1. BACKGROUND

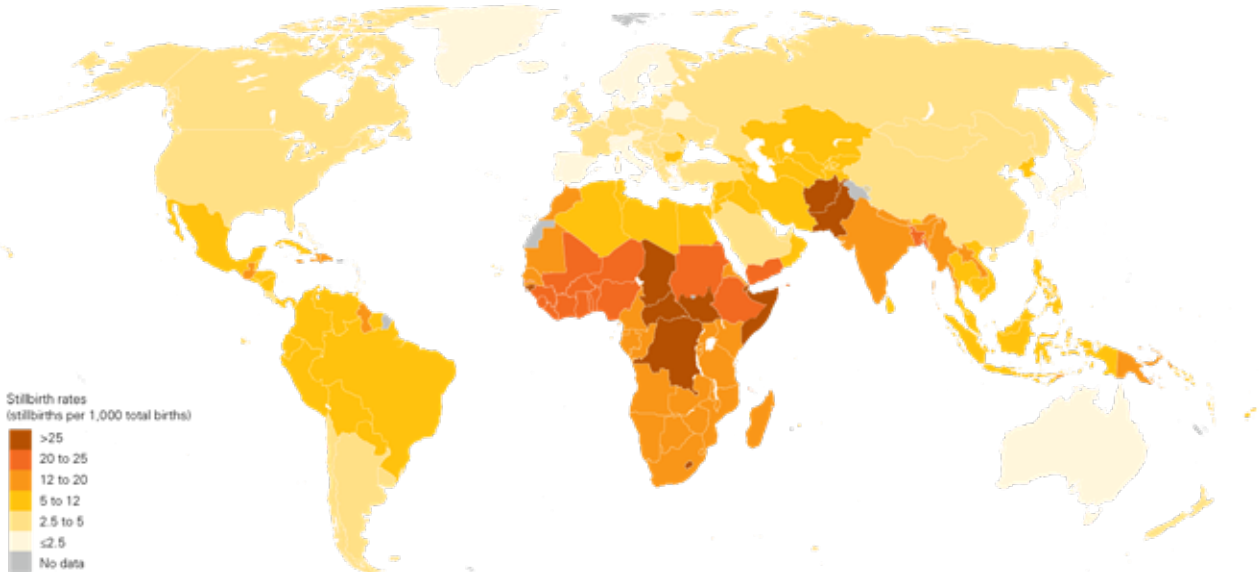
The toll of stillbirth

Stillbirth rates

Stillbirth, when a baby dies in the latter stages of pregnancy or during birth, is a devastating pregnancy outcome. One stillbirth occurs every 17 seconds worldwide – equating to around 1.9 million babies stillborn in 2021. These are babies whose mothers and families expected them to be born alive. Over three quarters of stillbirths occur in sub-Saharan Africa and South Asia (Figure 1.1). Low- and lower-middle-income countries account for 89% of all stillbirths, but only 71% of all live births. Forty-five per cent of all stillbirths occur after the onset of labour. Many of these stillbirths occur in full-term babies, and they are preventable with equitable access to high-quality pregnancy and childbirth care **(1)**. Over the past two decades, progress in lowering stillbirth rates has not kept pace with achievements in saving mothers' lives, nor with progress in preventing deaths of newborns in the first 28 days after birth. Between 2000 and 2021, the annual rate of reduction in the global stillbirth rate was just 2%, compared with a 2.7% reduction in neonatal mortality (deaths in the first month after birth) and 3.9% among children aged 1 month to 59 months **(1)**. Meanwhile, between 2000 and 2020, the global maternal mortality ratio (MMR) decreased by 2.1% per year **(2)**.

Nadége Ndi Rose, 20, is in labour in the maternity ward of Saint Luc Hospital, a privately run hospital in the town of Mbalmayo (Cameroon). Two health workers attend to her. Ms. Rose will deliver her fifth premature, stillborn baby. She has never received a prenatal consultation.

FIGURE 1.1: STILLBIRTH RATES, BY COUNTRY (2021)



Source: Never Forgotten: The Situation of Stillbirth Around the Globe. Report of the United Nations Inter-agency Group for Child Mortality Estimation, 2022. Note: Map does not reflect a position by UNICEF, or any collaborating organizations on this guide, on the legal status of any country or territory or the delimitation of any frontiers. The most recent national stillbirth rates for 195 countries are available at www.childmortality.org.

