


 GLOBAL ALLIANCE TO PREVENT PREMATURITY AND STILLBIRTH
an initiative of Seattle Children's

Ethical Dilemmas as Sentinel Events in Maternal & Child Health: A Model for Advocacy and Policy Change


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Where am I taking you?

- Gender equity as key to maternal & child health: Our work surrounding prematurity & stillbirth in developing countries.
- Ethical dilemmas as sentinel events.
- Translating dilemmas into Advocacy: A model for bearing witness in your practice
- Case from the Field



**“Women Hold up Half the Sky”
....and much more**



- Empowering women: valuable as an end in itself and as a powerful instrument for change in child survival and health, the health of families, and communities.

Preventable determinants

- Reproductive health problems comprise the leading cause of death and disability for women globally.
- Skewed prevalence of HIV in girls and young women, even in countries where rates of HIV have decreased (such as Brazil).
- Exposure to STDS (e.g., HPV) higher among girls living in poverty, and ethnic minorities.
- An epidemic of domestic violence: From female feticide, to genital cutting, trafficking of girls and women, child marriage, honor killings, physical abuse. (Source: Shaw, 2006)



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Understanding the problem: Looking deeper



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Maternal & Neonatal Deaths – Where?

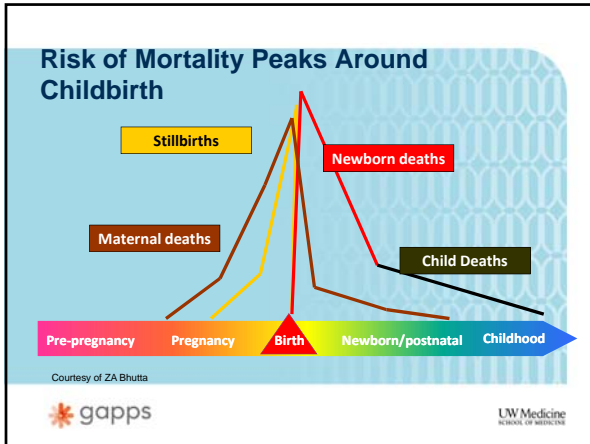
74% of maternal deaths could be prevented with access to trained birth attendants to address complications of pregnancy and childbirth.



Not seen as a disaster, and yet in 2006, more than deaths in Tsunami, Katrina, and Pakistan earthquake combined.



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Deadly pregnancies

- Every minute, at least one woman dies from complications related to pregnancy or childbirth – approximately 350,000 women each year.
- For every woman who dies in childbirth, 20 more will suffer injury, infection, or disease – approximately 10 million women each year.
- Sources: World Health Organization, 2010; Murray et al., 2010

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Top Five Complications causing 70% of Maternal Deaths

- Hemorrhage – 25%
- Infection – 15%
- Unsafe Abortion – 13%
- Eclampsia and Obstructed Labor – 8%
- Intrapartum stillbirths—30% of all stillbirths—are strongly associated with maternal morbidity and mortality.

Source: World Health Organization, 2010



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Top Five Complications causing 70% of Maternal Deaths

Root causes?

- **Unavailable, inaccessible, unaffordable, or poor quality care.**



Source: World Health Organization, 2010





The ripple effect of maternal mortality

- Deaths in childbirth inherently senseless and impact broader social development and well-being of families and communities.
- Nearly one million children are left motherless each year by these deaths.
- These children are 10 times more likely to die within the first two years of their mother's death.


Source: World Health Organization, 2010




international conference on
PREMATURITY & STILLBIRTH

May 7-10, 2009 | Seattle, WA, USA | www.gapps.org



GLOBAL ALLIANCE TO PREVENT PREMATURE DEATHS AND STILLBIRTHS



- High rates of preterm birth and stillbirth are not only markers for poor population health, but are sentinel markers for social and health inequalities facing women in these populations.



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Understanding women's experiences surrounding preterm and stillbirth



Kelley M. Hazemba A
Prelim data: "Women's experiences of preterm and stillbirth in rural and urban Zambia"

Ethical dilemmas as sentinel events

What do they signal?

