

The case for community action in ending vertical transmission of HIV and keeping infants and mothers alive

Washington, July 2012

Coalition on Children Affected By AIDS

Nigel Rollins

**Department of Maternal, Newborn, Child and Adolescent health,
World Health Organization**

**The goal of 'Elimination' ...
To reduce the number of
new paediatric infections
and improve the health and
survival of HIV-positive
mothers and their infants**



Any suggestions to make your work more effective?



- Organise community event
- Explain to family elders
- Counsellor meetings to share experiences
- Consistency between clinic and community



What do we mean by community action?

- Interventions or actions that are ...

- Community based
- Community directed

or result in ...

- Community mobilisation
- Community involvement

'... health system cannot achieve the PMTCT targets alone. The huge, as yet largely untapped, potential of families and communities must be harnessed to bring demand for quality services to scale up supportive environments. In turn, families benefit from social protection mechanisms to help them cope with the challenges of AIDS and to remain enrolled in programmes.'

The case for community action ...

- **What do we mean by community action?**
 - **Community based**
 - **Community directed**
 - **Community mobilisation**
 - **Community involvement**
- **Which community?**
 - **Mothers**
 - **Extended families**
 - **Local population**
 - **Health workers**

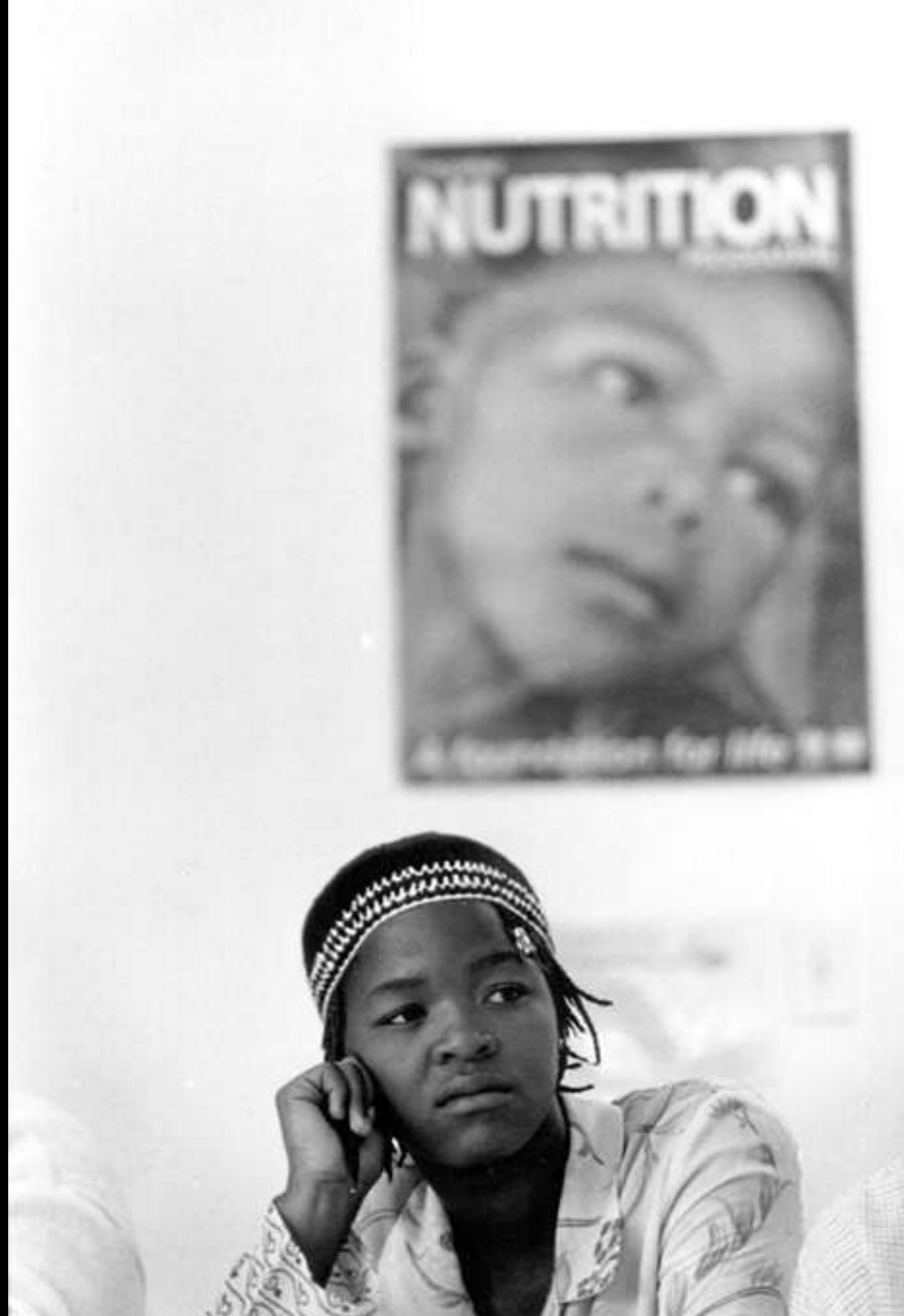
Relieved

Unaware

Scared



**Breastfeeding is not
just nutrition**





Rolling Stone
IMAGES
OF ROCK & ROLL

Natal Witness 4th February 1999

Baby cries, mum killed

“An Ermelo man who allegedly whipped a woman to death with a sjambok was arrested on Tuesday, Mpumalanga police said yesterday. The 33-year-old man allegedly whipped Ellen Nkosi to death at about midnight on Monday. Police said he shouted at her for not breastfeeding her baby to make it stop crying, and then whipped her” – Sapa



South Africa



South Africa

Building on cultural
and traditional
values

Exclusive
breastfeeding