A note on terminology around gender

This guide recognizes gender diversity among pregnant and birthing individuals. The terms "woman" and "mother" have been used throughout for brevity. The guide is intended to be inclusive of all pregnant and birthing individuals, even though some may not identify as a woman or as a mother (3).

Stillbirth is an increasingly critical global health problem. In 2000, stillbirths accounted for 23% of all under-5 deaths and stillbirths. By 2021, this figure had increased to 27% **(1)**. In sub-Saharan Africa, the estimated number of stillbirths increased from 765,000 in 2000 to 847,000 in 2021, as the growth in total births outpaced the decline in the region's stillbirth rate **(1)**. In some high-income countries (HICs), there are more stillbirths than neonatal deaths, and the number of stillbirths surpasses that of even infant deaths (deaths of children from 1 month to 12 months of age).

In 2014, 194 Member States endorsed the Every Newborn Action Plan (ENAP) **(4)** at the Sixty-seventh World Health Assembly. The ENAP set a target of 12 or fewer stillbirths per 1,000 total births in every country by 2030. More than 45 countries must more than double their current progress to meet this target **(1)**. ENAP also aimed to close equity gaps, meaning differences in stillbirth rates between the most and least advantaged groups. But few countries – even those with low overall mortality – have made progress in using data and targeted action to close these gaps.

Emotional and psychological toll

The experience of having a stillborn baby is a life-changing event with extensive and complex psychological, psychosocial and emotional impacts on parents and families **(5)**. For many parents, the unexpected loss of their child – and the care experienced following that loss – affects their approach to life and death, self-esteem and identity **(6)**.

> No one ever tells you that you're going to lose all context of yourself. Your life, your identity, your interests, your relationships – everything feels like you're figuring it out again for the first time." – Alex, mother of stillborn son Robin

Source: whatsyourgrief.com/loss-of-identity-after-stillbirth

While the mental health impacts of stillbirth vary in severity and manifestation, common emotional themes among bereaved individuals include shock, guilt, blame, a profound need to understand the cause of death and to remember the birth, and irrational and terrifying thoughts **(7)**. Multiple studies show that while these impacts appear to be most frequent and intense in the first few months following stillbirth, there are long-lasting, complex emotional and psychological impacts on birthing women and their partners. These long-lasting impacts include increased psychological morbidity in subsequent pregnancies and increased risk of severe mental health disorders **(8)**.

> The loss of my baby changed so many things about me. Telling people was so shameful. People [said] it was my fault that the baby died, and I started blaming myself too, telling myself that I was not careful enough. I went home [from work] everyday crying." – Oyele, Nigeria

Source: blogs.unicef.org/evidence-for-action/shrouded-in-silence-the-untold-story-of-stillbirths

Research also shows that the emotional aftermath of having a stillborn baby is often significantly influenced by social and cultural norms and contexts. In some cultures, stillbirth is perceived as the fault of the woman, resulting in public shaming and future discrimination. In other cultures, stillbirths are not recognized at all or are considered so-called "non-events", which may considerably impact the capacity of an individual to grieve **(9, 10)**. Studies have also found that, in certain contexts, the cheery, bustling environment of the labour and birthing ward is an extremely painful place for parents and families who have had a stillborn baby, and that well-intentioned attempts of health-care workers to provide comfort often have the opposite effect **(11)**.

While nothing can prevent the pain and grief of having a stillborn baby, the availability of culturally appropriate, person-centred care and psychosocial support may help to reduce the severity, magnitude and duration of its psychological and emotional toll on women and families.

Crystal and LP Nielsen say goodbye to their daughter Aleia Nielsen following her funeral on July 8, 2020. Aleia is their only daughter. Source: Stacey Fletcher

What do we mean by culturally appropriate care?

