of $1370 to save each life compared with $2143 for all interventions. This analysis reaffirms previous estimates that not only is prevention of stillbirths possible but prevention can be achieved at a reasonable cost of $2143 for each life saved.
Stillbirth Alliance, New York, NY, USA (A E P Heazell, D Siassakos MD, V Flenady PhD, K J Gold MD, C Stony BA, A M Wojcieszek [BPhySc]); Academic Centre for Women’s Health, University of Bristol, Bristol, UK (D Siassakos, C Burden MD); Southmead Hospital, Bristol, UK (D Siassakos, C Burden); Centre for Maternal Reproductive and Child Health, Department of Infectious Disease Epidemiology, London School of Hygiene & Tropical Medicine, London, UK (H Blencowe MRCPath); Center for Global Child Health, Hospital for Sick Children, Toronto, ON, Canada (Prof Z A Bhutta PhD); Centre of Excellence in Women and Child Health, Aga Khan University, Karachi, Pakistan (Prof Z A Bhutta, J Das MBA, A Rizvi MSC); Arizona State University for Global Child Health, Department of Family Medicine, Phoenix, AZ, USA (D Siassakos, C Burden)

Psychological and social effects of stillbirth

The period after stillbirth has extensive consequences for parents and their families. Much of the effect is non-monetary, resulting from the negative effects of grief, anxiety, fear, and suffering. These emotional factors have been described as intangible costs. Most all parents report negative psychological symptoms after a stillbirth. In the Listening to Parents study in the UK (n=473), 68% of mothers and 44% of partners reported four or more negative psychological symptoms at 10 days, reducing to 35% of mothers and 13% of partners at 9 months. This situation is over three times greater than after a livebirth, when 8–13% of mothers and 3% of fathers report depressive symptoms at about 9 months after the birth of their baby.

Family was the most frequently cited source of support for parents after a stillbirth, although family input was not universally positive (panel 3). This need for support between parents and the wider family could strain relationships. In the Listening to Parents study, 9% of mothers and 5% of partners reported difficulties in their relationship 9 months after the event, and a similar proportion reported issues with other family members (12% of mothers and 4% of partners). In the TEARS cohort in the USA (n=216), the mean Family Assessment Device score of respondents was 3–2 (range 0–5–4–0), in which a score of 4 indicates substantial dysfunction in family relationships. Ultimately, this tension might lead to relationship breakdown, which some studies report as more frequent in parents who have a stillborn child compared with a livebirth (odds ratio 1.40, 95% CI 1.10–1.79).

Systematic searching located 1082 relevant datapoints from 144 studies of the psychological effect of stillbirth (appendix pp 31–50). These data were summarised into 23 themes and thematic sentences of the effect on parents with variable frequency effect sizes (table). The most frequently reported experiences after stillbirth were negative psychological symptoms, including high rates of depressive symptoms, anxiety, post-traumatic stress, suicidal ideation, panic, and phobias. Although most studies evaluated these symptoms subjectively rather than with a formal clinical diagnosis, 60–70% of grieving mothers in HICs reported grief-related depressive symptoms that they regarded as clinically significant 1 year after their baby’s death. These symptoms endured for at least 4 years after the loss in about half of cases. If these figures are extrapolated to the 2.6 million women who had a stillbirth each year, an estimated 4.2 million women are living with depressive symptoms after stillbirth. Many parents reported persistent feelings of remorse or guilt for not being able to save their baby. Nearly 40% of grieving mothers in a convenience-sample survey in the USA were prescribed psychiatric drugs despite an absence of evidence for the efficacy of these drugs in this population. Parents responding to the ISA survey reported accessing internet forums (more than 85%), support groups (about 30%), or consulting with religious leaders (about 30%) or health-care professionals (about 35%) to address their psychological symptoms. Little difference was noted in the sources and frequency sought by parents from HICs and MICs (appendix p 69).