rates
increased from
<10% to 67%
among HIV-
positive
mothers at 4
months



Community based intervention



Exclusive breastfeeding promotion by peer counsellors in sub-Saharan Africa (PROMISE-EBF): a cluster-randomised trial

Thorkild Tylleskär, Debra Jackson, Nicolas Meda, Ingunn Marie S Engebretsen, Mickey Chopra, Abdoulaye Hama Diallo, Tanya Doherty, Eva-Charlotte Ekström, Lars T Fadnes, Ameena Goga, Chipepo Kankasa, Jørn I Klungsøyr, Carl Lombard, Victoria Nankabirwa, Jolly K Nankunda, Philippe Van de Perre, David Sanders, Rebecca Shanmugam, Halvor Sommerfelt, Henry Wamani, James K Tumwine, for the PROMISE-EBF Study Group

Summary

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See [Comment](#) page 378

Centre for International Health, University of Bergen, PO Box 7800, 5020 Bergen, Norway (Prof T Tylleskär MD, IM S Engebretsen PhD, A Hama Diallo MD, J K Nankunda MD, J I Klungsøyr MD, C Lombard MD, V Nankabirwa MD, P Van de Perre MD, D Sanders MD, R Shanmugam MD, H Sommerfelt MD, H Wamani MD, J K Tumwine MD)

Background Exclusive breastfeeding (EBF) is reported to be a life-saving intervention in low-income settings. The effect of breastfeeding counselling by peer counsellors was assessed in Africa.

Methods 24 communities in Burkina Faso, 24 in Uganda, and 34 in South Africa were assigned in a 1:1 ratio, by use of a computer-generated randomisation sequence, to the control or intervention clusters. In the intervention group, we scheduled one antenatal breastfeeding peer counselling visit and four post-delivery visits by trained peers. The data gathering team were masked to the intervention allocation. The primary outcomes were prevalence of EBF and diarrhoea reported by mothers for infants aged 12 weeks and 24 weeks. Country-specific prevalence ratios were adjusted for cluster effects and sites. Analysis was by intention to treat. This study is registered with ClinicalTrials.gov, number NCT00397150.

Among 2579 mother infant pairs, low intensity community peer support increased exclusive breastfeeding rates at 24 weeks of age, by between x4.7 to x9.8
For example 71% vs. 9% in Burkina Faso

