



November 10th, 2016

SEMINAR ON SEXUAL & REPRODUCTIVE HEALTH & RIGHTS AND STIGMATIZATION

Improving our understanding of the impact of stigma
on the right to sexual and reproductive health

“STIGMA and INFERTILITY”

Jan

Goossens



GLOBAL
ACCESS TO
INFERTILITY
CARE

BTC, Espace Jacquemotte, rue Haute – Hoogstraat 139, 1000 Brussels

The Willendorf Venus



Fertility goddess

28.000 – 25.000 BC

Refer to fertility and childbearing



<https://youtube.com/watch?v=hoxoghWiuiY>

Infertility: definitions (WHO 1975)

Primary infertility

The woman has never conceived despite cohabitation and exposure to pregnancy for a period of two years

Secondary infertility

The woman has previously conceived, but is subsequently unable to conceive, despite cohabitation and exposure to pregnancy for a period of two years

Infertility: biomedical causes

About 5%: anatomical, genetic, endocrinological or immunological factors

Remainder:

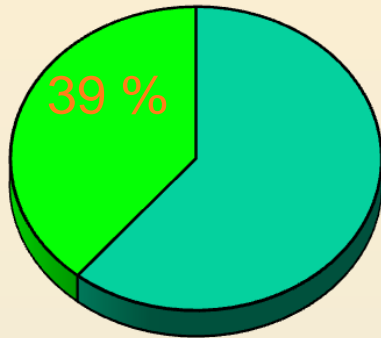
- * STDs (Chlamydia, gonorrhea)
- * unsafe abortions
- * poor obstetrical care
- * improper IUD insertion
- * toxic factors (environment/food) (!?)

Male and female factor infertility

- * Female (25-37%)
- * Male (8-22%)
- * Combination (21-38%)
- * Unexplained

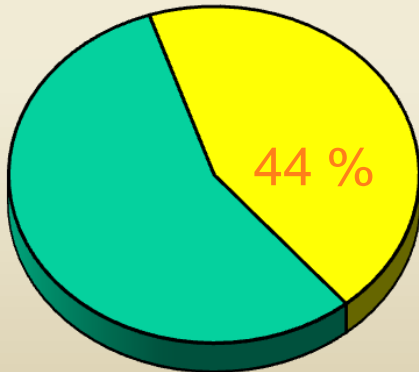
Reason(s) for infertility: infection-related tubal block

Asia

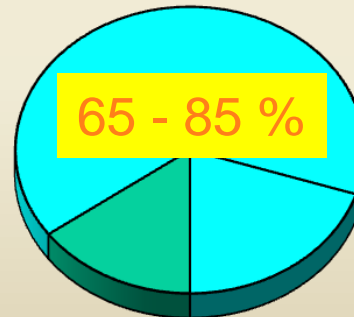


- STD's
- Post-partum infections/poor obstetrical care
- Illegal abortions
- Improper IUD insertion

