Premature Mortality in Pregnant South African Women with HIV: A Health, Development and Social Justice Problem

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Aims

1) Explore role of health research broadly
2) Discuss a particular health and social problem in South Africa: Consider problem of premature maternal and child mortality linked to HIV-related infections in SA
   - Share empirical findings of field research
3) Consider implications

Framing Questions

What role for research to address larger global health inequities taking place in countries around the world to create social change?

Particularly *health-related social injustices*?

The Aim of Health Research

Health research seeks **to systematically generate knowledge that can be applied to protect, promote and enable the health and well-being** of populations, individuals or groups (Mann, 1997).

Is Health Research:

- Theoretical?
- Value-neutral?
- Used for social change and social justice?

The Role & Philosophy of Health Research

1) Health research is fundamentally 'applied' – we *use* it to make changes that improve health/well-being of individuals and populations
2) Not 'value neutral' – the goal is a) understanding; b) improving
3) Researchers make contributions to knowledge that inform evolving health practice (clinical; health systems): *linking theory and practice*

Characteristics of Health Research

1) Research must be:
   - *Methodologically sound*
   - *Scientifically rigorous*
   - *Ethical*
   - *Culturally acceptable and appropriate (in local context)*

Characteristics of Health Research

1) **Applied social science health research** is both a social and a scientific process
2) We rely *on an evidence base* to understand the needs of populations in particular settings (stats are important)
3) Through robust research methods, we build on the existing evidence base
   - This is first step in developing policies and interventions to address and improve health or well-being

I. The Story of Global Health

What is Health Inequity?

What is a Health Inequity?

- Differences in health that are **unnecessary, avoidable, unfair and unjust** and systematically associated with social disadvantage that is frequent, substantial persistent, not random or occasional.
- **An inequity is a subset** of inequalities that is **deemed "avoidable" "unfair"**

Sources: Braveman and Gruskin, 2003; Whitehead, 1992

- **Health equity** is attainment of the highest level of health for all people
- **Achieving health equity requires valuing everyone equally** *with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices*, and the elimination of health and healthcare disparities

Source: US Dept of Health and Human Services

http://minorityhealth.hhs.gov

What are main trends in global health outcomes around the world (along key indicators)?

Key Message:

- **Research is critical to identifying, uncovering, understanding, 'shining light on' health inequities**

Global Health Trends

The “global health revolution” has resulted in improvements in life expectancy, maternal and child health

-Over three decades:

- An additional four months added to life expectancy each calendar year for some countries
- Reductions in infant mortality (Evans et al, 2001; MSF, 2000)

Global Health Trends

- Reductions in maternal mortality in Egypt, Pakistan, Brazil, Mexico, China, Bangladesh

- But health gains have not been evenly distributed…

Causes of Death: Global Trends (WHO, 2008)

High Income Countries (Generally):

- People will live to age 70
- Will die of chronic diseases: cardiovascular disease, lung disease, cancers, diabetes, dementia (Noncommunicable diseases or NCDs)

Middle Income Countries (Generally):

- People will live to 70
- Will die of same chronic diseases but also
- TB, HIV/AIDS and road traffic accidents are leading causes of death (NCDs and other)

Causes of Death: Global Trends (WHO, 2008)

Low Income Countries (Generally):

- Less than 1 in 5 people will live to age 70
- 1/3 of deaths are in children under age 15
- Will die of infectious diseases:

- Lung infections, diarrhoeal diseases, HIV/AIDS, tuberculosis, and malaria
- Complications in pregnancy and childbirth

Top Two Causes of Death, Globally For Women

Women of reproductive age (15-44):

1. HIV/AIDS, capturing **19%** of all deaths
2. Complications from pregnancy and childbearing, contributing **15%** of total deaths *(The Lancet*, 2010)

Key Messages of Global Trends

- *Variations in life expectancy rates among countries* and between people in the same country
- *Differential causes of death* in regions of the world
  - Most developed countries affected by chronic lifestyle diseases: non-communicable diseases (NCDs)
  - *Infectious disease and growing burden of NCDs in developing countries*:
    - With mix of NCDs (*associated with wealth*), and infectious diseases and other preventable conditions (diarrhea) (*associated with poverty*)

Implications: Global Health Disparities/Inequities

- Inequalities exist in health outcomes between nations and among population groups in same country
  - Poor health outcomes correlate with lower social and economic status, ethnic and other racial characteristics and poorer access to and quality of care (Anand et al, 2004)
- Disparities in health achievements reveal **different life chances** people have
- **A global justice concern:** "Differences in health outcomes between population groups challenge our sense of justice and provoke our scientific curiosity"(Tim Evans et al, 2001, p. 12)

II. The South Africa Story - National Indicators

(within larger Global Health Story)

But First…

Comparing Epidemic Severity and Impact

What is Severity of HIV in the US?