Mma bana study

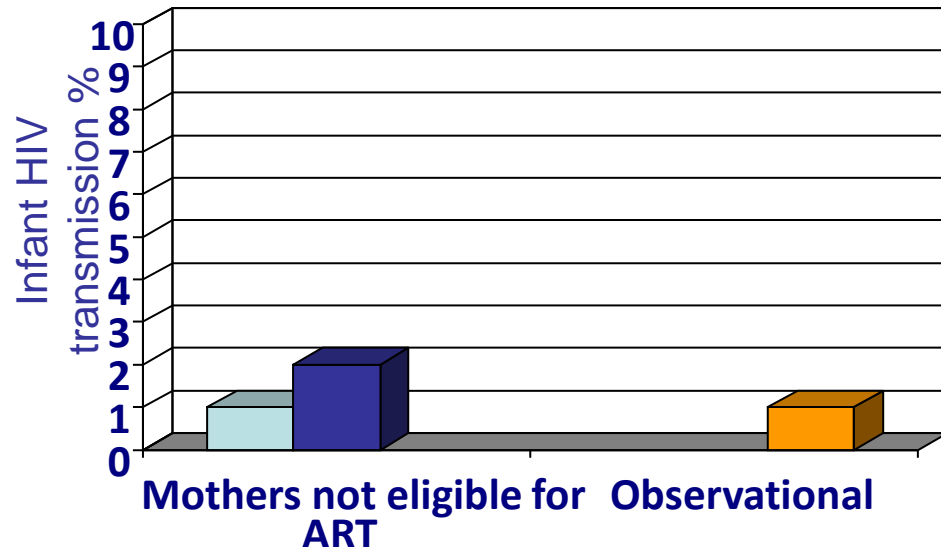
2 randomised arms and one observational

Mothers not eligible for ART received either:

lopinavir/ritonavir and combivir } for 6m

or abacavir/AZT/3TC } while BF

Mothers eligible for ART – outcomes observed



1248 pregnant women referred to study sites. After counselling about study interventions, 110 (8.8%) declined enrolment as preferred to give formula feeds.

Antiretroviral Regimens in Pregnancy and Breast-Feeding in Botswana

R.L. Shapiro, M.D., M.P.H., M.D. Hughes, Ph.D., A. Ogwu, M.B., B.S., D. Kirch, M.S., S. Lockman, M.D., C. Moffat, M.B., Ch.B., M.P.H., J. Makhema, M.B., Ch.B., M.R.C.P., S. Meys, M.P.H., I. Thior, M.D., K. McIntosh, M.D., E. van Widenfelt, B.S., J. Leidner, M.S., K. Powis, M.D., M.P.H., A. Asmelash, M.D., M.P.H., E. Turnbare, M.B., Ch.B., S. Zwerski, M.S.N., U. Sharma, Ph.D., M.P.H., E. Handelsman, M.D., K. Mburu, B.Pharm., O. Jayeoba, M.B., Ch.B., E. Moko, M.B., Ch.B., S. Soula, M.D., E. Lubega, M.D., M. Akhtar, M.B., Ch.B., C. Wester, M.D., M.P.H., B. Tsomola, M.D., W. Snowden, Ph.D., M. Martinez-Tristani, M.D., L. Mazhani, M.D., and M. Essex, D.V.M., Ph.D.

ABSTRACT

BACKGROUND

The most effective highly active antiretroviral therapy (HAART) to prevent mother-to-child transmission of human immunodeficiency virus type 1 (HIV-1) in pregnancy and its efficacy during breast-feeding are unknown.

METHODS

We randomly assigned 560 HIV-1-infected pregnant women (CD4+ count, >200 cells per cubic millimeter) to receive cotrimoxazole, zidovudine, and lamivudine (the nucleoside reverse-transcriptase inhibitor [NRTI] group) or lopinavir-ritonavir plus zidovudine-lamivudine (the protease-inhibitor group) from 26 to 34 weeks' gestation through planned weaning by 6 months post partum. A total of 170 women with CD4+ counts of less than 200 cells per cubic millimeter received nevirapine plus zidovudine-lamivudine (the observational group). Infants received single-dose nevirapine and 4 weeks of zidovudine.

RESULTS

The rate of virologic suppression to less than 400 copies per milliliter was high and did not differ significantly among the three groups at delivery (96% in the NRTI group, 93% in the protease-inhibitor group, and 94% in the observational group) or throughout the breast-feeding period (92% in the NRTI group, 93% in the protease-inhibitor group, and 95% in the observational group). By 6 months of age, 8 of 709 live-born infants (1.1%) were infected (95% confidence interval [CI], 0.5 to 2.2); 6 were infected in utero (4 in the NRTI group, 1 in the protease-inhibitor group, and 1 in the observational group), and 2 were infected during the breast-feeding period (in the NRTI group). Treatment-limiting adverse events occurred in 2% of women in the NRTI group, 2% of women in the protease-inhibitor group, and 1% of women in the observational group.

CONCLUSIONS

All regimens of HAART from pregnancy through 6 months post partum resulted in high rates of virologic suppression, with an overall rate of mother-to-child transmission of 1.1%. (ClinicalTrials.gov number, NCT00270296.)