Latin America



Africa



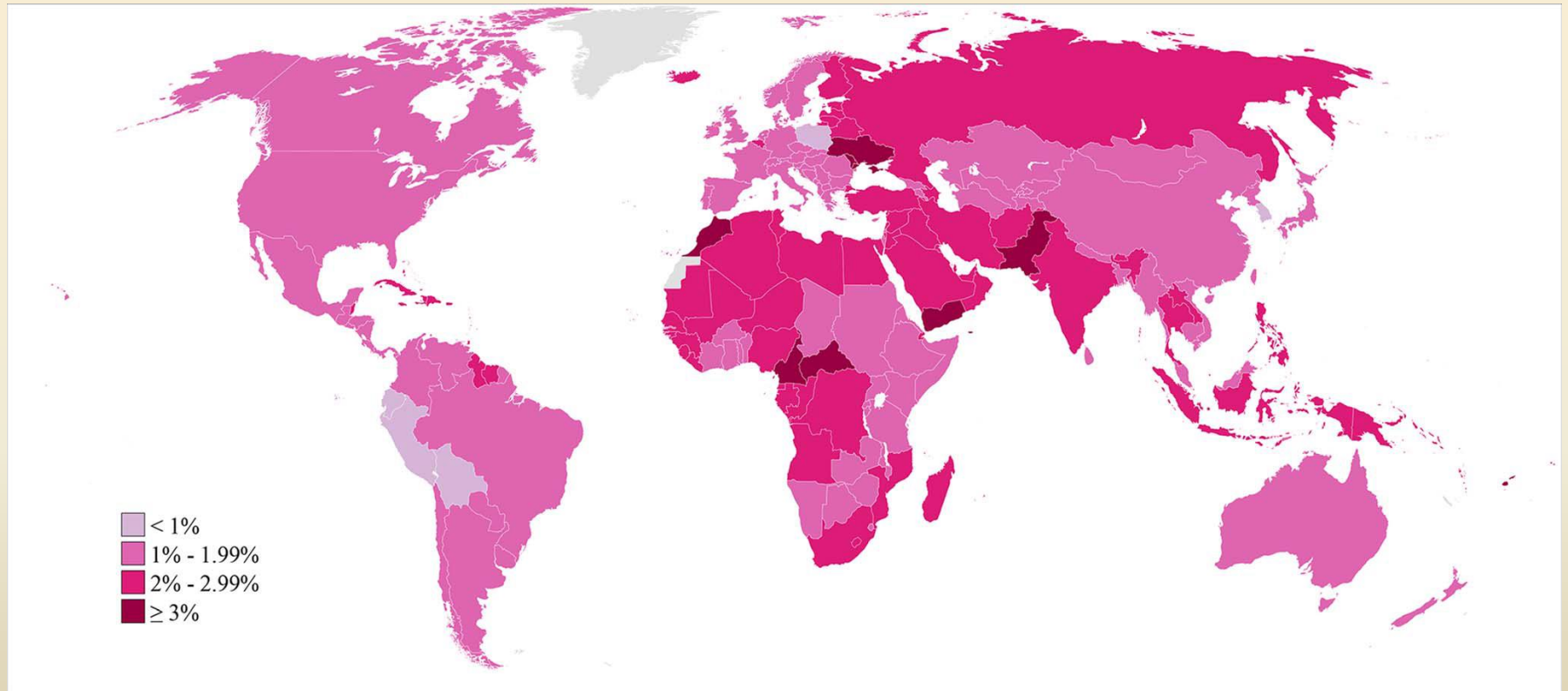
Infertility: prevalence

The large majority of childless couples are residents of low-income countries

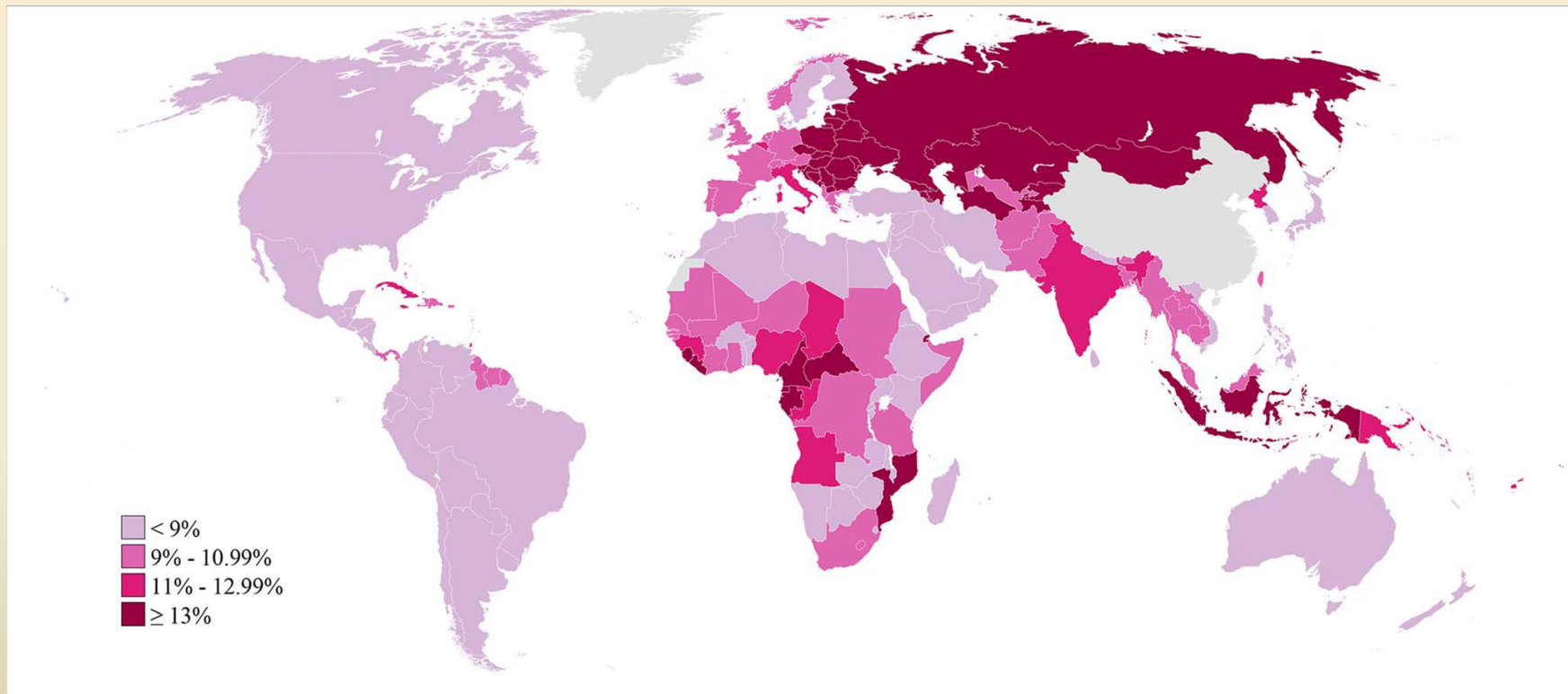
- **World wide estimate:** 8-12 % of couples experience some form of infertility during their reproductive lives (WHO 1991); 60-80 million couples (WHO 1997)
- **Differences** among countries and in countries.
E.g. various African countries: 20-30% ('infertility belt') (Ericksen & Brunette 1996)
- **Imprecise estimates:**
 - * whose definitions used? (demographic – medical)
 - * primary or secondary?