Q. What % of people are living with HIV in the US?

Comparing Epidemic Severity and Impact

US HIV Prevalence =

0.6% of US population

Comparing Epidemic Severity and Impact

Q. What % of people are living with HIV in the countries of southern Africa?

HIV Prevalence in Southern Africa

Swaziland, 26%; Lesotho, 23.6%; Mozambique, 11.5%; **Botswana, 24.8%;** Namibia, 13.1%, **South Africa, 17.8%;** Zimbabwe, 14.3%; Zambia, 13.5%, Malawi, 11%

Source: UNAIDS epi country profiles, 2009 data


Click to enlarge
TANZANIA
ZAIRE
L. Malawi
Luangwa R.
Nyika
North Luangwa
MALAWI
ANGOLA
South Luangwa
Mfuwe
ZAMBIA
Lilongwe
Kafue
Lusaka
Lower Zambezi
Zambezi R.
Liwonde
Mana Pools
Blantyre
Kunene R.
L. Kariba
Matusadona
Victoria Falls
Serra Cafema
Caprivi
Chizarira
Harare
Chobe R.
Chobe
MOZAMBIQUE
Etosha
Hwange
Namib Desert
Okavango Delta
ZIMBABWE
Skeleton Coast
Maun
Beira
NAMIBIA
Makgadikgadi Pans
Bulawayo
Matopos
Central Kalahari
Gonarezhou
Swakopmund
Windhoek
Mashatu
Walvis Bay
BOTSWANA
Limpopo R.
Limpopo R.
Kruger
Vilanculos
Bazaruto Archipelago
Namib Naukluft
Kalahari Desert
Gaborone
Sabi Sands
Sossusvlei
Madikwe
Pretoria
Maputo
INDIAN OCEAN
Johannesburg
SWAZILAND
Fish River Canyon
Greater St. Lucia Wetland Park
SOUTH AFRICA
Hluhluwe & Umfolozi
Orange R.
Kimberley
Richards Bay
MADAGASCAR
ATLANTIC OCEAN
LESOTHO
Durban
Anjanjavay Mahajanga
Addo Elephant
Antananarivo
Perinet
Stellenbosch
George
Cape Town
Port Elizabeth
Cape Point
Knysna
Plettenberg Bay
Hermanus
Isalo
Tulear
Cape of Good Hope

Identifying the Research Problem

How do you, as a researcher or PhD student figure out what the research problem is?

1. Select General Topic
2. Map the Topic
3. Conduct Extensive Literature Review
4. Figure out What We Know; What We Don't
    1. Identify the gaps in our knowledge base/understanding
5. Turn a Social Problem into a Research Problem and Question
    - Ex. Suicide in young people is rising, why?
    - Intimate partner violence exists in all income and resource settings, why?
    - HIV infection is rising in the US South, why?

South Africa

Total population: 53 million **(**Statistics South Africa, 2011)

People with HIV/AIDS: 5.3 million (UNAIDS, 2009)

Population in urban areas: 60% (StatsSA, 2010)

GNI per capita: US$6,100 (World Bank, 2010, Atlas methodology)

OECD classification: Upper middle income country (OECD, 2010)