From the Division of Infectious Diseases, Beth Israel Deaconess Medical Center (R.L.S.); the Departments of Immunology and Infectious Diseases (R.L.S., S.L., I.T., K. McIntosh, I.L., M.E.), and Biostatistics (M.D.H., D.K.), Harvard School of Public Health; the Infectious Disease Unit (S.L.) and the Department of Obstetrics, Gynecology, and Reproductive Biology (R.T.), Brigham and Women's Hospital; the Division of Infectious Diseases, Children's Hospital (R. McIntosh); and the Departments of Medicine and Pediatrics, Massachusetts General Hospital (R.P.) — all in Boston; the Botswana Harvard AIDS Institute (A.O., C.M., J.M., S.M., I.T., E.W., A.A., E.T., K. Mburu, O.J., E.M., S.S., E.L., M.A., C.W.) and the Botswana Ministry of Health (L.M.) — both in Gaborone, Botswana; the National Institutes of Health, National Institute of Allergy and Infectious Diseases, Bethesda, MD (S.Z., U.S., E.H.); GlaxoSmithKline, Greenford, United Kingdom (W.S.); and Abbott Virology, Abbott Park, IL (M.M.). Address reprint requests to Dr. Shapiro at the Division of Infectious Diseases, Beth Israel Deaconess Medical Center, 110 Francis St., Suite 6B, Boston, MA 02215, or at rshapiro@hsph.harvard.edu.

N Engl J Med 2010;362:2282-94.
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Cuba

Cluster randomised trial in 32 polyclinics (18 provinces)

- National initiative
- Engaged leaders – '*shared vision*'
 - Mayors, heads of Provincial and local health services
 - Presidents of local communities including Federacion Mujeres Cubana
 - Health facility staff and facilities prepared
 - Circles of grandmothers and grandfathers
- Staff trained and clinic developed own posters etc
- Women and children engaged at facilities and in communities
- Diversity of approaches
- Fathers and men included

Redressing a social perception



Using different media and approaches



**Including
fathers**



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Significant increase in exclusive breastfeeding rates and especially delayed introduction of other foods

WANTED

MATTHIAS RATH 

FOR THE DEATH OF



NTOMBEKHAYA

Ntombekhaya was persuaded to take Rath's drugs instead of antiretrovirals. Others have also died on Rath's illegal experiment.

These are the people who should have stopped Rath, but did not!



Minister of Health
Mkhomo Mkhomo
Tshameka



Western Cape
MDC for Health
Pieter Uys



Registrar of
Medicine
Hlungane
Zokufa

TAC is taking the Minister of Health to court to make her stop Rath.



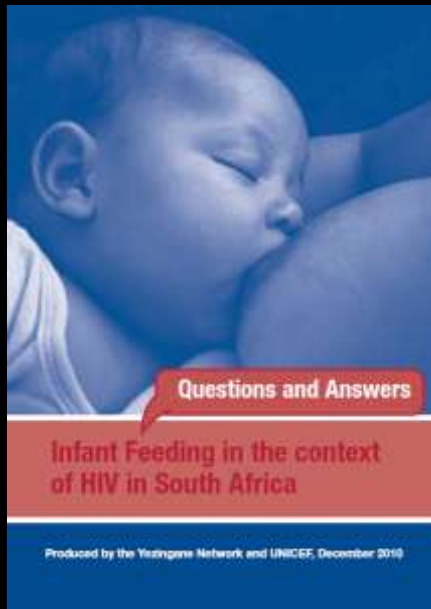
South Africa

An 'activated' civil society

Constitutional court: TAC vs. Minister of Health

Court ordered government to:

- immediately remove all restrictions on the availability of nevirapine in hospitals which are not research sites
- develop comprehensive programme & specifically employ counsellors at all public facilities



Why successful?

- Attention to detail (facts, science)
- Having lawyers learn about HIV/AIDS
- Combining legal arguments with real life stories & case histories
- Use of experts on range of issues
- High level of public awareness
- Alliances between activists, PWAs, scientists, health professionals & lawyers

Community health worker interventions to improve maternal and newborn survival

- 1. Cluster-RCT in 6 districts of central Ghana: Effect of home visits during pregnancy and postnatal period by CHW**
Preliminary results: moderate improvement in early and exclusive breastfeeding; mortality impact 8-14% but not statistically significant
- 2. Cluster-RCT in Hala, Pakistan: Effect of community-based interventions**
Results: 15% reduction in neonatal mortality, 21% reduction in stillbirths
- 3. Cluster-RCT in one district in India to evaluate mortality impact of IMNCI**
Preliminary results: 18% reduction in IMR, 13% in NMR
- 4. Country-wide evaluation on mortality impact of IMCI implementation in Egypt**
Preliminary results: Annual rate of mortality decline 6.3% after IMCI implementation compared with 3.3% before IMCI