 - * who is counted? (married) women (age?), men, couples
 - * some of the data are old

Prevalence of **primary infertility** among women who seek a child, in 2010. Infertility prevalence is indexed on the female partner; age-standardized prevalence among women aged 20–44 y is shown here.

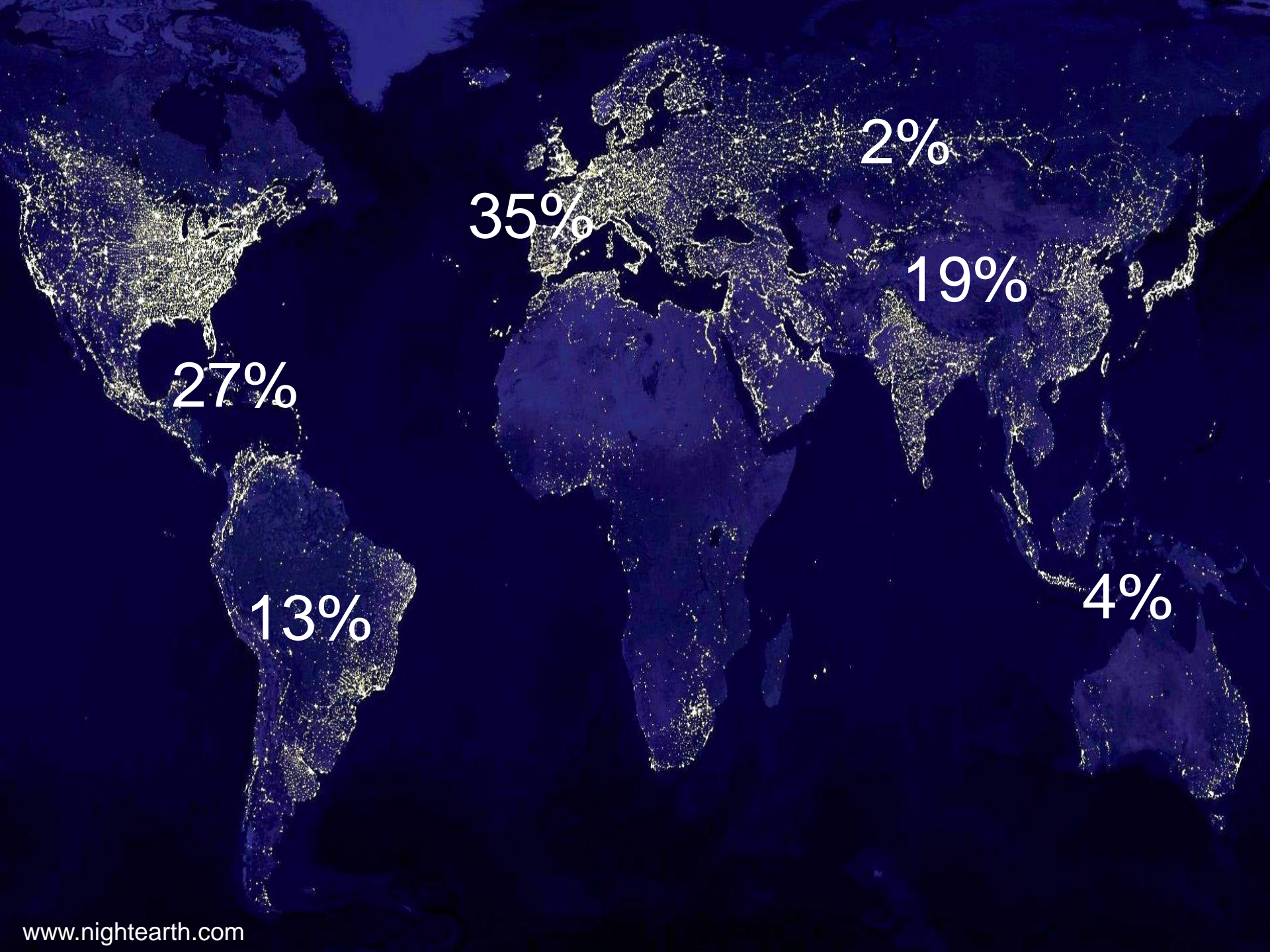
Mascarenhas MN, Flaxman SR, Boerma T, Vanderpoel S, Stevens GA (2012) National, Regional, and Global Trends in Infertility Prevalence Since 1990: A Systematic Analysis of 277 Health Surveys. PLoS Med 9(12): e1001356. (doi:10.1371/journal.pmed.1001356.g003)