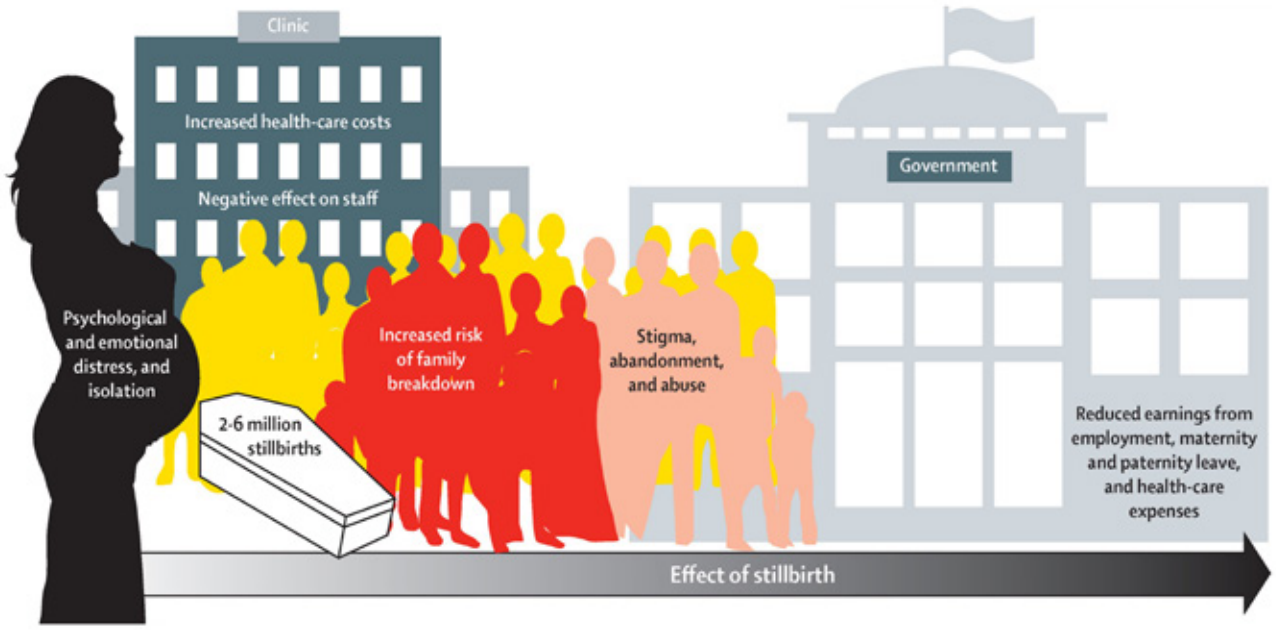
This guide defines culturally appropriate care as care that is informed by, respectful of and aligned with the woman's particular cultural beliefs and norms, while also adhering to accepted global norms on human rights and respectful maternity care, such as the International Declaration on Human Rights and the Respectful Maternity Care Charter.

Financial and societal toll

Estimating the economic and societal toll of stillbirth is challenging, but it is necessary to understand the cost-effectiveness of interventions to prevent stillbirth and to improve care after a baby dies. The losses attributed to stillbirth can be difficult to estimate because they include direct costs (the financial cost of health service use when a baby dies), indirect costs (the cost of loss of productivity or human resources) and intangible costs (the non-monetary costs that largely reflect the emotional impact of stillbirth) **(12)**. Figure 1.2 depicts the effect of stillbirth including direct, indirect and intangible costs associated with the baby, mother, family, health services, society and governments.

In 2018, Campbell and others estimated the mean direct cost per stillbirth to be £802. Inflated to 2022 values, and converted to US dollars for global comparison, this is approximately US $1,000 per stillborn baby **(13)**. The direct cost of parental anxiety and depression was approximately US $820 per stillborn baby **(10)**. Costs of care in subsequent pregnancies varied depending on the cause of the stillbirth, and it was greatest for unexplained stillbirths, approximately US $5,500 per case **(14)**. In addition to its effect on parents, the death of a baby has a negative impact upon staff, estimated to be US $900 per case **(13)**.

FIGURE 1.2: THE EFFECT OF STILLBIRTH ORIGINATING WITH THE DEATH OF THE BABY, AFFECTING MOTHER, FAMILY, HEALTH SERVICES, SOCIETY AND GOVERNMENT



Source: Reprinted from The Lancet, Vol. 387, Heazell, Siassakos, Blencowe, et al., Stillbirths: economic and psychosocial consequences, pages 604–616, Copyright (2016), with permission from Elsevier. Note. 2.6 million stillbirths each year reflects the estimate at the time of publication of the figure (2016); the 2021 estimate is 1.9 million stillbirths.