Do not all work, in the same way, in different settings

Systematic review on community participation to increase skilled care at birth



- Review of the evidence from studies that link community participation in health programmes to specific direct and indirect maternal and newborn health outcomes
- First study: Marston C et al. (2009) *Effect of community participation interventions on maternal health and HIV prevention: a systematic review.*
- Currently being updated – exclusive focus on MNH and expanded search - 9,854 reports, including **227** full texts. **Fifteen** met the inclusion criteria, pertaining to **10** separate interventions

Initial conclusions

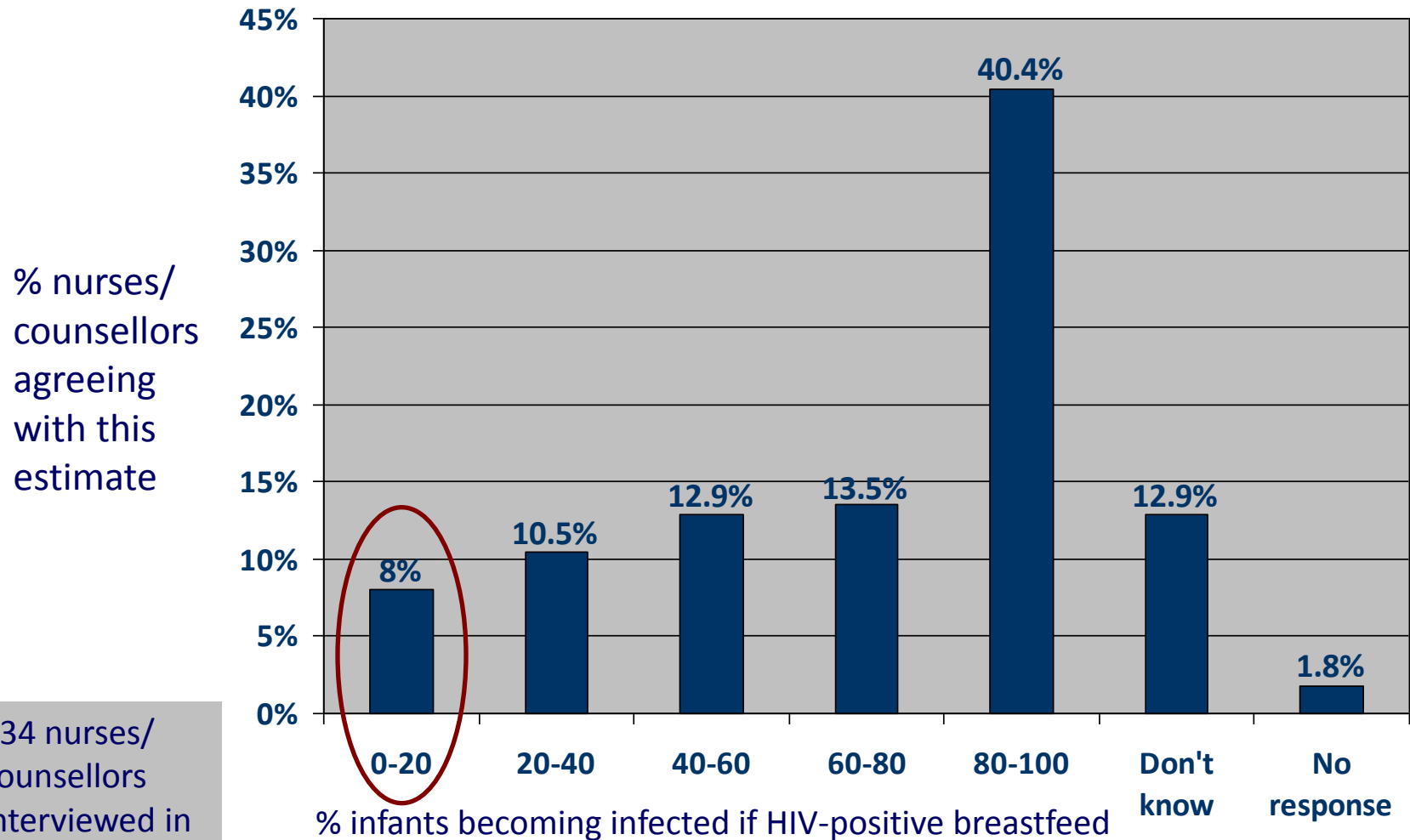


- Community participation involved encouraging people to talk about their health problems and services, and acting, or helping them act, on what they said
- Five of the included interventions were associated with positive effects on maternal and neonatal outcomes
- Two other community participation programmes increased births in health facilities and one additional programme also reduced neonatal mortality and stillbirths but success could not be attributed solely to the participation component.
- The successful interventions involved raising community awareness of maternal and newborn health problems, and encouraging dialogue **although this was also done in the interventions where no effect was shown.**