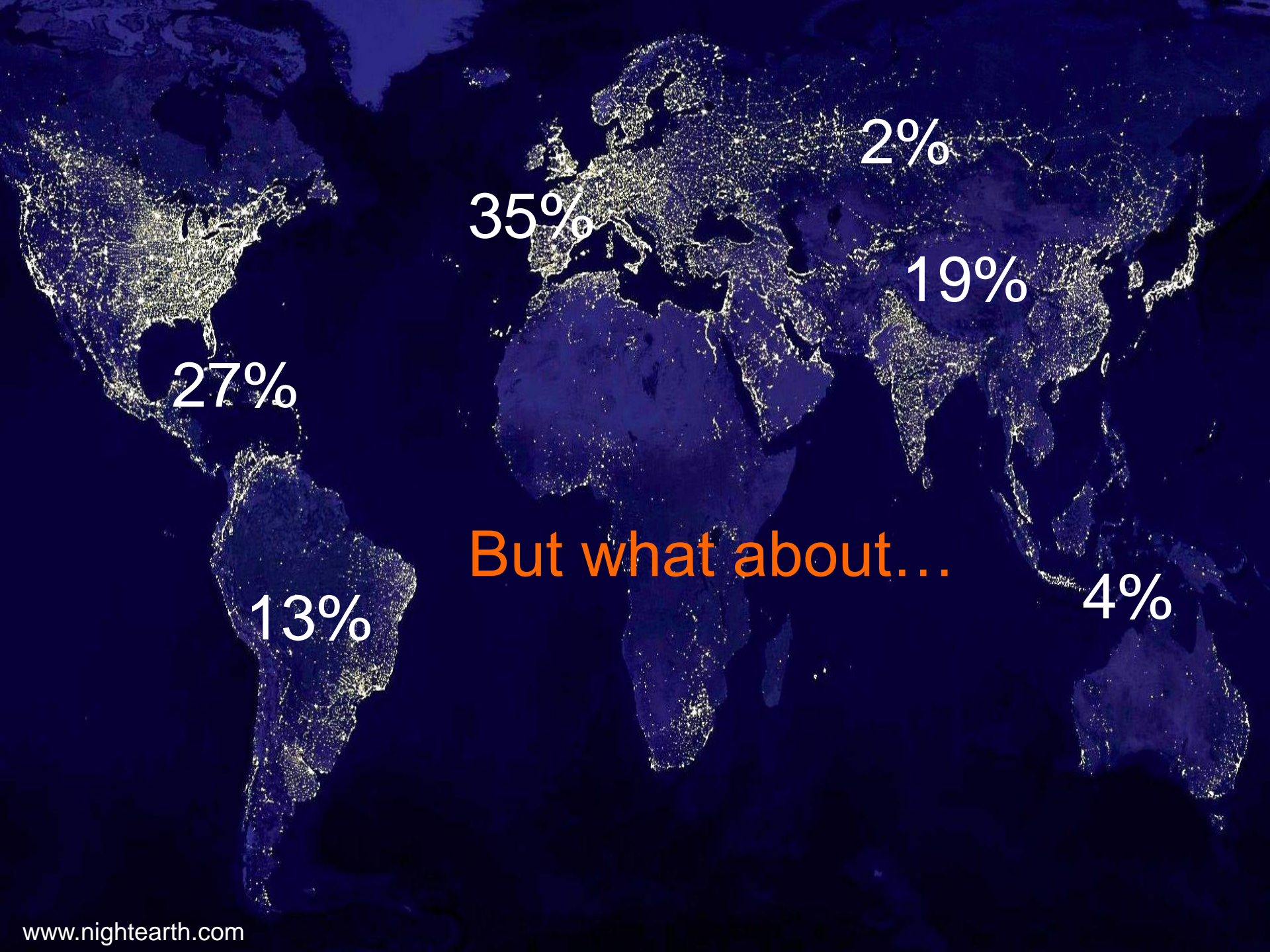


Prevalence of **secondary infertility** among women who have had a live birth and seek another, in 2010. Infertility prevalence is indexed on the female partner; age-standardized prevalence among women aged 20–44 y is shown here. [doi:10.1371/journal.pmed.1001356.g004](https://doi.org/10.1371/journal.pmed.1001356.g004)









35%

2%

19%

27%

13%

But what about...