- Deeper, structural causes
 - Socio-economic determinants of health
 - Gender inequality
 - Poverty
 - Break down in legal protections
 - Discrimination & Other Injustices
 - Barriers to Access
- Cultural norms or beliefs
- Breakdowns in Communication



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Dilemmas Fueled by Gender Inequalities

Difficult choices and silent burdens

- Women's experience of value trade-offs and reproductive choice:
 - birth spacing
 - financial trade-offs for family and siblings
 - nutrition for self vs. family during pregnancy
 - occupational stresses



Photo B. Kosloff

Psychosocial Barriers to seeking health care

- Reporting pregnancy complications and stillbirths carry costs for women.
 - Reporting infections and STDs can lead to stigma, abuse by husband, and abandonment.
- Attitudes of altruism and neglect of woman's own health—do not see their health as primary, or even connected to child's health.
- Fatalism about illness and neonatal loss.



Photo Credit: Richard Lord

Women's Cross-cultural Experiences of Stillbirth



- "When I lost my second baby my husband left me and said that I am no good."
- "We help the women who have lost a baby to clean themselves to be acceptable again to her husband"
- "For many men, we think maybe it is a sign the woman has cheated while pregnant."

Source: Kelley M. Hazemba A.
Prelim data: "Women's experiences of preterm and stillbirth in rural and urban Zambia"



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Empowered Women are Healthier Women



- Social and political marginalization impacts demand for prenatal and antenatal interventions.
- Literacy, education, and empowerment known to improve access to prenatal, delivery and postnatal care.

Wise P. Transforming preconceptional, prenatal, and interconceptional care into a comprehensive commitment to women's health. *Womens Health Issues* 2008.



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Dilemmas Fueled by Poverty

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Tinsman Kids Center
For Pediatric Oncology

The Sophie's Choice of Poverty

In Subsistence living:

- A bus ticket to the hospital in Lusaka vs. Feeding other siblings for the next five months.
- For those who do come to SBCU, most leave other children back at home.
- *"My husband will travel to come pay the hospital bill but there is no one to work the fields while he comes. Our other children are left there too."*



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- **Among the highest causes of maternal death in childbirth could be prevented with better access to safe, facility births, with skilled birth attendants.**

- In Lusaka, most women who chose to give birth at home did so because they could hire a midwife's services with small food items.
- When complications arise, they are too far from a facility.
- (Source: Hazemba, Siziya preliminary data, 2010)



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A Dilemma at the Programmatic Level: Home Births vs. Facility Births



- Improving the safety of home births through TBA training programs

Vs.

- Improving access to facility births and emergency OB care
- Not mutually exclusive but challenging when prioritizing scarce resources within political agendas.



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Reflects a broader challenge in global health:

- The need to address immediate and short-term needs with less-than-ideal interventions, against longer-term and systematic needs with more ideal solutions.
- **Can we implement “least-worst” solutions and still aim higher?**



Photo Credit: Marie-Agnès Heine WHO Uganda



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The Challenge: Non-ideal Care Becomes Standard of Care

- Failures to compromise costly in lives and morbidity.
- Compromises get entrenched as standards of care and can undermine political will.

“Temporary” medical tents, Haiti



Photo credit: Andres Leighton, The Associated Press.



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Solutions: How to Bear Witness and Effect Change



PATHOLOGIES OF POWER
PAUL FARMER

First ask: What's upstream?

- **Social determinants:**
 - Illiteracy
 - Poverty
 - Lack of political power
 - Lack of autonomy in reproductive health



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Next ask: What's downstream?

- **Unintended Effects:**
 - Higher maternal mortality/disability
 - Higher child mortality/morbidity
 - Impact on health of families
 - Impact on health of communities



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YOU ARE HERE



Upstream

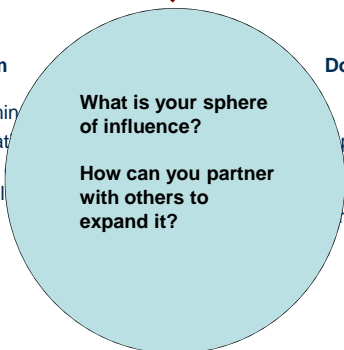
- Determinants
- This patient
- Social, political

Downstream

Impact for this
for more
change

What is your sphere of influence?

