2. OPPORTUNITIES TO OVERCOME CHALLENGES IN ADDRESSING STILLBIRTH

What are the challenges?

Despite recent progress in including stillbirths in global data tracking for child mortality (1), stillbirths remain hidden in terms of social recognition, investment and programmatic action, due to failures in five broad categories (27): lack of equity in access to care; lack of quality of care; societal perceptions; data gaps; and programmatic challenges (Figure 2.1). These broad categories describe why preventable stillbirths – which can be avoided via the actions of health systems – continue to occur. They also underscore why quality care after stillbirth is often lacking. Examples of specific challenges are shown in <u>Annex 1</u>.

FIGURE 2.1: FRAMEWORK OF THE CHALLENGES IN ADDRESSING STILLBIRTHS

Lack of equity in access to care

Equity in maternal health means all women have access to – and can utilize – the right care at the right time, regardless of their race, social status, ethnicity, religion, age, sexuality or other individual characteristics. Health-care authorities must take steps to ensure maternal health services are available to all women, and especially those most likely to need them but least likely to use them. These include migrant women, refugees and women and families living in fragile and humanitarian response settings.

the stillbirth was caused by stress the conflict induced.

Lack of equity in access to care Lack Programmatic of quality challenges of care Challenges addressing stillbirths Societal Data gaps perceptions © UNICEF/UNI166910/d'Aki In 25 July 2014 in the State of Palestine, Soha Mosleh lies on a cot as she recovers in the maternity ward of Al-Shifa Hospital in Gaza. On the second day of the recent escalation of violence between Israel and Gaza, Ms. Mosleh, who was in her ninth month of pregnancy, left her home in Zeitoun district in search of a safer place to take refuge. "It felt like a stone," she says of vaginal pain she began to experience. Once in hospital, she gave birth to a stillborn baby girl. According to her doctors,

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Poverty devastated me; I had four stillbirths in a row. Most people are illiterate and poor here. They are conservative; they do not allow their women to go for check-ups. But rich women do not face such issues; they have more freedom than us."

Source: Zakar, Zakar, Mustafa, et al. (woman in Pakistan, 2018) (28)

Lack of quality of care

The stillbirth rate is a key indicator of quality of care during pregnancy and childbirth.

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Quality of care is defined by WHO as "the extent to which health-care services provided to individuals and patient populations improve desired health outcomes ... health care needs to be safe, effective, timely, efficient, equitable and people-centred" (29).

Evidence shows that a higher frequency of antenatal visits by women and adolescent girls is associated with a reduced likelihood of stillbirth. This reduced risk is due in large part to increased opportunities for health-care professionals to detect and - together with women - manage potential complications. Compared with four contacts, eight or more contacts for antenatal care can reduce perinatal deaths (stillbirths and newborn deaths) by up to 8 per 1,000 births (30). But there remain many barriers to providing high-quality antenatal care. Barriers to providing quality intrapartum care also exist, and approximately half of all stillbirths result from complications during labour and birth (31). There are many challenges to improving quality of care relating to emotional, informational and system factors such as staffing and funding issues (32).

Societal perceptions

The significant loss of life due to stillbirth is frequently unrecognized and hidden from view. Common challenges countries and societies face include persisting stigma and taboos that keep stillbirth hidden (33), as well as the limited recognition of and provision for stillbirths within the legal framework in many countries. There is also a need for greater community awareness of the grief and trauma of stillbirth and how to respond to it, as this is a crucial step towards reducing the isolation, grief and stigma that many parents experience (see <u>Chapter 1</u> and <u>Suppression of grief: a case study from India</u>).

Our society finds it very difficult to talk about death and finds it very difficult to talk about intense emotion, and the death of a little baby or a child is such a painful and confronting area for people."

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– Deborah de Wilde, volunteer, Stillbirth Foundation Australia

Source: <u>Senate Select Committee on Stillbirth Research and Education.</u> 2018 Report



Suppression of grief: a case study from India

Mrs S, a 29-year-old woman, was enjoying her first pregnancy in 2019. In her eighth month of pregnancy, a routine growth scan showed swelling in the baby's head with destruction of brain matter (gross hydrocephalus with very thin cerebral cortex). Both parents were counselled, and the prognosis of the baby was explained. Family support helped Mrs S as she waited for spontaneous labour. After nine months of pregnancy, a beautiful baby boy was born still. Mrs S was asked if she would like to see and hold her baby. The baby had been dressed nicely with head cap in place (to conceal the procedure marks), but Mrs S refused. She asked her obstetrician to take a picture of her baby in case she ever wanted to see the picture in the future. At the time, there was no apparent grief expression.