4%



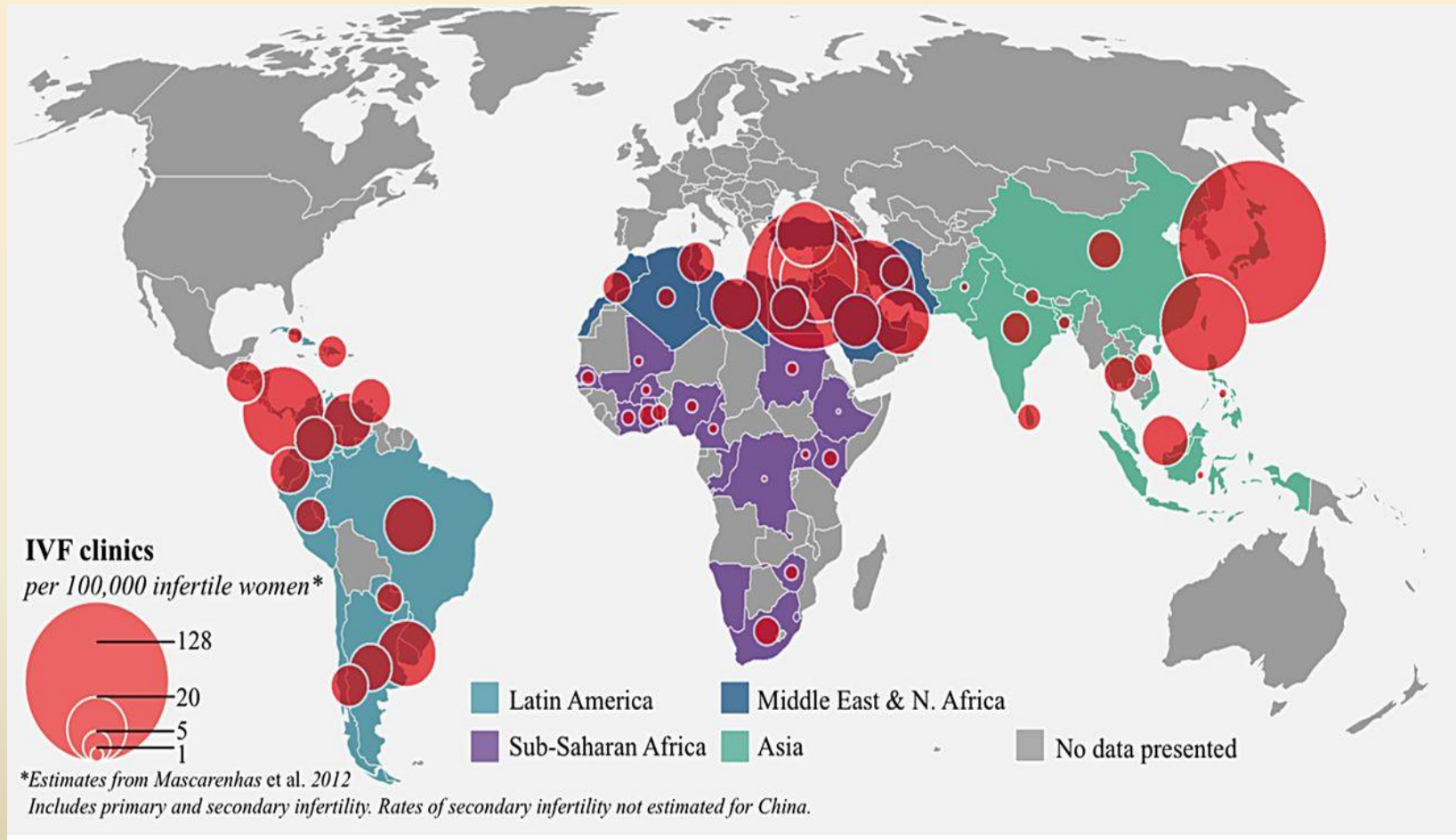
Infertility Care: not available or too costly