Psychological distress persisted into subsequent pregnancies when parents reported differing emotions (eg, relief and worry, hopeful optimism, and panic attacks or depressive symptoms). Women tended to report volatile emotional states, whereas fathers tended to report suppression of their feelings. Parents were afraid to prepare for the birth of their subsequent baby and avoided general antenatal classes because they felt, as parents, they were outside the boundaries of normality. Some women struggled to differentiate their dead baby’s identity from their subsequently-born live baby.

The capacity to express and integrate grief reactions was a crucial part of parents’ psychological responses. Many studies described disenfranchised grief, when...
parents felt their grief was not legitimised or accepted by health professionals, family, or society.\textsuperscript{15-17} This issue was particularly evident in LMICs, in cultures where talking about death is taboo, and where the dead baby was not yet deemed to be a person.\textsuperscript{18,19} In these contexts, mothers’ accounts suggested that they suppressed grief in public, instead choosing to deal with the emotions privately and alone.\textsuperscript{20,21} These accounts are supported by responses to the ISA survey of care providers (LMIC n=117, HIC n=2020). Fewer care providers from LMICs agreed that a death before birth is the same as the death of a child (19% LMIC vs 33% HIC) and more care providers attributed stillbirth to a mother’s fault (4% LMIC vs 0-5% HIC) compared with HICs. Respondents from LMICs more frequently agreed that parents should forget about their stillborn baby and have another child (26% LMIC vs 3% HIC) and parents should not talk about their stillborn baby (12% LMIC vs 4% HIC; appendix p 71).

Fathers reported feeling unacknowledged as a legitimately grieving parent. The burden of these men keeping feelings to themselves increased the risk of chronic grief.\textsuperscript{22} Differences in the grieving process between parents can lead to incongruent grief,\textsuperscript{23,24} which was reported to cause serious relationship issues, from conflicts about sexual intercourse to marital breakdown.\textsuperscript{25,26} Although family and friends were often essential for effective support,\textsuperscript{27} respondents to some studies reported that family members had unrealistic, unhelpful expectations of recovery after stillbirth.

Many studies described the adverse effects of stillbirth on siblings, a surviving twin, and subsequent children, including issues with parent–child relationships, which could affect siblings’ physical and mental health in the longer term.\textsuperscript{28,29} Some parents described anxiety with respect to the wellbeing of children of other parents.\textsuperscript{30} Stillbirth was reported to have adversely affected the emotional wellbeing of grandparents and other family members.\textsuperscript{31}

For some mothers, stillbirth affected their approach to life and death, self-esteem, and their own identity.\textsuperscript{32-34} Some mothers reported losing their sense of control, including during subsequent pregnancies, and their confidence in parenthood and child-rearing. Some women avoided contact with babies, creating social isolation and worsening depressive symptoms.\textsuperscript{35} Some mothers were hesitant to meet neighbours or those who had known them when they were pregnant. Many women stopped going out, leading to voluntary social isolation. Social isolation could also be involuntary, with parents reporting stigmatisation, resulting in them feeling less valued as members of society.\textsuperscript{36} In reports from some LMICs,\textsuperscript{37-39} women reported being substantially less valued by partners, families, and society. In extreme circumstances, this situation has led to spousal abuse, enforced divorce, and rejection by family and society, partly based on beliefs that women who have stillbirths are possessed by evil spirits or have procured abortions.

In the period shortly after the stillbirth, changed body image was important.\textsuperscript{40-42} Some women reported being embarrassed by their body after pregnancy. Others wanted to keep a pregnant body shape, maintaining a connection with their baby. Some women linked the grief to their physical body through physical symptoms, such as pain and by developing an image of themselves as unattractive and ugly. Such negative self-perceptions decreased sexual activity and pleasure. Women reported pressures to delay or prioritise conception originating from themselves or from family and society.\textsuperscript{43,44} Chronic pain and fatigue, increased substance use, employment...
### Psychological effect of stillbirth on parents