How can you partner with others to expand it?



**Then...
Aim Higher!**

- (1) Ask: What is possible?
- (2) Do your best with limited resources – be creative; don't take no for an answer.
- (3) Bearing witness: Call it like you see it. ***If not you then who?***
- (4) Aim Higher: Advocate and partner, to address gap and move toward ideal.



**What's possible?
Opportunities Right in Front of Us...**

Examples from the data on neonatal deaths:

- 3 million newborn deaths can be prevented with low-cost, low-tech interventions
 - Marginal cost of adding neonatal resuscitation training and equipment for midwives: <\$0.02 per capita per year
 - Most deaths could be prevented with simple interventions such as:
 - Thermoregulation
 - Breast feeding, Kangaroo care
 - Early treatment of infections
 - A very small minority of patients require costly intensive care



Photo: Christabel Enweronu-Laryea

Slide Credit: Maneesh Batra

Aiming higher? Avoid the Luddite Trap

If root causes of maternal and neonatal deaths and injury are poverty and socioeconomic inequality, it is tempting to acquiesce.

Innovation & Addressing Determinants not mutually exclusive.

Use of innovation, medical technology, modern medicine + development economics to effect longer-term change.

Don't give up on the antenatal steroid program, new NICU, or low cost alternative to CPAP



New incubators in NICU – Kiwoko, Uganda

**The Power of Moral Outrage:
Senseless Deaths and Unacceptable
Dilemmas**

- The majority of these neonatal deaths are highly preventable
- Majority of preterm births would be healthy, term infants
- In many cases, with low cost interventions.
- Dilemmas created by poverty or political disenfranchisement are unacceptable dilemmas, which no one should face.
- Creates imperative to address root causes.



Photo Credit: Richard Lord

The power of joy...



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**Case Discussion
From the Field:**

- Health behavior survey for Ministry of Education and Department of Community Medicine at the University Teaching Hospital and University of Zambia School of Medicine, with add-on qualitative interviews.
- Orphans and vulnerable children in urban districts of Lusaka, Zambia, ages 12-19.



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The Sentinel Dilemma: Abuse in Foster Situations for Children Orphaned by HIV/AIDS

"When my father passed away in 2004, in 2005 my mother also died. We were told to live with our Aunt. She began bringing men into our house. The men now try to rape my young sister when I am not around. They try to do it to me too. I feel neglected. There is no one to listen to my views. They do not show seriousness to us. It pains me and disturbs my school work."

(Source: Patel, Kelley, Siziya, Hazemba, 2009)



Measures taken

- **Immediate action:** Head of orphanage made aware of situation; counseling and evaluation of living situation; confidential and free medical evaluation; moved to a different foster home.

Asking: What's Upstream? What is fueling this dilemma?

- Widespread belief among Zambian men that sex with a virgin cures HIV
- Recognized as the leading cause of child abuse in Zambia.
- Among our group, 86.9% of the kids disagreed with this widespread belief.
- 10% of boys and 66.7% of girls admitted to having been forced to have sex
- Defilement Laws passed: <14, attempt to raise to 16 yrs. and to increase penalties.
- Support for sexual violence almost non-existent
- How to give children, especially young girls, a voice?

Measures taken

- **Midterm response:** Support for sexual violence was almost non-existent. Now rape clinic at UTH, spearheaded by Chief of Pediatrics, Dr. Chintu.
- Training on sexual violence, self-esteem, incorporated into health program and peer network.
- **Longer-term:** Defilement Laws passed: <14, attempt to raise to 16 yrs. and to increase penalties. Trying to improve access to rape clinic.
- **Unintended Consequences Downstream?** What will the impact be on availability of fostering situations for children orphaned?

Thank you...

- Alice Hazemba, RN, MPH
- Craig Rubens, MD, PhD
- Maneesh Batra, MD, MPH
- Bill & Melinda Gates Foundation
- Global Alliance to Prevent Prematurity and Stillbirth, Seattle Children's Hospital and Research Institute



Photo Credit: Richard Lord