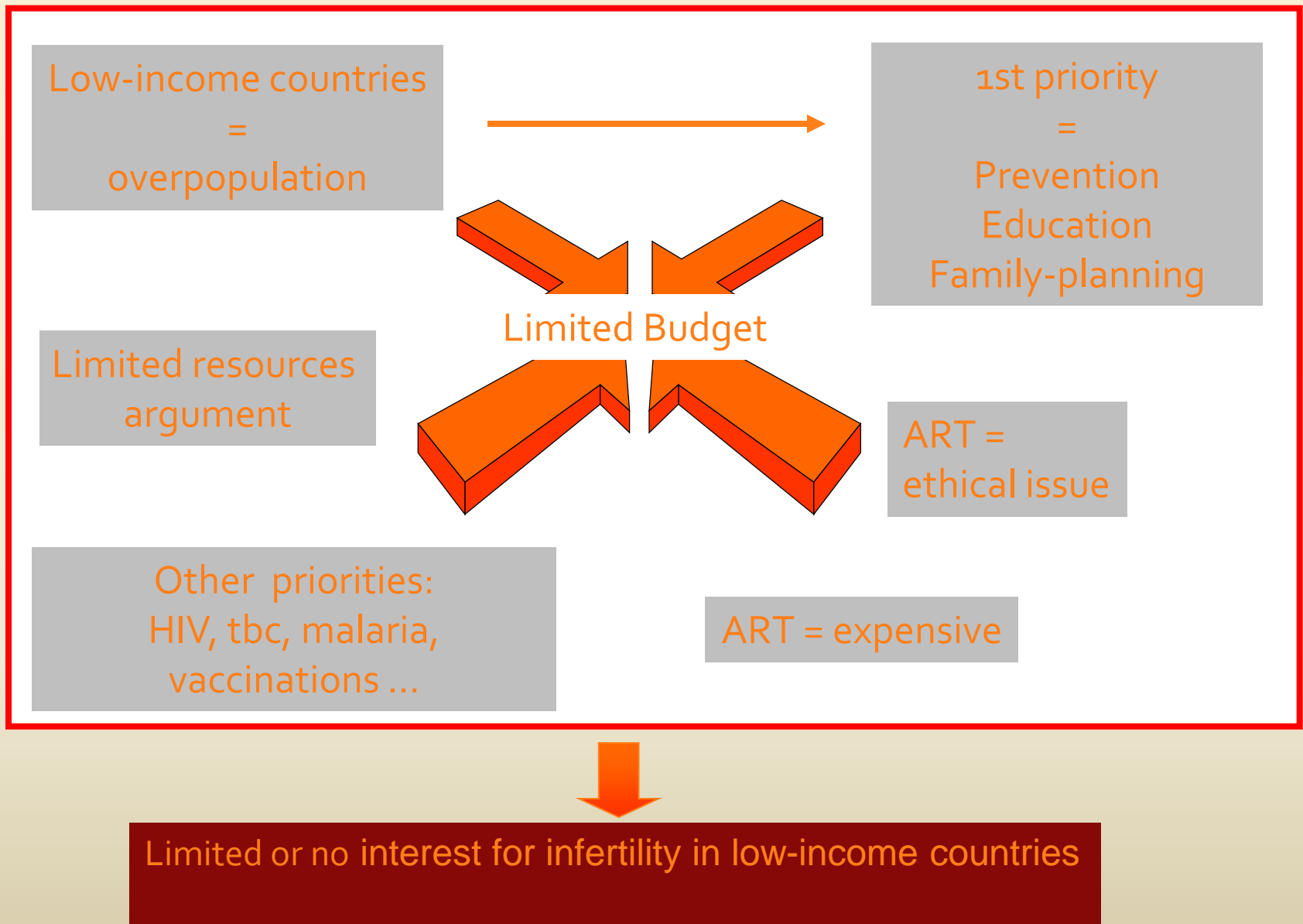
<2%

131 IVF-centres in Africa (vs 1638 in Europe)

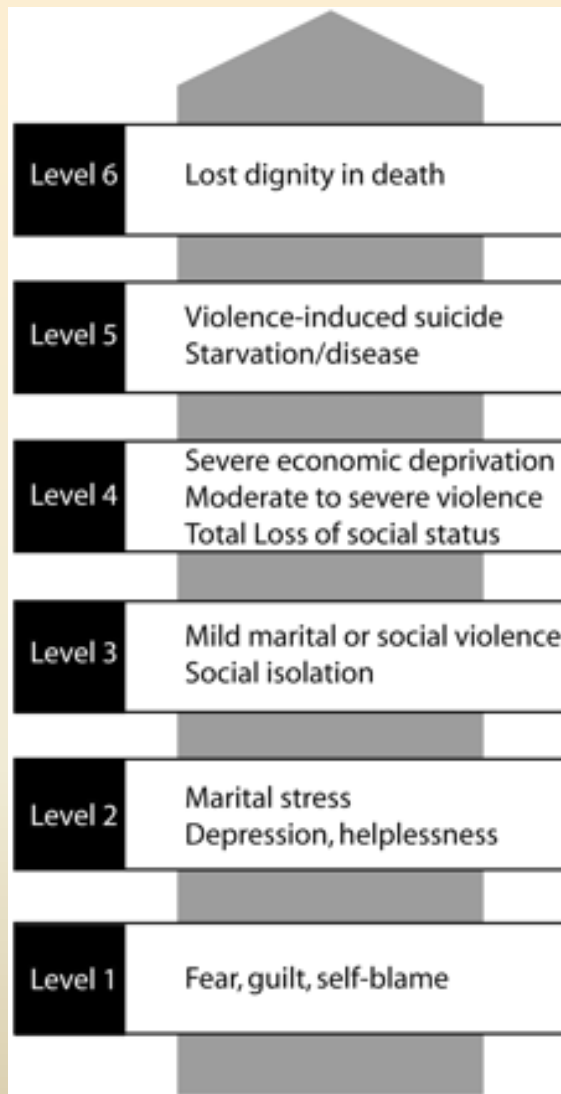


IVF-centers in low-income countries





Consequences of infertility



Low-income countries/transitional societies

High-income societies

WHO Current Practices and Controversies in Assisted Reproduction, *"Infertility and social suffering,"*
Daar & Merali, 2001

Consequences of infertility are numerous:

- Stress
- Depression
- Low-self esteem
- Guilt
- Marital problems
- Polygamy
- Sexual problems
- Violence
- Stigmatisation
- Repudiation
- Socio-economic Isolation
- Disinherited
- Neglected by the entire family and even the local community
- Suicide

Indirect consequences: increase in HIV-prevalence

- Multiple partners (the “search” for a child)
 - 3 times higher

Example: Study of the impact of infertility on women in Mozambique

(Gerrits 1997, 2002)

- Emotional impact:
feeling worthless, sad, jealous, guilty
- Conjugal relationship:
threat of divorce and husband leaving
- Family/lineage:
concern about continuation of wife's lineage
- Community:
exclusion from ceremonies and social events
- Economic:
Lack of social security and support; treatment costs

Value of children – importance of motherhood

- Bring marital security/stability
- Old age security and economic support
- Maintaining the lineage
- Spiritual benefit
- Funeral traditions
- Various kinds of practical help
- To bring love in the family
- Social status
- Religious beliefs

Infertility and childlessness
serious concern indeed...

But, avoid generalizations
and stereotyping

Impact on conjugal relationship

- not per sé negative!

(Inhorn 1996) – study among 100 infertile and 90 fertile women in Egypt

46 % of marriages (of infertile women) in Inhorn's study in Egypt were depicted as extremely strong and loving – Why so?

- Personal characteristics of men
- Cousin marriages
- Christian marriages
- Love marriages
- Previous pregnancies
- Religious husbands
- Infertile husbands

Perceived stigma and stress among women in Ghana varies

(Donkor, 2007) – quantitative study, 615 women, visiting clinics

- Women with higher levels of education felt less infertility-related stress and stigma
- So, the social status of infertile women derived from other factors than child bearing can minimize the impact of stigmatization and stress, related to infertility.

Child/fertility – seeking behaviour: 'Quest for conception' (Inhorn 1994) and others

- Traditional healers
(herbal and spiritual healers; traditional specialists, diviners, priests)
- Biomedical treatment (availability and quality?)
- Having extramarital relationships (men / women?)
- Fostering / adoption (religious and cultural objections)

Depending on:

- Availability, affordability and accessibility of various services
- Gender and kinship → decision making
- Context: policy, moral/religious

World community statements

1. “Men and woman of full age, without any limitation due to race, nationality or religion, have the right to marry and to raise a family”. This statement was adopted 60 years ago at the 1948 UN Universal Declaration of Human Rights and can’t be misunderstood: it implies the right to access to fertility treatments when couples are unable to have children.
2. At the United Nations International Conference on Population and Development in Cairo in 1994 the following statement was made “Reproductive health therefore implies that people have the capability to reproduce and the freedom to decide if, when and how often to do so ... and to have the information and the means to do so ...”
3. UN Millennium Declaration, signed in September 2000 : “Achieve, by 2015, universal access to reproductive health”.
4. In 2001, on the occasion of a WHO meeting on "Medical, Ethical and Social Aspects of Assisted Reproduction" in Geneva, a call for the integration of infertility into existing sexual and reproductive health care programmes in developing countries was made.
5. In 2004 the World Health Assembly proposed five core statements, including “the provision of high-quality services for family-planning, including infertility services”.

Is infertility care a reproductive right ?

As infertility is a condition that can lead to “marital demise, physical violence, emotional abuse, social exclusion, community exile, ineffective and iatrogenic therapies, poverty, old age insecurity, increased risk of HIV/AIDS, and death” it is suggested that reproductive rights must include the right to assist fertility when fertility is threatened, in addition to the right to control high fertility. (Inhorn, 2009)



- Sarah has AIDS: international program
- Sophia: pregnant: international program
- Margareth: has just delivered a baby: international program
- Joyce: safe abortion: international program
- Maria: childless: ...

The numbers:

\$21.7 Billion for AIDS/HIV

\$ 2.7 Billion for malaria

\$?? For infertility?