<table>
<thead>
<tr>
<th>Effect</th>
<th>Frequency</th>
<th>Example quotes (country)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stillbirth has been associated with a number of emotional and psychological symptoms</td>
<td>77%</td>
<td>“I am depressed, saddened, hurt, empty, guilty and lonely. I cry every day. I will mourn him forever.” (Australia)</td>
</tr>
<tr>
<td>Parental grief following stillbirth might not be legitimised by health professionals, family, and society (disenfranchised grief)</td>
<td>31%</td>
<td>“A number of mothers recalled suicidal thoughts because of their desire to be with their baby” (USA)</td>
</tr>
<tr>
<td>Stillbirth might have a positive or negative effect on relationships—eg, through different grief reactions (incongruent)</td>
<td>29%</td>
<td>“Women shared their distress that their motherhood of their dead babies was denied by others. One participant recounted that when she told her sister she was not sure she was ready for Mother’s Day rituals, her sister replied ‘Well, you’re not a mother—you have to have your baby first.’” (USA)</td>
</tr>
<tr>
<td>In subsequent pregnancy some parents might experience psychological distress</td>
<td>27%</td>
<td>“This perceived lack of social understanding left these mothers alone and uncomfotred. Added to this, the silence was aggravated by the failure of friends and family to acknowledge the loss and grieve as real. They experienced people avoiding them, or treating them as though they had never been a mother” (Australia)</td>
</tr>
<tr>
<td>Stillbirth might change parents’ approach to life and death, self-esteem, own identity, and sense of control in subsequent pregnancy, parenthood, and child-rearing</td>
<td>26%</td>
<td>“Women shared their distress that their motherhood of their dead babies was denied by others. One participant recounted that when she told her sister she was not sure she was ready for Mother’s Day rituals, her sister replied ‘Well, you’re not a mother—you have to have your baby first.’” (USA)</td>
</tr>
<tr>
<td>Stillbirth can have an adverse effect on siblings, including the surviving twin, and subsequent children</td>
<td>24%</td>
<td>“You’re happy that you are [pregnant] but you can’t be that innocent...Am I confident? No! Will I relax? No. There is not a point that I will relax until they are out and breathing.” (USA)</td>
</tr>
<tr>
<td>After stillbirth some parents might seek isolation, can change their uptake of religious practice, approach to sexual intercourse, engagement with health promoting activities, work, and social media and this behaviour might continue into subsequent pregnancies</td>
<td>20%</td>
<td>“Some parents relied on their spirituality to deal with their loss. For some parents this was in the form of praying; for others, it was going to church” (USA)</td>
</tr>
<tr>
<td>Some parents feel the need to suppress outward grief, including during subsequent pregnancy</td>
<td>18%</td>
<td>“I cry when I talk to a real person so it was easier to talk to someone online, less emotional” (USA)</td>
</tr>
<tr>
<td>Stillbirth might lead to avoidance of activities that remind them of the pregnancy and the baby</td>
<td>13%</td>
<td>“I know a girl who was in school and married off by her parents. After the marriage, she repeatedly lost her new-borns and was divorced. Not to face the humiliation in the village she ran away to a city and now she is a commercial sex worker.” (Ethiopia)</td>
</tr>
<tr>
<td>Parents report stigmatisation, rejection, and spousal abuse</td>
<td>13%</td>
<td>“Every time I walked into the living room, my in-laws lowered their voices. Mostly, they stopped talking. I disappointed them because I didn’t give them a descendent like every daughter-in-law should do. I felt unwomanly, since I failed to have a baby.” (Taiwan)</td>
</tr>
<tr>
<td>Parents might have mixed feelings towards the decisions they made—eg, post mortem or seeing and holding their baby</td>
<td>13%</td>
<td>“In the limited time available for mothers to meet the child, mothers did not know how to spend time with their child, and had multiple hesitations due to their child being dead, and regretted this later on.” (Japan)</td>
</tr>
<tr>
<td>Parents might have external or internal pressures to prioritise or delay conception</td>
<td>9%</td>
<td>“Some mothers did not plan on a subsequent pregnancy because of their concern about their ability to deal with another perinatal loss” (USA)</td>
</tr>
<tr>
<td>Bereaved parents might become hypervigilant with siblings and subsequent children, and anxious about other people’s children</td>
<td>8%</td>
<td>“All mothers shared stories of feeling out of control, especially when faced with normal or common childhood events, such as tooth loss, middle ear infection, or being stung by a bee. These events were enough to cause them to feel hyptena and intense fear they were about to lose another child.” (Australia)</td>
</tr>
</tbody>
</table>