Knowledge of nurses and counsellors about the risk of HIV transmission through breastfeeding

Qu: If 100 HIV-infected mother breastfeed their children up to 2 yrs, how many children will be infected? *(mother and child do not receive any ARVs)*



% nurses/
counsellors
agreeing
with this
estimate

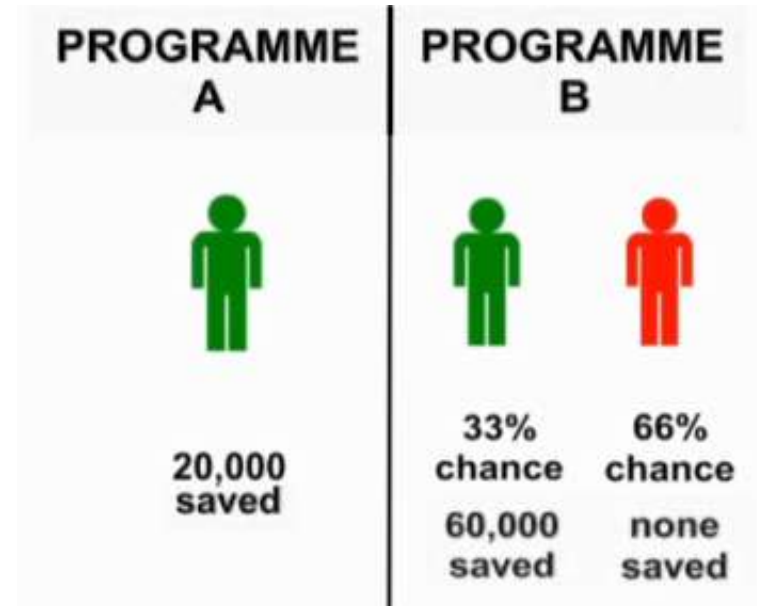
334 nurses/
counsellors
interviewed in
4 countries

How information is presented

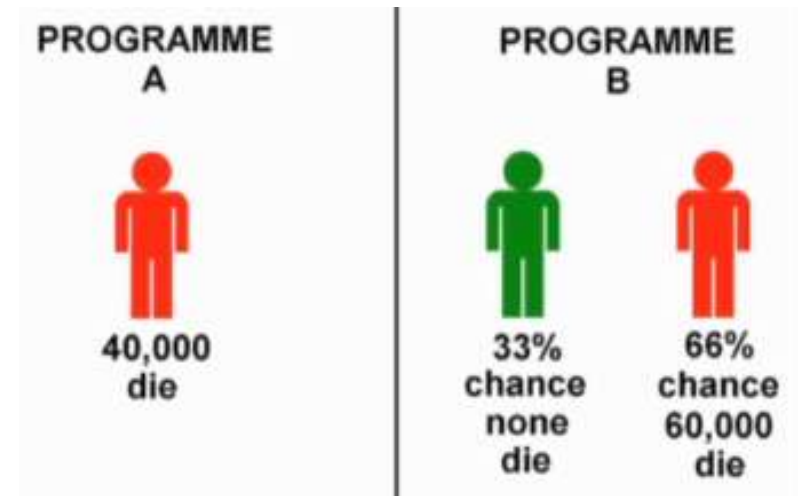
BBC (UK). Bang. 2011

"The UK is preparing for an outbreak of a new epidemic, and it's predicted that 60,000 people will die. You have to decide between two programmes, A or B, to combat the disease."