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Biomedical services in public health system in Sub-Saharan Africa

(Gerrits and Shaw 2010, review of studies done in SSA)

- 'Unpredictable, uncoordinated and incomplete'
- Haphazard and incomplete infertility examinations
- No systematic training of health workers
- Hardly any counselling
- Referrals from one level to the other disorganized
- Lack of systematic record keeping

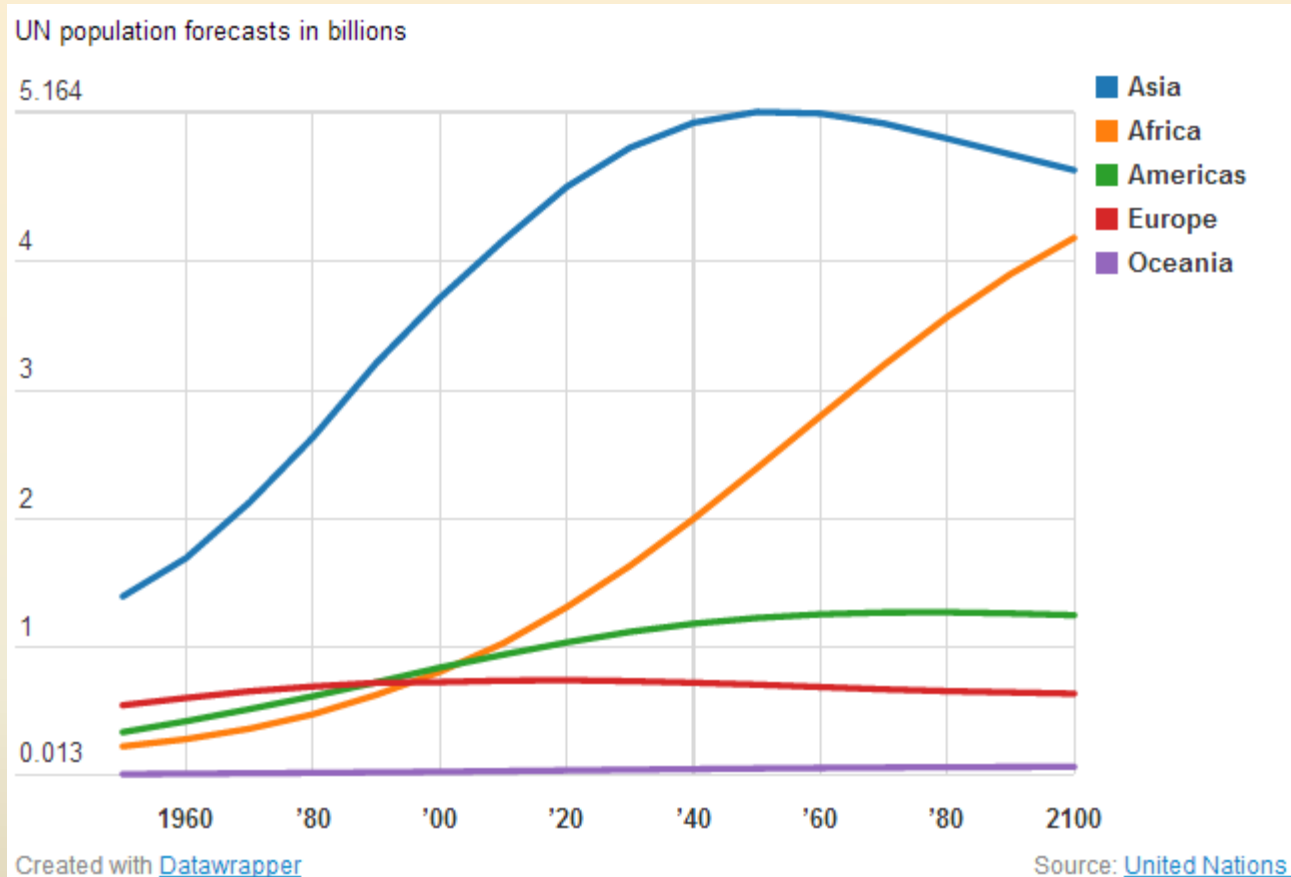
Why should we care ? (do we have good reasons to stigmatize?)

- Infertility not very prevalent in low-income countries
- Infertility is not a serious problem for people in low-income countries
- Individual problem, not a public health problem, not a problem of the nation...
- Overpopulation is a real problem
- The problem of infertility can only be solved when using very expensive treatments

Why should we care?

1. Overpopulation is a real problem
2. The problem of infertility can only be solved when using very expensive treatments

World population growth forecast



Should we worry?





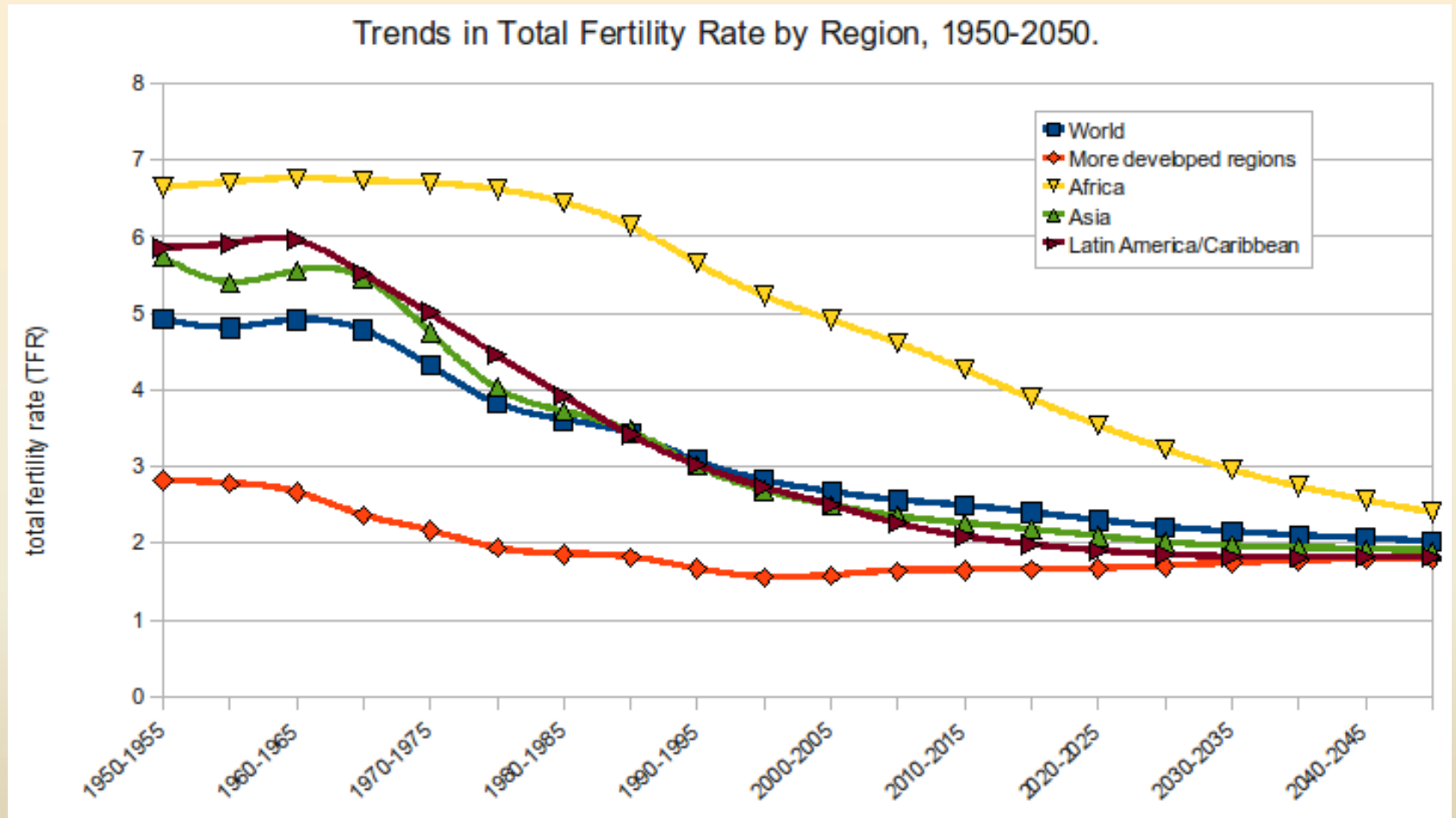
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CALM
AND
DON'T
PANIC**