(Table continues on next page)
Bereaved parents might increase or decrease their use of health-care services, and in subsequent pregnancy, fathers might express a desire to be more included in care

Chronic pain and fatigue can occur after stillbirth

Some parents described parental pride after the birth of their stillborn baby

Employment difficulties and financial debt are potential effects of stillbirth

Stillbirth can motivate parents to engage with health-care improvement, including public awareness

Increased substance use has been reported for some parents

Women might develop a complex emotional response to body image

Stillbirth has an adverse effect on the wider family

For some parents, quality of life might be affected in the long term

Some couples experience competing emotional reactions to sexual relationships

Psychological effect of stillbirth on professionals

<table>
<thead>
<tr>
<th>Psychological effect of stillbirth on professionals</th>
<th>Frequency effect size*</th>
<th>Example quotes (country)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stillbirth has a powerful psychological effect</td>
<td>95%</td>
<td>“I think it’s possible to experience too much grief in this work” (Ireland)</td>
</tr>
<tr>
<td>Emotional response or distancing</td>
<td>40%</td>
<td>“It is a mixture of everything, anxiety, rage, oppression, impotence…” (Spain)</td>
</tr>
<tr>
<td>Trauma</td>
<td>42%</td>
<td>“...I had to cut off my emotions to just get through it” (USA)</td>
</tr>
<tr>
<td>Guilt</td>
<td>35%</td>
<td>“It shook me to my core” (USA)</td>
</tr>
<tr>
<td>Anger</td>
<td>30%</td>
<td>“…you’ve got anger, huge anger, especially where a mistake has been made or something has been missed” (Ireland)</td>
</tr>
<tr>
<td>Fear</td>
<td>30%</td>
<td>“It sort of haunted me for a couple of days… I had some issues falling asleep that night and getting the images out of my head” (Australia)</td>
</tr>
<tr>
<td>Stress</td>
<td>30%</td>
<td>—</td>
</tr>
<tr>
<td>Anxiety</td>
<td>25%</td>
<td>—</td>
</tr>
<tr>
<td>Blame</td>
<td>20%</td>
<td>—</td>
</tr>
<tr>
<td>Depression</td>
<td>20%</td>
<td>—</td>
</tr>
<tr>
<td>Frustration</td>
<td>15%</td>
<td>—</td>
</tr>
<tr>
<td>Sadness</td>
<td>15%</td>
<td>—</td>
</tr>
<tr>
<td>Powerlessness</td>
<td>10%</td>
<td>—</td>
</tr>
<tr>
<td>Challenge to faith</td>
<td>5%</td>
<td>—</td>
</tr>
<tr>
<td>Humiliation</td>
<td>5%</td>
<td>—</td>
</tr>
<tr>
<td>Stillbirth has a professional effect</td>
<td>65%</td>
<td>“Is this the one that is going to blame you?” (USA)</td>
</tr>
<tr>
<td>Effect of litigation</td>
<td>30%</td>
<td>“If you… lose a mother or a baby, you will lose your license, your income, your work” (USA)</td>
</tr>
<tr>
<td>Fear of disciplinary action</td>
<td>10%</td>
<td>—</td>
</tr>
<tr>
<td>Fear of public censure</td>
<td>5%</td>
<td>—</td>
</tr>
<tr>
<td>Exposure</td>
<td>5%</td>
<td>—</td>
</tr>
<tr>
<td>Professionals need support</td>
<td>65%</td>
<td>“I think what would be helpful… is having that debriefing time after it’s over and not being directly assigned” (Canada)</td>
</tr>
<tr>
<td>Education</td>
<td>30%</td>
<td>“…they do not teach you the necessary strategies to provide support in these situations” (Spain)</td>
</tr>
<tr>
<td>Peer support</td>
<td>5%</td>
<td>“…we need to support each other and not tear each other down” (USA)</td>
</tr>
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*(Table continues on next page)*
For the ReaCH group, University of Organization database see knowledge/toolkit/10/en
For the International Labour Organization database see http://www.ilo.org/global/lang-en/index.htm