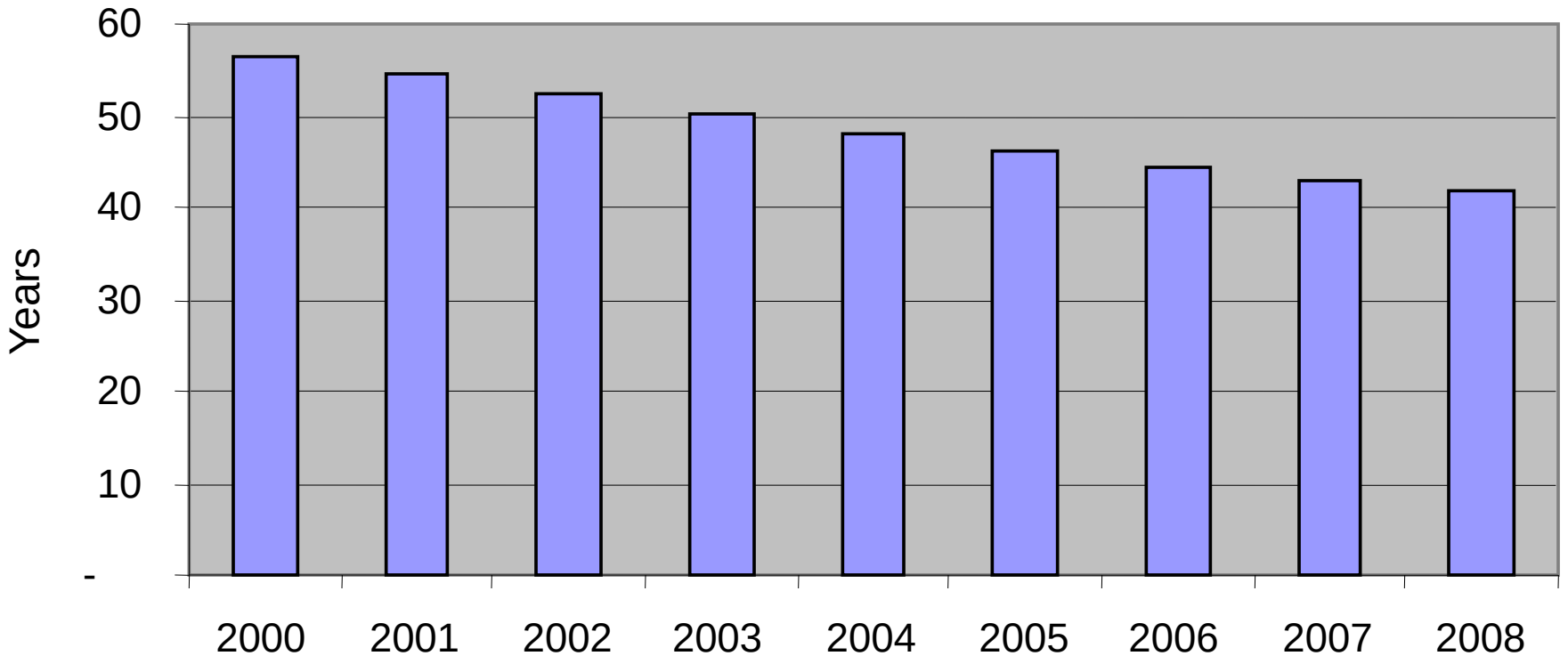
Health expenditure as % of GDP: 8.5% (SA Dept of Health, 2009)

Unemployment rate: 24% (StatsSA, 2011)

Adult literacy rate: 89% (UNICEF, 2011)