After the death of their baby, the couple were so distressed that they left their jobs and went abroad, in the hope of escaping painful memories. Mrs S conceived again and gave birth to a healthy baby girl. After almost two and a half years, Mrs S called her previous obstetrician and requested the pictures of her lost son. She shared that, at the time of her son's death, she had been under intense sociocultural pressure to avoid seeing him. Her family had been supportive, but they thought that the baby was a bad omen and that seeing him may bring bad luck for her next pregnancy. When the obstetrician shared the pictures with Mrs S, she started crying. She had not cried over her son until this point, which led to a build-up of self-guilt over the course of her delayed grieving. The obstetrician understood her situation and told her that it's normal to cry. The obstetrician suggested she seek counselling for ongoing support.

Data gaps

One of the challenges in conducting epidemiological studies of stillbirth – and for developing and implementing evidence-based interventions, training programmes and health policies to reduce stillbirth – has been the lack of precise, high-quality and complete data on stillbirths. Lack of attention to the issue coupled with inadequate funding and human resources have contributed to these gaps. Failure to disaggregate data has led to lost opportunities to prevent stillbirths. For example, without disaggregated data by timing of death, there is no capacity to monitor intrapartum stillbirths, which are largely preventable.

Many stillbirths are not recorded due to social stigma, or where there are no legal requirements to do so. Even where data are available, their use has been frequently hampered by lack of effective communication to the public, national governments, funders, health-care providers and others on the emotional and financial cost of stillbirth (10, 31).

Data are also required to address specific actions to prevent stillbirth and monitor care after death. Data that are already routinely collected to track intrapartum and antenatal care, including content, quality, coverage and equity, could be better used to inform stillbirth prevention. More data are needed to quantify all stillbirth-related direct and indirect costs (see <u>Chapter 1</u>).

Programmatic challenges

Programmatic gaps, such as a failure to provide clear local protocols for diagnostic investigation into the causes of stillbirth (<u>Annex 1</u>), exacerbate challenges in addressing stillbirth. Such gaps may reflect a lack of organizational and political commitment to stillbirth prevention and to providing respectful and supportive care to families after stillbirth, as well as the inaccurate belief that stillbirth is not preventable. Policies and guidance for programmatic approaches to care after stillbirth (including bereavement care and care in subsequent pregnancies) are crucial and require multilevel <u>leadership</u>.

Opportunities along the continuum of care

The continuum of care refers to the continuity of individual care that is necessary throughout the life cycle, from birth to death and between places of care provision, to ensure survival and good health. It has become a primary focus of efforts to reduce maternal, newborn and child deaths and stillbirths, and to improve quality of care globally (34, 35). The continuum of care involves provision of comprehensive services, including clinical care, outpatient services and community-based care, provided by midwives, nurses, obstetricians, gynaecologists, paediatricians, neonatologists, general medical practitioners, community health workers, allied health workers and others. It spans adolescence, preconception, pregnancy, childbirth, the postnatal period and the early childhood period, as well as following death - with an emphasis on reducing inequities (34). Integration between programmes and across stages of the continuum is key to ensuring quality of care so that no woman, baby or child falls through the cracks (34).

Guidelines and best practice

Existing guidelines from WHO provide a comprehensive summary of interventions along the continuum of care. While not aimed specifically at stillbirth prevention, many of the recommended interventions for preconception, antenatal and intrapartum care will help to prevent stillbirths. Selected recommendations for postnatal care are applicable for the physical care of women who have given birth to a stillborn baby. **However, there are no dedicated WHO guidelines specific to care after stillbirth.**



Preconception care

→ WHO Preconception Care to Reduce Maternal and Childhood Mortality and Morbidity (36)

Antenatal care

→ WHO Recommendations on Antenatal Care for a Positive Pregnancy Experience (30)

Intrapartum care

- → WHO Recommendations: Intrapartum Care for a Positive Childbirth Experience (37)
- → WHO Managing Complications in Pregnancy and Childbirth: A Guide for Midwives and Doctors – 2nd Edition (38)
- → WHO Labour Care Guide: User's Manual (39)

Postnatal care

→ WHO Recommendations on Maternal and Newborn Care for a Positive Postnatal Experience (3)

WHAT YOU CAN DO:

- → Local level: Ensure access to relevant and upto-date clinical practice guidelines; implement the recommended interventions.
- → Mid-level: Link with local politicians to develop a campaign to raise women's awareness of the services to which they are entitled, and to hold government and health-care workers accountable for their performance.
- → Policy level: Secure funding for implementation and adaptation of guidelines in your setting.
- → Take action using the advocacy guidance provided in <u>Chapter 4</u>.