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See Online for appendix For the OneHealth Tool database see http://www.who.int/workforcealliance/knowledge/toolkit/en/
For the International Labour Organization database see http://www.ilo.org/global/lang-en/index.htm

difficulties, and financial debt were also reported. Some studies described a longlasting negative effect on quality of life.

The consequences of a stillbirth were not exclusively negative. Some couples reported feeling closer. Parental pride was reported by some parents after contact with their baby. For some, deciding to see or hold their baby brought a sense of finality that contributed to the grieving process. Some parents engaged in therapeutic activities; seeking solitude, changing their uptake of religious practice, and changing their approach to sexual intercourse or engagement with health promoting activities, work, and social media (table). Some parents campaigned for, and contributed to, health service improvements to help other families. Many parents changed the way they accessed health-care services, especially in subsequent pregnancies when fathers became more involved.

Effect of stillbirth on professionals

All 20 studies (19 exclusively from HICs and one with respondents from HICs and LMICs) included in the systematic review of the effect on professionals undertaken for this paper (appendix pp 51–53) documented a substantial personal and professional burden for staff involved with caring for families during and after stillbirth. Four themes emerged from the data for staff: psychological effects, professional effects, need for support, and positive effects (table). The psychological effect was most frequently reported as somatic, including symptoms of trauma, diminished emotional availability, stress, and affective states such as guilt, anger, blame, anxiety, and sadness. The professional effect of stillbirth was characterised by fear of litigation and disciplinary action. In one study, data from LMICs suggested that professionals attending to a woman who has had a stillbirth could result in loss of livelihood and public humiliation.

Most studies (n=13) emphasised the need for further education and professional support for staff, especially in terms of the psychosocial care and communication skills needed after a stillbirth. 11 studies suggested that peer support was valuable, even though this guidance was usually informal. However, an absence of structured institutional and peer support was stressed. Seven studies showed the risk of vicarious traumatic stress, and depressive and psychological symptoms such as guilt, self-blame, self-doubt, and grief. Importantly, those health workers who felt that they had received adequate training in stillbirth care were less likely to report guilt and fear of litigation.

In six studies, staff also reported feeling some positive gains, such as a sense of honour or privilege at being able to support parents experiencing the death of their baby. Some staff cited personal growth and the development of a special bond with parents and staff. In four studies, staff reported more confidence and comfort, with fewer negative effects, when they had more direct clinical experience with stillbirth.

These findings suggest that, although mothers, partners, and their families endure most of the effects of stillbirth, the event also has a substantial effect on health-care providers. The negative effects could be addressed by education, training, and provision of formal and informal support during and after stillbirth, and encouragement of positive experiences of caring for parents after stillbirth.

Interventions to maximise wellbeing for bereaved parents and families

Table: Thematic sentences derived from meta-synthesis of studies assessing psychological effect of stillbirth on parents and on health-care professionals.

<table>
<thead>
<tr>
<th>Frequency effect size</th>
<th>Example quotes (country)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institutional support</td>
<td>5%</td>
</tr>
<tr>
<td>Stillbirth can have a positive effect</td>
<td>30%</td>
</tr>
<tr>
<td>Benefit of experience</td>
<td>20%</td>
</tr>
<tr>
<td>Sense of honour</td>
<td>10%</td>
</tr>
<tr>
<td>Privilege</td>
<td>5%</td>
</tr>
<tr>
<td>Special bond with parents</td>
<td>5%</td>
</tr>
<tr>
<td>Making a difference</td>
<td>5%</td>
</tr>
</tbody>
</table>

Table: Thematic sentences derived from meta-synthesis of studies assessing psychological effect of stillbirth on parents and on health-care professionals.
support groups, families making and sharing memories, autopsy, psychological interventions, and interventions with various components.  