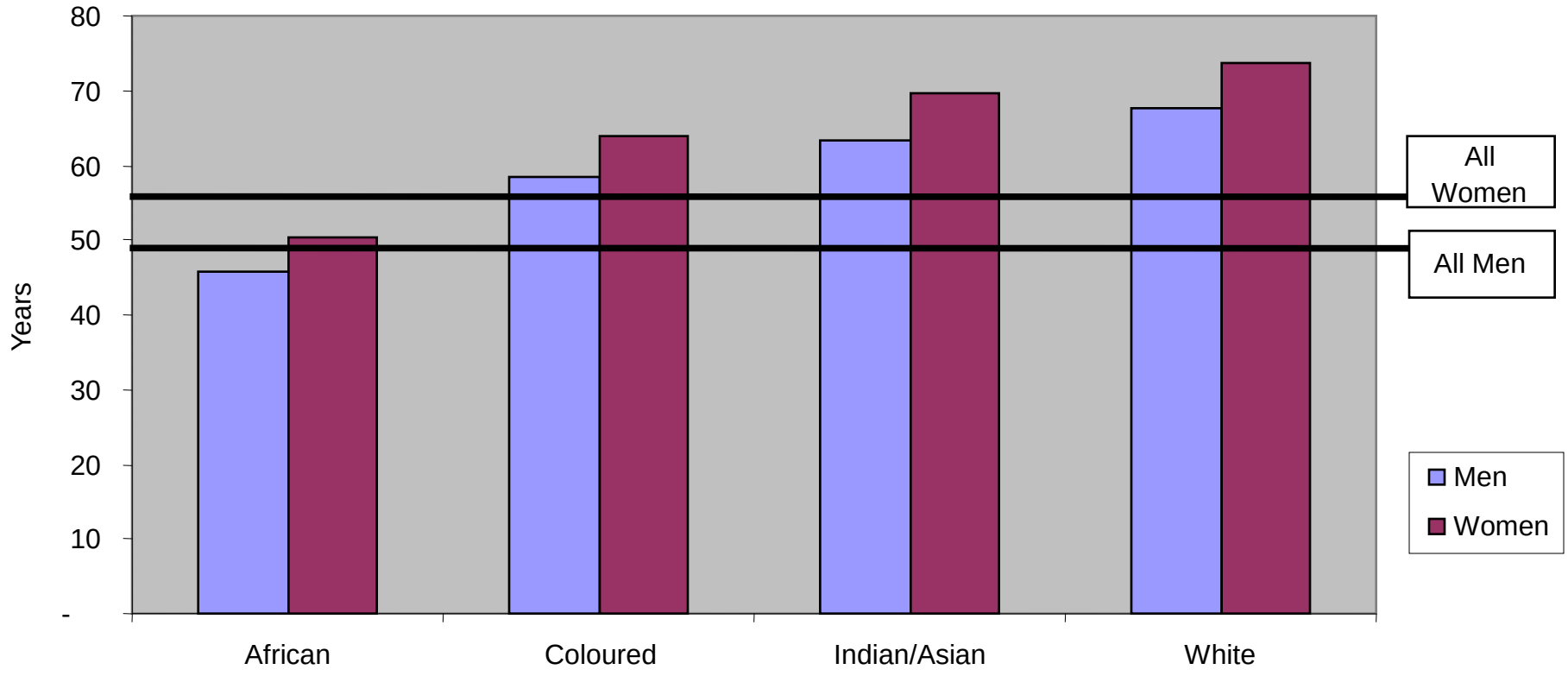
Life Expectancy - South Africa

Figure 1 SA National Life Expectancy at Birth



Life Expectancy - South Africa

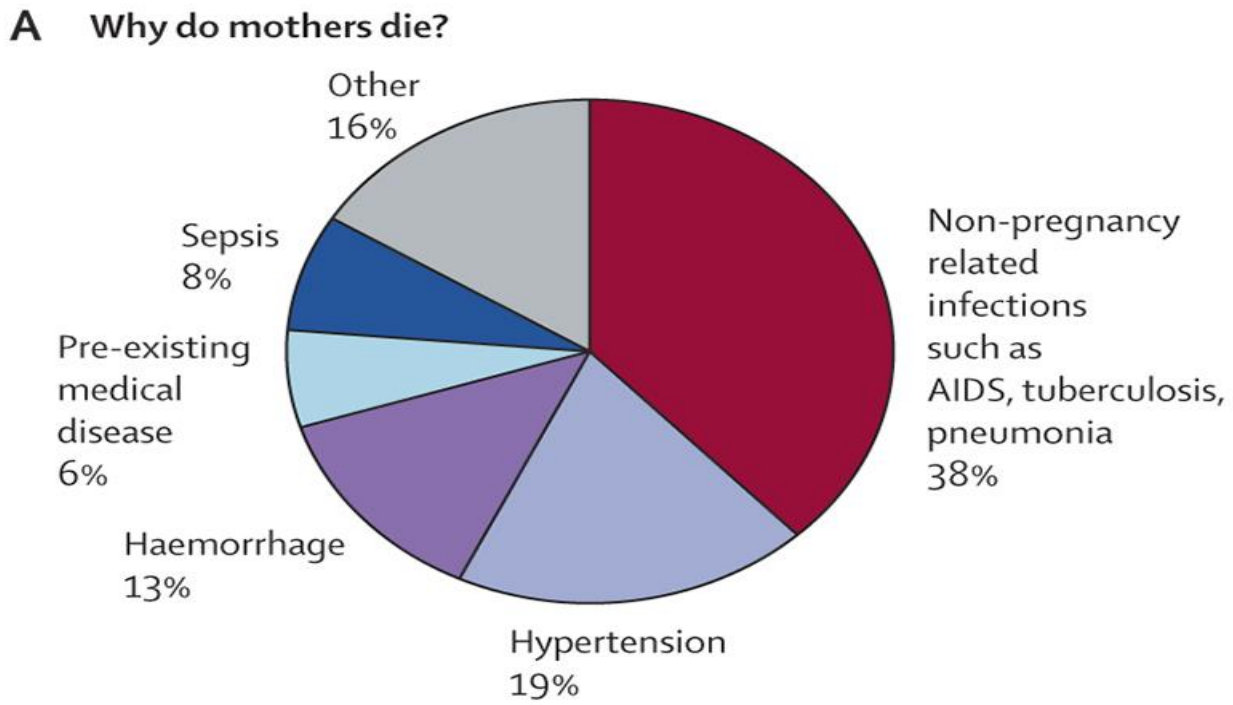
Figure 2 Life Expectancy at Birth



Trends in Maternal Mortality, 1990 to 2008