What about stillbirth, specifically?

Delivered by skilled providers in an enabling environment, the continuum of care approach is critical to stillbirth prevention and care when stillbirth occurs, through improving the health of every woman and every baby. Figure 2.2 shows actions for stillbirth prevention and care at each point along the continuum of care, drawing from existing guidelines and best practice. Essential elements of bereavement care are included, with further detail in <u>Chapter 3</u>.

Box 2.1 outlines essential elements of physical care, which should not be lost in bereavement support, especially as stillbirth is often associated with maternal health conditions. It is critical that physical care of the woman is provided with sensitivity and compassion.

FIGURE 2.2: THE CONTINUUM OF CARE: ACTIONS FOR STILLBIRTH PREVENTION AND CARE

HEALTH FACILITY	 Reproductive health care, including family planning and prevention and treatment of STIs* Peri-conceptual folic acid supplementation Preconception planning for women with known medical conditions 	 ANC bundles of care (components context- dependent**) Dual testing for HIV/syphilis Management of pregnancy complications 	 Skilled care at birth*** Fetal monitoring Continuity of care Basic and comprehensive EmOC Choice of labour companion 	 Assessment and care of physical needs, including information and advice around lactation, postpartum pain, contraception, diet 	 Referrals for women with previous stillbirth Counselling services and support 	
COMMUNITY	Reproductive health care, including family planning and prevention and treatment of STIs	 Counselling and birth preparedness Referral for antenatal complications 	 Choice of labour companion Referral for intrapartum complications 	 Postnatal assessment and follow-up Referral for postpartum complications 	Counselling services and support	
	ADOLESCENCE AND PRECONCEPTION CARE	ANTENATAL CARE	Activated when • Respectfu • Managem • Decision s	BEREAVEMENT CARE PATHWAY: Activated when stillbirth is diagnosed • Respectful and sensitive communication; psychosocial support for parents • Management of labour and ongoing physical care of the woman • Decision support for stillbirth investigations		
			 Opportunities for memory-making and contact with the baby Death certificate and audits 			

ANC: antenatal care; EmOC: emergency obstetric care; STI: sexually transmitted infection

* Plus other public health measures to improve the general health and well-being of all women of reproductive age.

** May include interventions such as umbilical artery doppler ultrasound screening, maternal smoking cessation and awareness of fetal movements, maternal vaccinations, environmental precautions (such as mosquito netting), informed decision-making around timing of birth, group B streptococcus testing and others.

*** Includes monitoring of labour progress and maternal status, as per the <u>WHO Labour Care Guide: User's</u> <u>Manual</u> (39).

BOX 2.1: ESSENTIAL ELEMENTS OF PHYSICAL CARE OF WOMEN AFTER DIAGNOSIS OF STILLBIRTH

Labour and birth

- → Sensitive shared decision-making on options for timing and mode of birth (vaginal or caesarean birth)
- Discussion of options for pain relief and management of the third stage of labour (for vaginal births)
- → Planning for a birthing companion, according to the woman's preferences
- → Treatment for any maternal conditions

Postnatal care

- Comprehensive postnatal physiological assessment
- → Management of postpartum perineal and uterine pain following vaginal birth
- → Pain management and wound care following caesarean birth
- Dietary advice and information for preventing constipation
- → Lactation management, including lactation suppression where required
- Treatment of breast engorgement and prevention of mastitis
- → Comprehensive contraceptive information and services
- Ongoing treatment for any maternal conditions and counselling around subsequent pregnancy planning

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A doctor checks Hameeda Abdul, 25, who lies in bed following a Caesarean section at Qatar Hospital in the port city of Karachi. Hameeda's baby was stillborn, and Hameeda almost died due to complications from severe anaemia, low blood pressure and Hepatitis C. This was her eighth pregnancy; she has four surviving children. All her previous deliveries were conducted at home. Doctors said they were lucky to save her life.