Scenario 1



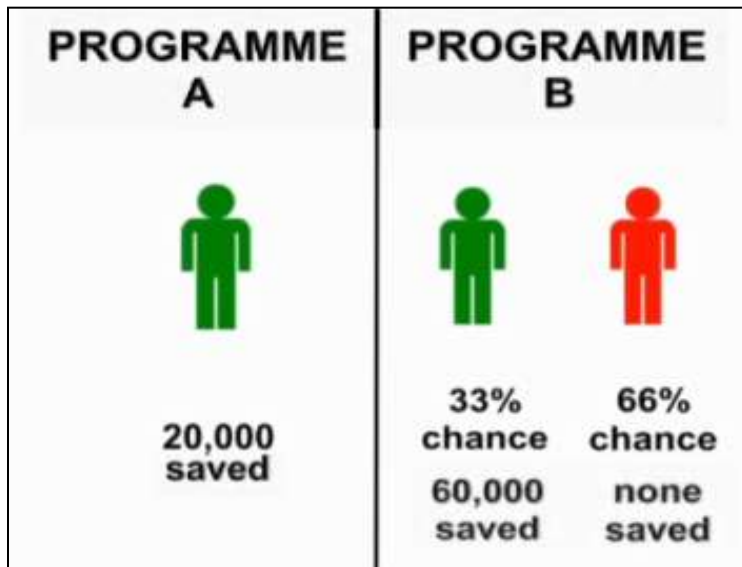
Scenario 2



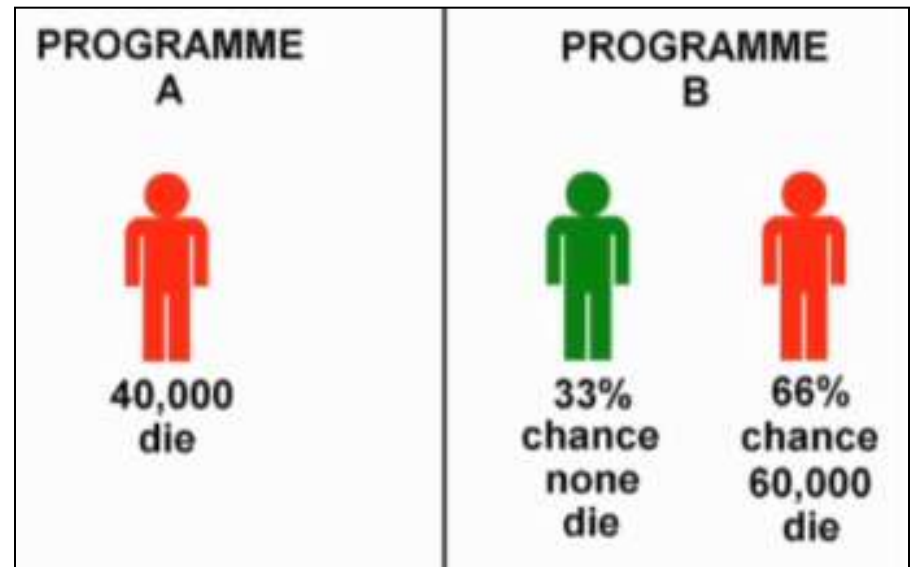
The way information is presented in Scenario 1 emphasises lives saved, while Scenario 2 emphasises deaths. However, the numbers add up the same. Both programme have 20,000 deaths, and both programme have the same gamble.

Results:

- In Scenario 1 most people choose the certainty of A
- In Scenario 2 most people choose the gamble of B.