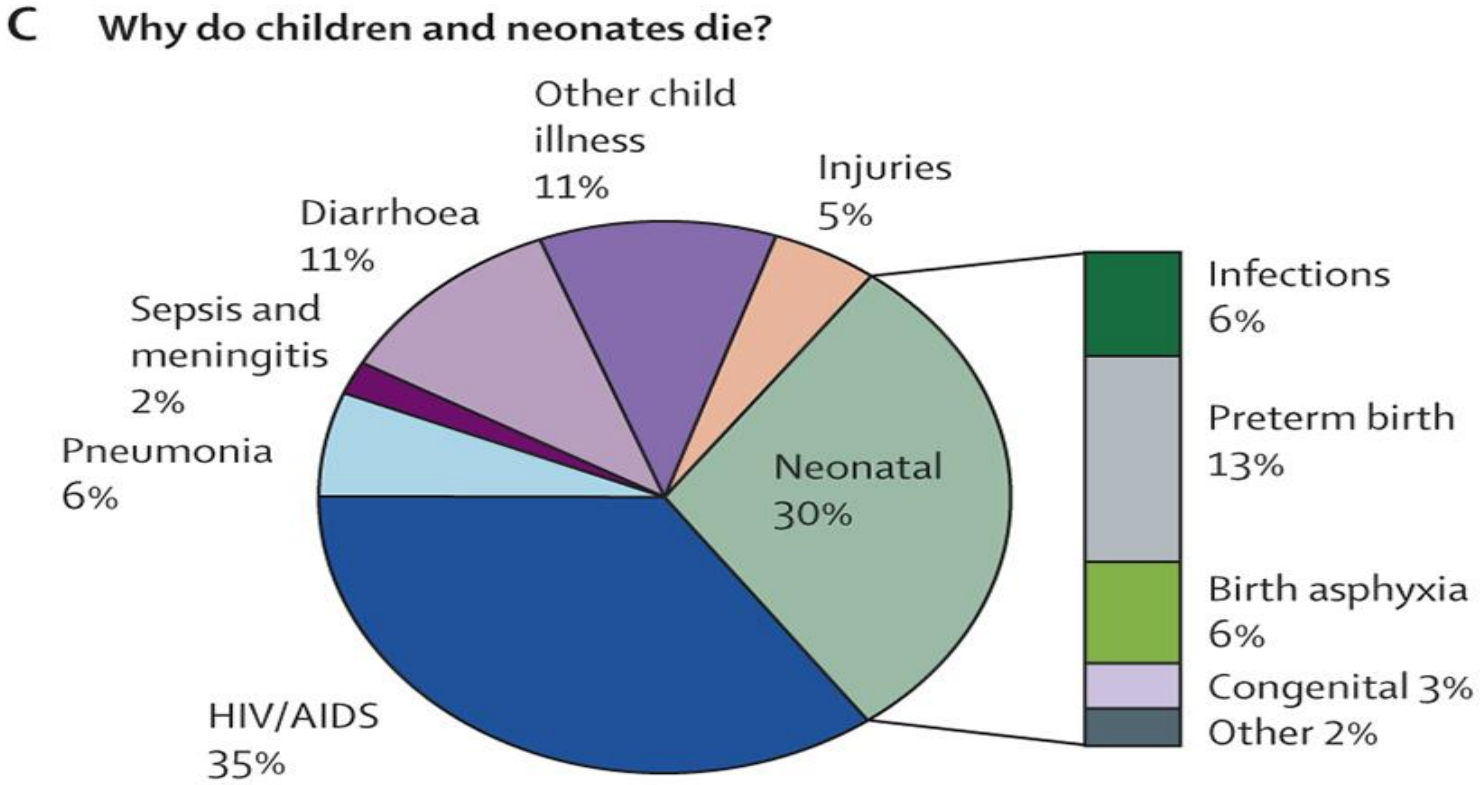
- *Global trend*: decline in maternal mortality (1990 to 2008) for some countries (Hogan et al, 2010; Blaauw and Penn-Kekana, 2011)
- *South African trend*: maternal mortality doubled (Chopra et al, 2010; Pattinson et al, 2008, 2009)