A systematic review grouped the intangible costs of stillbirth into eight themes: profound grief, depression, social isolation, relationship issues, sibling issues, return to normality, need for support, and life-changing event **(12)**. These extensive intangible costs are experienced by mothers, as well as fathers/partners, siblings, grandparents and other family members. These intangible costs may lead to financial costs, which are frequently met by parents alone and are likely much greater than the direct and indirect costs.

Few countries provide maternity or paternity leave following stillbirth, leading to loss of earnings or presenteeism (being present at work, but with lowered productivity) **(10)**. Taking the impact of stillbirth into account, the investment required for effective interventions to save babies' lives is reduced to US $2,143 per life saved, compared with $3,994 if neonatal deaths are considered alone **(10)**. Capturing all these aspects of the stillbirth burden indicates the large economic cost of stillbirth that is ultimately borne by governments and societies.

Impact on health-care providers

Health-care providers are at risk of developing professional burnout due to the psychological impact of working through stressful events, including being with women who experience stillbirth **(15)**. For health-care providers, significant negative impacts of caring for families after stillbirth include personal distress, feelings of overwhelm, trying to "hold it together", difficulty concentrating and difficulty returning to work after the event **(16-20)**. Secondary traumatic stress and symptoms of post-traumatic stress disorder have also been reported among health-care providers attending traumatic births, including stillbirths **(21)**. A study in Kenya and Uganda showed sadness, frustration, guilt and shame were commonly experienced, and health-care providers exhibited blame, fear and negative behaviours such as passing the responsibility of communication with families to others **(22)**. Another study from Papua New Guinea showed health-care providers felt at risk of physical violence from angry relatives after caring for a woman who had a stillborn baby **(23)**.

> Any time I care for a woman who has had a stillbirth, it is devastating for the woman and her family but also for me as the caregiver. I have to deal with my own grief and that of the woman and her family, and yet culturally it is not acceptable to grieve in public since the society does not consider the stillborn as a human being..." – Midwife from Malawi

Source: Homer, Malata, ten Hoope-Bender (2016) **(24)**

However, there is evidence of some positive impacts, especially when health-care providers feel they can provide quality bereavement care. Caring for families can be rewarding when health-care providers are able to connect with families, offer opportunities to create special memories, listen to – and share – grief and make a positive difference **(25)**.

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A woman unpacks baby clothes and blankets in her home in Lusaka (Zambia). She has just returned following the stillbirth of her baby. She believes her baby was stillborn due to complications related to her diabetes and HIV-positive status.

Underlying risk factors associated with stillbirth

Risk factors are conditions or characteristics that increase a person's risk or chance of developing a disease, or of experiencing an adverse health outcome such as stillbirth. These risk factors may act directly or indirectly, by increasing the risk of other, more direct causes of death. For instance, infection is a risk factor that can directly cause death, while lack of skilled providers is an indirect risk factor that could contribute to a death. Risk factors for stillbirth commonly increase the risk of other adverse birth outcomes as well, including preterm birth, low birthweight and neonatal death. Figure 1.3 depicts one model of stillbirth risk (called the social ecological model) and the multilayered risk factors that impact stillbirth, including maternal, family, community, health system and structural risk factors. Examples of specific risk factors are shown in Table 1.1, in accordance with this model. The table provides a list of example risk factors, but it is not exhaustive. It is important to note that such risk factors may interact with one another in complex ways, potentially amplifying risk **(26)**.