Professional support to enable parents to share their experiences with others, and social support from family and local social networks were both associated with lower rates of depression and better mental health than those without this support.  

A specific psychological intervention  

in Brazil was associated with a range of positive effects, finding that inclusion of family members in the intervention reinforced network support.  

A US study  

reported that support groups were associated with significant improvement in scores on the revised Impact of Events Scale. Programmes with many components generally increased parents’ satisfaction, with those more satisfied reporting less grief.  

Where measured longitudinally, this effect was maintained for up to 2 years. Finnish fathers receiving an intervention with various components reported stronger personal growth and less blame and anger than Finnish fathers who did not receive the intervention.  

The key findings of all included studies (qualitative and quantitative) were mapped to Sarafino’s taxonomy of social support. This system comprises five support elements: tangible, emotional, esteem, informational, and network and belonging (appendix pp 56–67).  

All effective interventions, and all qualitative studies of interventions with positive participant responses, included emotional support. Nine studies  

included informational support and ten addressed tangible support. Usually, this tangible support was help from staff to see and hold the baby after birth (14 studies, including HICs and LMICs). Two studies included esteem support, such as helping parents to reclaim a lost sense of motherhood or fatherhood. Eight studies included networking and belonging. Positive staff attitude was universally appreciated.  

Data pertaining to specific groups of people were reported only from HICs. This finding showed that fathers, siblings, and female partners need to be acknowledged and included in interventions, to mitigate their experiences of the negative effects of stillbirth. Interventions for siblings need to be tailored for their age and maturity. The need for esteem support for family members was particularly apparent, including recognition of continuing status as father or co-mother, sister or brother, and grandparent, even after the death of the baby that created these social roles.  

Variation in access to what works by cultural context  

Access to support groups or services is not equitable. In the three surveys (panel 2) on parents that were analysed in this paper, 54–93% of parents in HICs were given information about support groups or services compared with 12% of parents in LMICs. Information about grief and psychological symptoms (16% in LMICs vs 52% in HICs) was given less frequently in LMICs than for physical symptoms (28% vs 47%), but this was not the case in HICs. The perceived effectiveness of support groups varied, but 77% of respondents to the ISA survey who used a group reported benefit. Lower amounts of support available for parents in LMICs might account for a greater proportion of parents rating their follow-up care as poor compared with HICs (60% vs 38%; appendix p 69).  

In the systematic review of what works for mitigating the negative consequences of stillbirths, eight of ten studies in LMICs included only women. The only positive factors reported by respondents from Malawi were basic physical care and brief information giving from nurses, which were seen as surprising but welcome occurrences. Studies in Tanzania,  

Ethiopia,  

and India,  

suggested that having a stillborn baby can lead to maternal abuse, social abandonment, and divorce. Despite feelings of grief and loss, mourning in these countries was actively discouraged and suppressed, and interventions such as families seeing and holding the baby and taking mementoes, were not culturally acceptable. This situation was echoed in care providers’ responses to the ISA survey (LMIC n=117, HIC n=2020), which reported that parents in LMICs were less likely than those in HICs to be offered contact with their baby (35% in LMICs vs 94% in HICs), the opportunity to see and hold their baby (42% in LMICs vs 95% HICs), make memories (35% in LMICs vs 87% in HICs), and name their baby (39% in LMICs vs 83% in HICs) after a stillbirth.  

The main support mechanisms reported in the included LMIC studies were family and local religious communities, rather than health-care professionals and wider society as noted in HICs. In these contexts, interventions designed to improve emotional and informational support might depend on enhancement of community esteem for those who have had a stillbirth, especially through key religious groups. Networking and belonging support interventions could be primary mechanisms for improving women’s wellbeing after a stillbirth in LMICs.  