Causes of Maternal Deaths – South Africa



Source: South African Every Death Counts Writing Group. 2008. *Lancet* 371, p. 1298. Used with permission from the authors.

Causes of Infant & Neonatal Mortality - South Africa



Source: South African Every Death Counts Writing Group. 2008. *Lancet* 371, p. 1298. Used with permission from the authors.

Key Message

- Poor health for black women of reproductive age and children:
  - Declining life expectancy
  - Rising maternal and child mortality:
    - 40% of deaths attributed to AIDS
  - HIV prevalence in white women = 0.6%
  - **HIV prevalence** in black pregnant women = **30%** (consistently over the last 10 years)

The Puzzle

- SA is upper middle income country
- Relatively high density of healthcare workers, though shortage in public health system: *36 to 50% of nursing/doctor posts unfilled in some locations*
- Good infrastructure
- High levels of specialised knowledge in medicine and public health
  - Health and development poor for these groups, against context of global health improvements

The Puzzle

- HIV services freely available in public sector for women/children since 2002
- HIV preventable in children
- Treatable in pregnant women and children
- Treatment very effective in managing HIV, improving quality of life and health

Research Question

- **Only 14.6% of pregnant women and 10% of children** were gaining access to HIV prevention and treatment services (UNAIDS/WHO, 2006)
- If life-saving ART and PMTCT is **freely available** in the public health system:

- **Q.** What are the ***primary barriers*** **to access and delivery** of HIV services for these population groups in SA public health system?

Study Objective

1. To answer research question
2. To understand problem of poor HIV service uptake/delivery at:

- **System Level**
- **Individual Level**

3. Make facility level and policy level recommendations

Qualitative Research Study

1. Rooted study in social context:

Considered interplay between individual behaviour, social cultural norms and health system operations

2. Used “continuum of care” as framework to track a woman’s journey through public health system:

- ✓ *Prenatal care ward*
- ✓ *Labor and delivery ward*
- ✓ *Postnatal/postpartum care ward (after patient is discharged)*
- ✓ *Paediatric ward*

Research Duration & Ethics

- Research conducted from March 2008 to February 2009 (one year)
- **Ethics permissions** received from four facilities; two provincial Depts of Health; two universities
- **Research ethics procedures** followed and **informed consent** received from all participants

Research Sites (four facilities)

- 1 *academic public hospital* in **urban** Johannesburg
- An *academic public hospital*
- A *public hospital* and
- A primary health *clinic* in a **resource poor largely rural** region of Eastern Cape province
- **Offered urban-rural comparison**

Data Collection and Analysis

In-depth semi-structured interviews with:

- 83 HIV-positive women
- 32 caregivers of HIV-positive children
- 38 key informants (doctors, nurses, lay counsellors and key experts)
- Translators present during interviews – conversations in Xhosa and Zulu – translated immediately into English for probing
- Record review of patient files: treatment regimen, health provider actions, e.g., counseling received