FIGURE 1.3: SOCIAL ECOLOGICAL MODEL OF STILLBIRTH RISK

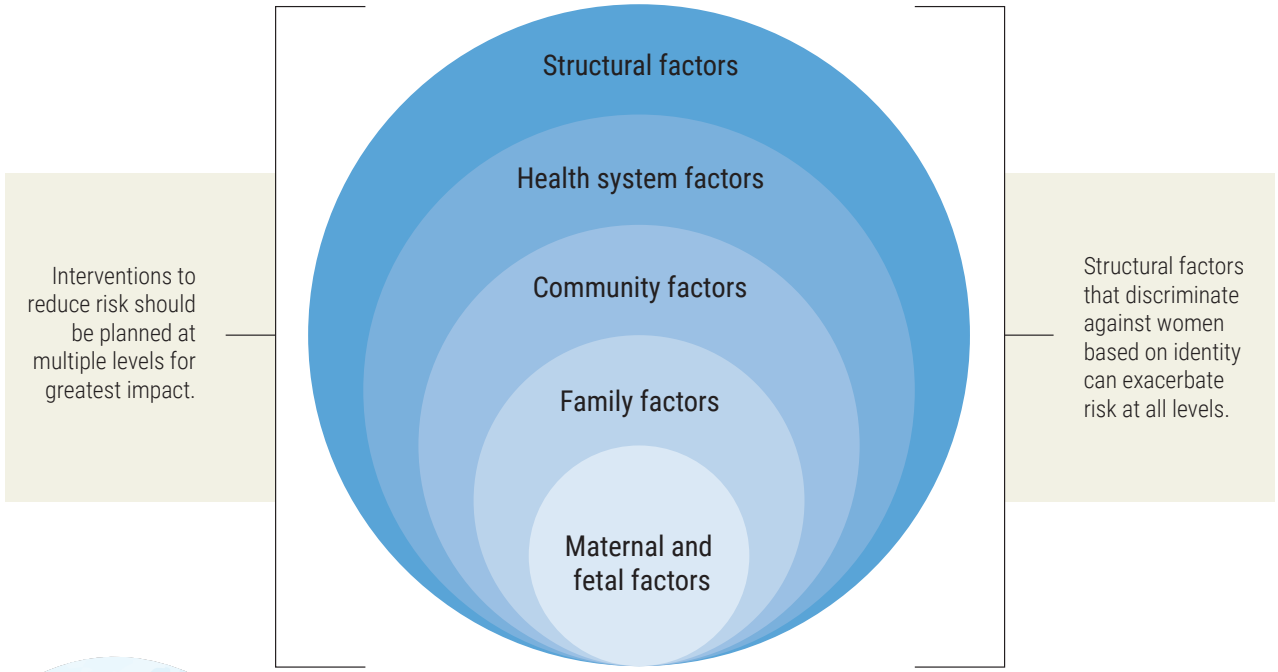

TABLE 1.1: STILLBIRTH RISK FACTORS ACCORDING TO THE SOCIAL ECOLOGICAL MODEL

Model component	Examples of risk factors
STRUCTURAL RISK FACTORS	
Discrimination and inequity	Based on race, ethnicity, religion, sexual orientation, gender identity or other characteristic
	Denial of services or poor quality of care; lack of respectful care
	Lack of policies protecting reproductive health
HEALTH SYSTEM RISK FACTORS	
Health workforce	Lack of skilled care providers, especially for night shifts and in rural areas
	Lack of initial training and continuing education on risk management
	Poor supervision and accountability
Quality of care	Lack of continuity along the care continuum
	Substandard care factors including (but not limited to) failure of care providers to recognize and manage risk, failure to follow clinical practice guidelines, and poor communication
	No/delayed referral for high-risk pregnancies
	Missing or poor-quality obstetric care during labour and birth
Health infrastructure and supplies	Lack of health infrastructure, such as clean water, electricity, medical supplies
	Poor supply chain for essential supplies such as oxygen and anaesthesia
COMMUNITY RISK FACTORS	
Long travel distance and poor access to care	Lack of specialty care in rural areas
	Long distances, lack of road and transport infrastructure, cost of travel
Unsafe neighbourhoods	High levels of crime, violence and insecurity on the street
Environmental exposures	Lack of clean water and sanitation services; indoor and outdoor air pollution
FAMILY RISK FACTORS	
Family structures and dynamics	Emotional and physical abuse
	Lack of autonomy over health and health-care decision-making
MATERNAL AND FETAL RISK FACTORS	
Financial, emotional and interpersonal stress	Poverty or low income and associated food or housing insecurity
	Lack of social or family support
Remoteness and rurality	Lack of access to transportation
	Lack of access to and availability of emergency obstetric services
Lack of self-efficacy	Low health literacy leading to a poor understanding of health information
Physiological or biomedical	Maternal age 35 years or older
	High body mass index/obesity
	Pre-existing conditions such as hypertensive disorders, malaria, HIV infection
	Poor nutritional intake; substance use such as tobacco, alcohol, opiates
Placental/fetal	Fetal growth restriction; pre-eclampsia/eclampsia; infection
	Antepartum or intrapartum haemorrhage

Note: This list provides examples of risk factors; it is not intended to be exhaustive.