Summary of what works  

On the basis of these data, the key element of what works to reduce the effects of stillbirth on bereaved parents and families can be summarised as seeing through the eyes of those affected. This includes staff who understand what different parents and families need and when they need it; communities that acknowledge grief and loss and do not stigmatise those who have had stillbirths; employers who provide effective leave arrangements; and governments that provide tangible support, such as funeral costs, and paid leave from work commitments.  

The consequences of stillbirth  

Stillbirth is associated with substantial direct, indirect, psychological, and social costs to women, and to their families, society, and government (figure). These
include: medical care and investigations at the time of stillbirth and in subsequent pregnancies; funeral costs; grief and negative psychological effects; reduced social functioning; family and relationship disruption and breakdown; and negative effects on employment. The effect of stillbirth is enduring, and can persist for years. Similar issues, particularly direct health care and funeral costs\(^\text{101}\) and the lasting effects on family function have been described for maternal death.\(^\text{61,62,84,102,103}\) In addition to families, the effects on staff and subsequent implications for staff wellbeing and future service quality and delivery must be considered. Depending on the setting, costs might be met by the government, insurance companies, or individuals and their families. Before this Series paper, these various costs of stillbirth have not been considered together. We argue that this situation has led to an underestimation of the economic, social, emotional, and psychological burden of stillbirth.

**The worldwide effect of stillbirth: how to address research gaps**

Our systematic approach has shown large gaps in available data with respect to costs and interventions that might reduce the burden of stillbirth by preventing these events or their negative consequences. Few studies established the direct costs of stillbirth in the perinatal period or subsequent pregnancies; all studies were from HICs. Studies that reported on the psychological and social costs of stillbirth or practices that might reduce the subsequent negative effects are concentrated in HICs (n=177), which have a low-burden of stillbirth, with little or no data available from high-burden LMICs (n=26; appendix p 68). As most components of effective care were identified from studies in HICs, the data obtained are similar to a review restricted to only HICs.\(^\text{90}\) Although some themes are consistent between HICs and LMICs, other factors, such as stigma and social isolation, seem to be particularly relevant in LMICs.\(^\text{47,51,53,63,104,105}\) Therefore, to appreciate the full cost of stillbirth, tailored research is urgently needed to establish direct, psychological, and social costs of stillbirth, particularly in LMICs and in marginalised women and their families.

In all settings, very little information is available about what works for fathers or partners and other family members. Substantial comparative research on effective interventions to mitigate the effects of stillbirth is missing in all contexts. Where evidence does exist, effective care seems to include emotional, informational, and to an extent, tangible support, in terms of practical or financial help, at and around the time of diagnosis and birth. On the basis of questionnaire data, parents greatly valued support to help with direct financial costs (such as funeral arrangements) when it was provided by governments or insurance schemes.

Little emphasis is given in intervention studies to networking and belonging support, and almost none to esteem support. In all settings, but particularly in LMICs, these components can form a basis to address stigma, taboos, and social rejection for bereaved mothers. Fear of loss of esteem and of exclusion from social networks has the potential to stifle attempts to allow women to express and to deal with their grief, potentially leading to long-term costs. By contrast, where local family and social (notably religious) networks were supportive, mothers, in particular, reported positive benefits. Likewise, some parents and staff (in both LMICs and HICs) believed that they had grown spiritually, and had gained substantial coping skills as a result of their experience.

![Figure: The effect of stillbirth originating with the death of the baby, affecting mother, family, health services, society, and government](image-url)

Widespread themes of direct, indirect, and intangible costs are shown.
Acknowledgment of the personal and professional cost of stillbirth on staff is essential, for their personal wellbeing and to enable health workers to deliver effective care to bereaved parents.

In LMICs, an intervention that addresses stillbirth at a health-care, societal, and community level could make two major gains. The first could be the adoption of preventive measures, including improved communication of health messages, monitoring, support and care for women pre-pregnancy, antenatally, and during delivery, and improving the health of the mother and her baby. The second could be destigmatisation of stillbirth, thereby reducing the negative consequences, especially for women.