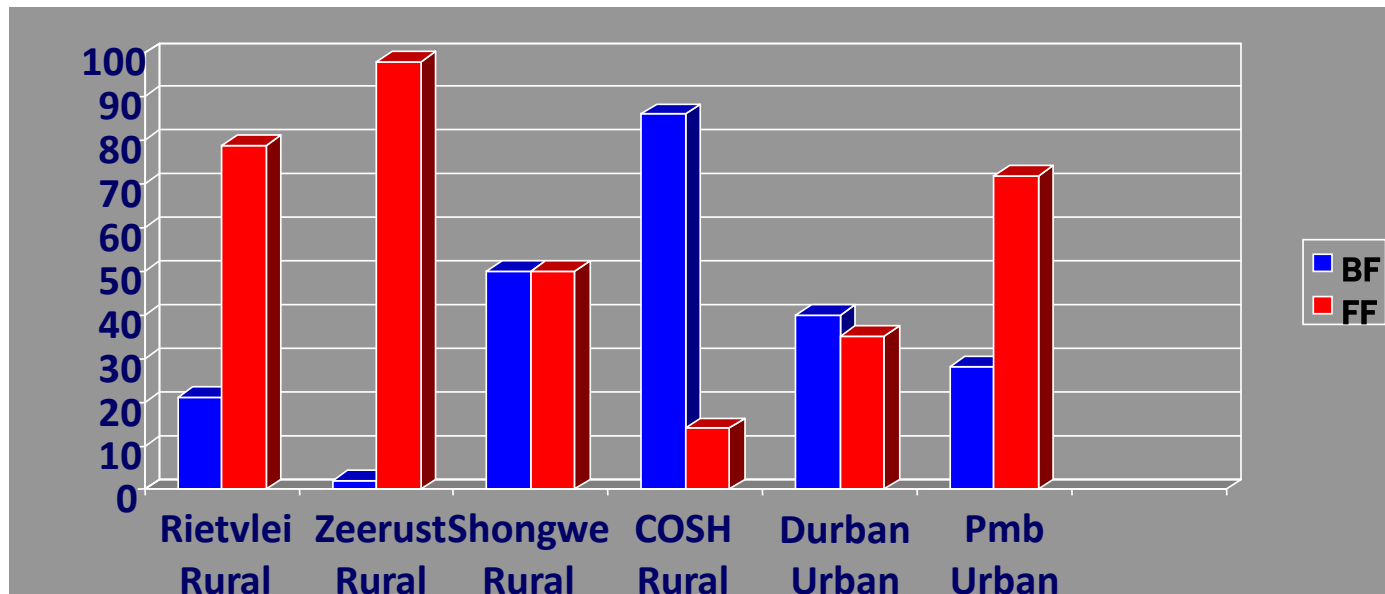


Scenario 1



Scenario 2

Feeding at some PMTCT sites in South Africa



The quality of infant feeding counselling translated into HIV free survival of infants

Woldenbeset. IAS 2009

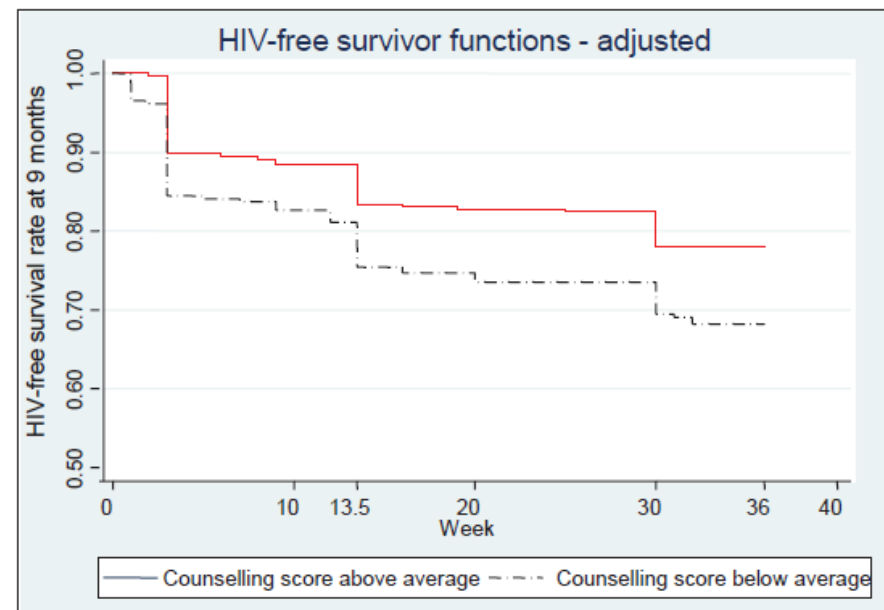


Figure 1: Kaplan Meier survival curve of the HIV free survival rate by counselling group

Community action to end vertical transmission of HIV

..... and keep infants and mothers alive?

What is needed so that health workers will want to promote breastfeeding with ARVs and HIV-positive mothers will want to breastfeed?

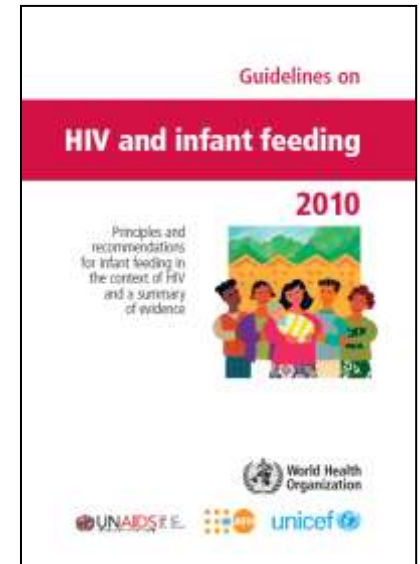
Not ... 'either, or'

Community ...

- Engagement
- Mobilization
- Inclusion

Facilities ...

- Readiness
- Reliability



Context will define the needs and opportunities

- Non-engagement, no mobilization or inclusion of communities will impose a ceiling on the potential outcomes
- Health systems and communities need to enter into 'coalitions' if comprehensive and sustained benefits are to be achieved

What's needed?

- ✓ Rationale
- ✓ Proof of principle – community-directed interventions and community 'activation' improve outcomes
- ? More research



What's needed?

More research

- ? Impact and cost-effectiveness of mothers' support groups
- ? How to better link facilities with community as partners
- ? Which community action is most effective and feasible according to setting
- ? How to scale up and sustain the relevant community action



**Families,
communities
and health systems**