Grounded Theory Method

- Purposive sampling
- Constant comparative method of data collection
- Collect, coding and analyze data, identifying key themes through memoing
- And identification of core categories as they emerge
- With hypothesis or theory generation
- Aiming to reach data saturation: thick and rich descriptions from respondents

Demographics of Women

- Black South African women of African descent
- 18-41years of age
- 95% of women were:
  - Formally unemployed
  - Classified as poor (< $2 p/day)
  - Economically dependent on a partner/husband or father

Findings

Facility/System Level

- *Insufficient* numbers of health *staff assigned to HIV services*
- *Late payment* of lay HIV *counsellors* with subsequent *absenteeism*

  - i.e., pregnant women arrive for prenatal care and there is no one to provide HIV testing and counselling

Facility/System Level

- *Failure to test pregnant women* for HIV due to test kit shortages
- *Delays in returning CD4 results to patient files,* which delays ART initiation
- *Inadequate knowledge of PMTCT and ART* by health personnel
- *Poor quality of counselling* (on infant feeding)
- *Poor* (or no) *systems for data capturing* and tracking
- **Implication:** E*ffectiveness of the programmes* at district, provincial, national level is largely unknown

Individual Level

- ***Stigma*** *Fear of HIV positive test result, fear of partner's reaction*
- ***Psycho-social/mental health*** *effects*
- ***Economic dependence*** *on partner*
- ***Poverty*** *– affects ability to pay for transport to attend clinic appointments*

Discussion

- A single system- or individual-level obstacle reduced the likelihood of women accessing ART or PMTCT
- These *impediments*, when *concurrent*, often resulted in *denial of prevention and treatment*

Discussion

<u>Health personnel</u> acted, or failed to act, as:

- **Vital connectors** to testing, counselling and treatment – and to the health system
- **Providers of strategies and support** for adherence, disclosure and formula feeding for women
- Too frequently, **health personnel missed service delivery opportunities** due to absenteeism or burnout

Two Key Insights from Research

1. *Health system is vehicle for good health* There are many aspects of HIV service delivery within the health system which can be addressed and improved

2. *Additional SDH* Ensuring good health for these population groups will not result solely from interventions within the health system due to existing structural poverty and socio-cultural norms

Beyond the Health System: Social Determinants of Health

Individual factors that impact on health:

- ***Poverty and unemployment***
  - Lack of money for transport to clinic
  - Economic dependence on partner/husband and fear of being left
- ***Intimate partner violence***
- ***Accepted socio-cultural practices*** Infant feeding
- ***HIV stigma*** *(experienced or anticipated)*

Recommendations

- *Identifying clear scopes of practice* for health personnel (nurses, doctors, lay counselors)
- *Ensuring autonomy of nurses over resources* at facility level: training them as decision-makers and leaders of health teams
- *Linking performance management to facility- wide* interventions
- *Introducing formal monitoring and evaluation* in facilities
- *Addressing poor employment conditions* of lay counselors
- *Improving pyscho-social support* in clinics/hospitals

Recommendations

- Establishing *robust systems for data collection and utilization*
- *Ensuring* continuous *supply of HIV test kits*
- *Improving* HIV service delivery in *labor wards*
- Providing *quality* HIV, treatment and PMTCT *counseling* services through repeat training
- *Greater attention to* HIV service delivery in *postnatal care*
- *Rural area allowances* for staff recruitment

Disseminating Research for Policy-Making/Social Change

- Partnerships with human rights lawyers/medical doctors/other researchers
- *Strategically Disseminate/Publish* to reach different target audiences:
  - *Judges and human rights lawyers: law journals*
  - *Doctors, nurses, health providers: health journals*
  - *The public: newspaper op ed pieces*
  - *Research conferences: research/academic community, students*

What Counts as Evidence?

- *Evidence that is 'most needed' varies by context* – resource-poor countries have the least data
- In SA Context:
- Clinic (hospital)-based data very important because this is the domain of Dept of Health

  -they are responsible for service delivery and care (by law)

Questions for Discussion

1. Is premature mortality in women with HIV in SA a problem of public health or of social justice?
2. What is the role of the state, civil society and the health department to address this problem?
3. What role for health disparities research and policy work?
4. How do we use research for long-term social change?

Thank you!