Interpretation of the cost of stillbirth

In view of the research gaps identified, comprehensive estimates of the costs of stillbirth cannot be derived at present to inform cost-effectiveness analyses. Data for the financial costs of the sequelae of stillbirth are not routinely collected in any country. Wide variation in monetary and opportunity costs between different countries, such as those relevant to health-care provision or lost labour productivity, mean that such data must be local to be meaningful. Data for the psychological and social costs are also scarce, particularly with regard to LMIC settings, fathers, the wider family, and health-care providers. Finally, any cost-effectiveness analysis must include a decision on how the loss of life to the baby is to be measured. Consequently, any attempt to assign a worldwide cost to stillbirth—in monetary terms or with summary measures of health such as QALYs and DALYs—would be misleading at present.

Despite the substantial costs of stillbirth set out in this Series paper, the extent of the total loss associated with stillbirth is substantially affected by whether the stillbirth is also counted as a loss in one’s right (ie, as a loss to the baby). Economic evaluations of interventions to prevent stillbirths have to make the critical decision of whether and how to count this loss. Women’s rights and values must be respected, including access to safe termination of pregnancy; however, recognition must also be given to the fact that most women who have had stillbirths had wanted pregnancies. Similar evaluations of interventions to reduce neonatal mortality typically show results based on the time-discounted life expectancy of surviving infants.9 To avoid undervaluation of interventions that10 prevent stillbirth, these controls should be assessed in this same way.11,12

The use of QALYs in guidance by National Institute for Health and Care Excellence and early iterations of DALYs apply discounting techniques to accommodate time-discounting of future benefits, such as a longer life, giving 25 QALYs lost or 32 DALYs associated with stillbirth.13,14 The appropriateness of time-discounting of health benefits is the subject of debate. Without discounting, stillbirth would be associated with 86 DALYs on account of the loss to the baby. Alternatively, Jamison and colleagues15 suggest that deaths before age 2 years should be adjusted according to extent of cognitive development or so-called acquired life potential. With time-discounting, this adjustment gives stillbirth DALY values of between 5 and 9 years; without time-discounting this figure would give DALY values of between 14 years and 26 years. Thus, proposals for how to value the life of a stillborn baby vary greatly. How these babies are valued can make a difference of orders of magnitude to the overall loss attributable to stillbirth (appendix p 26). For example, a study16 of the cost-effectiveness of a syphilis screening programme for pregnant women in Mwanza City, Tanzania, estimated a cost of $92·56 per DALY averted without including stillbirths and $8·88 per DALY averted if stillbirths were included as a loss to the deceased.

Conclusion

Despite the gaps in the evidence, the findings in this Series paper suggest that the burden of stillbirths is substantial yet greatly underappreciated. This undervaluation might contribute to the slow pace of change to address stillbirths on national and international platforms, as identified by Frøen and colleagues.17 Crucially, although the costs of stillbirth prevention might seem substantial in LMICs and HICs, the combined direct, indirect, and intangible costs of stillbirth are almost certainly greater still. We call on the global community to recognise the enduring effect of stillbirth on parents, families, staff, societies, and health and social care systems, to develop strategies to collect data for the cost of stillbirths and to use that information to invest in strategies, local services, and practices to prevent stillbirth and to invest in interventions to reduce the negative effects of stillbirth.

Contributors

AEPH was responsible for overall coordination and oversight of the Series paper and the writing process. JM and TR modelled values assigned to stillbirth. AEPH and MR analysed published questionnaire data. HB searched the International Labour Organization databases. DS and CS were responsible for the systematic review of psychological effects on parents. JC, KG, DN, and KG’D were responsible for the systematic review of psychological effects on parents. SD and OKM were responsible for the systematic review of economic studies, direct costs, and costs in subsequent pregnancies. VF and AMW were responsible for the design and analysis of the international questionnaire. AEPH and MR analysed published questionnaire data. ND and HETS helped put the paper into international context. JD, AR, and ZAB were responsible for using the Lives Saved Tool analysis. All named authors contributed to the conceptualisation, development, writing, and finalisation of the paper: AEPH is the overall guarantor.

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