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Fertility Rate worldwide





**UNITED NATIONS
SUSTAINABLE
DEVELOPMENT
SUMMIT 2015**
25 - 27 SEPTEMBER

Keys to a sustainable world

=

Fight poverty

Basic health

Womens Empowerment

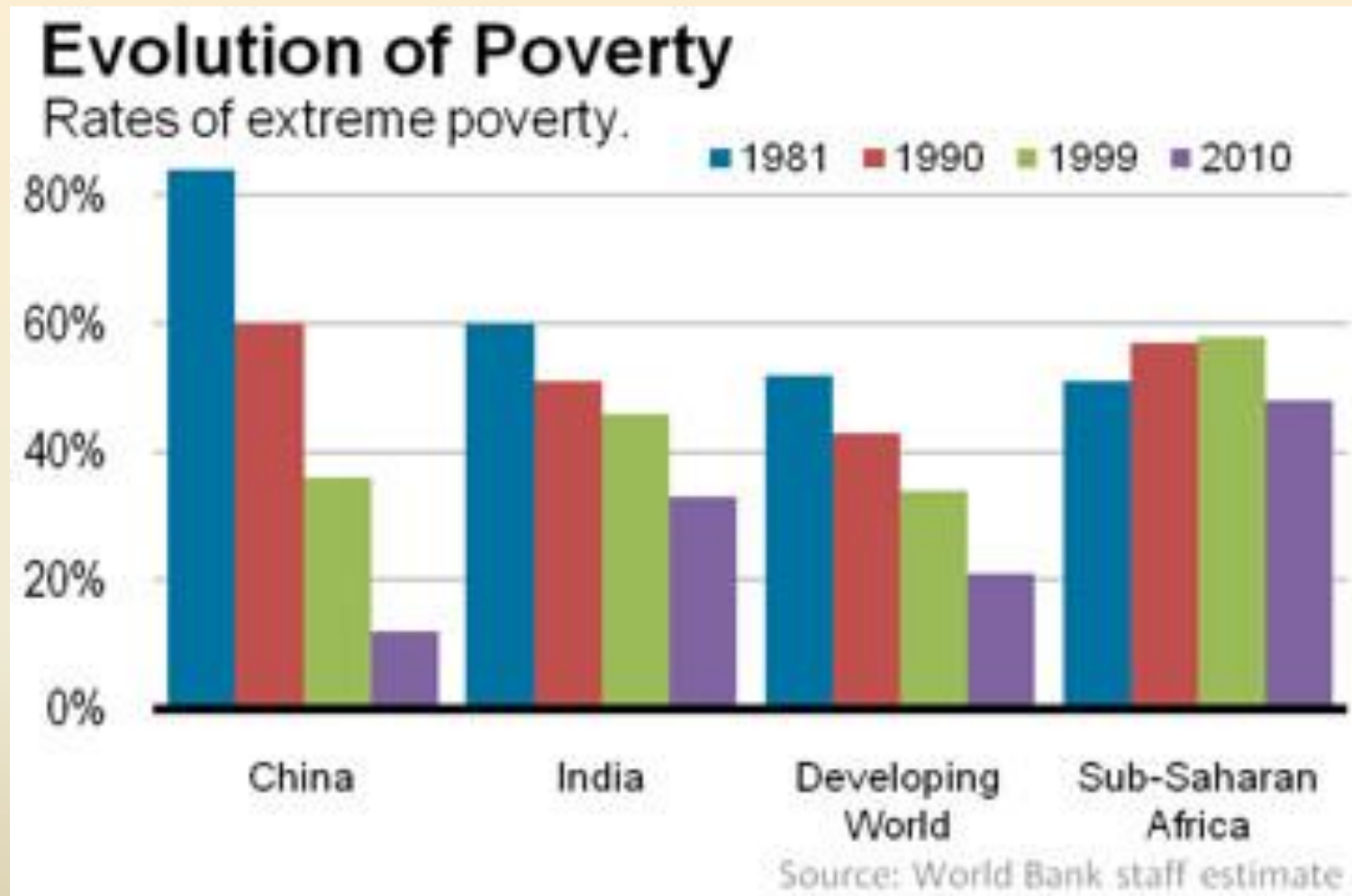
Education

Emphasize good practice in Reproductive Health

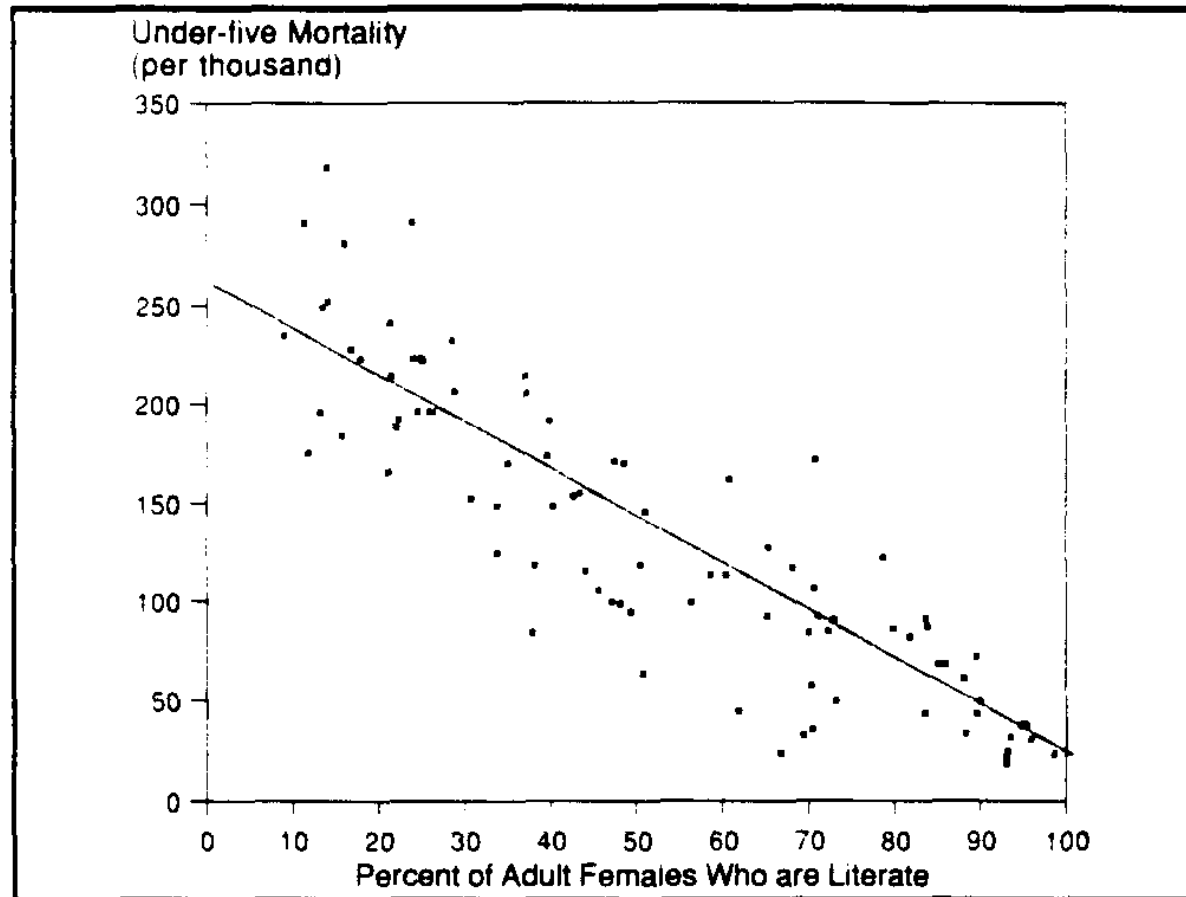


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There's a decline...



Under-five mortality rate and Literate women

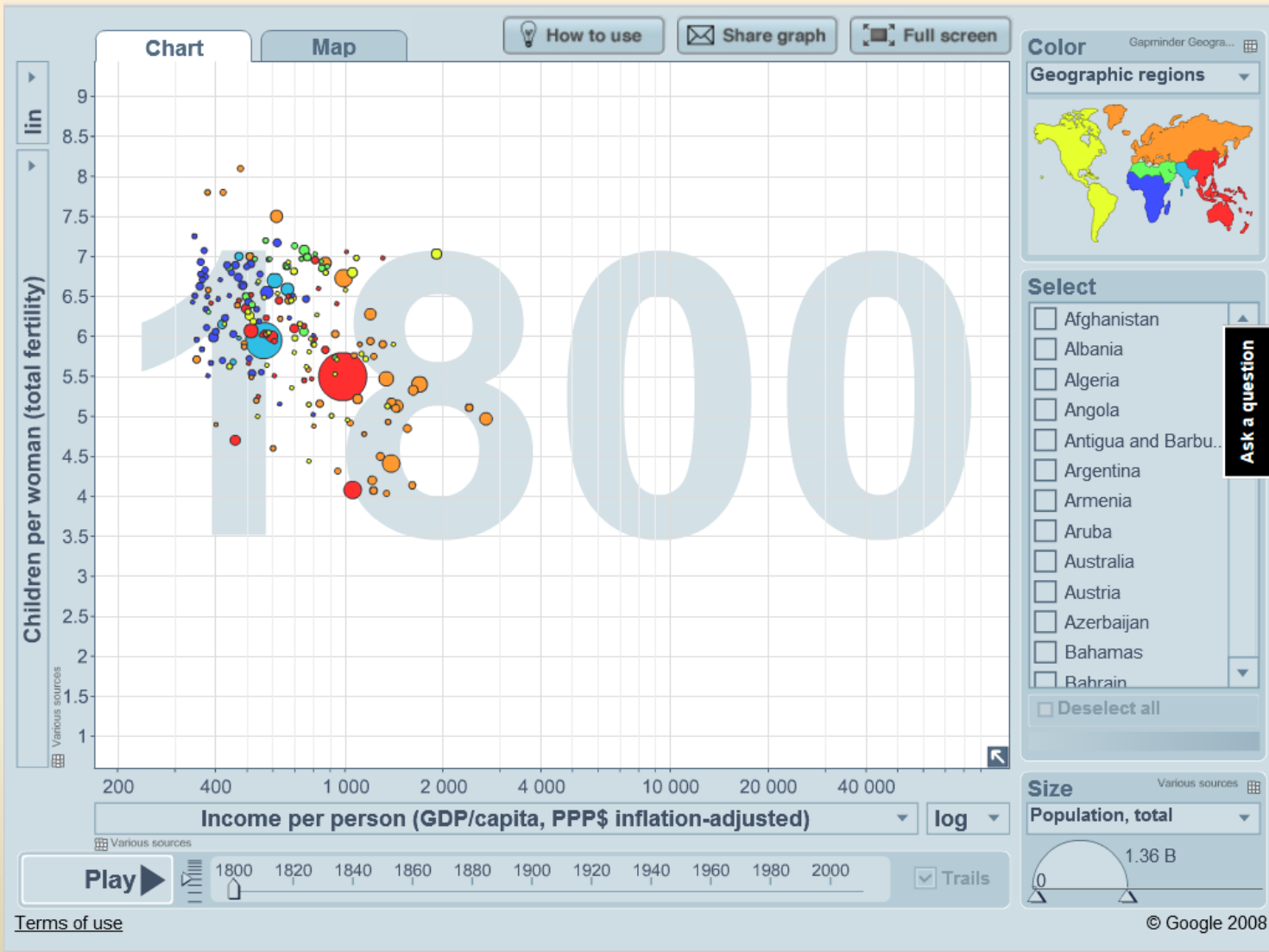


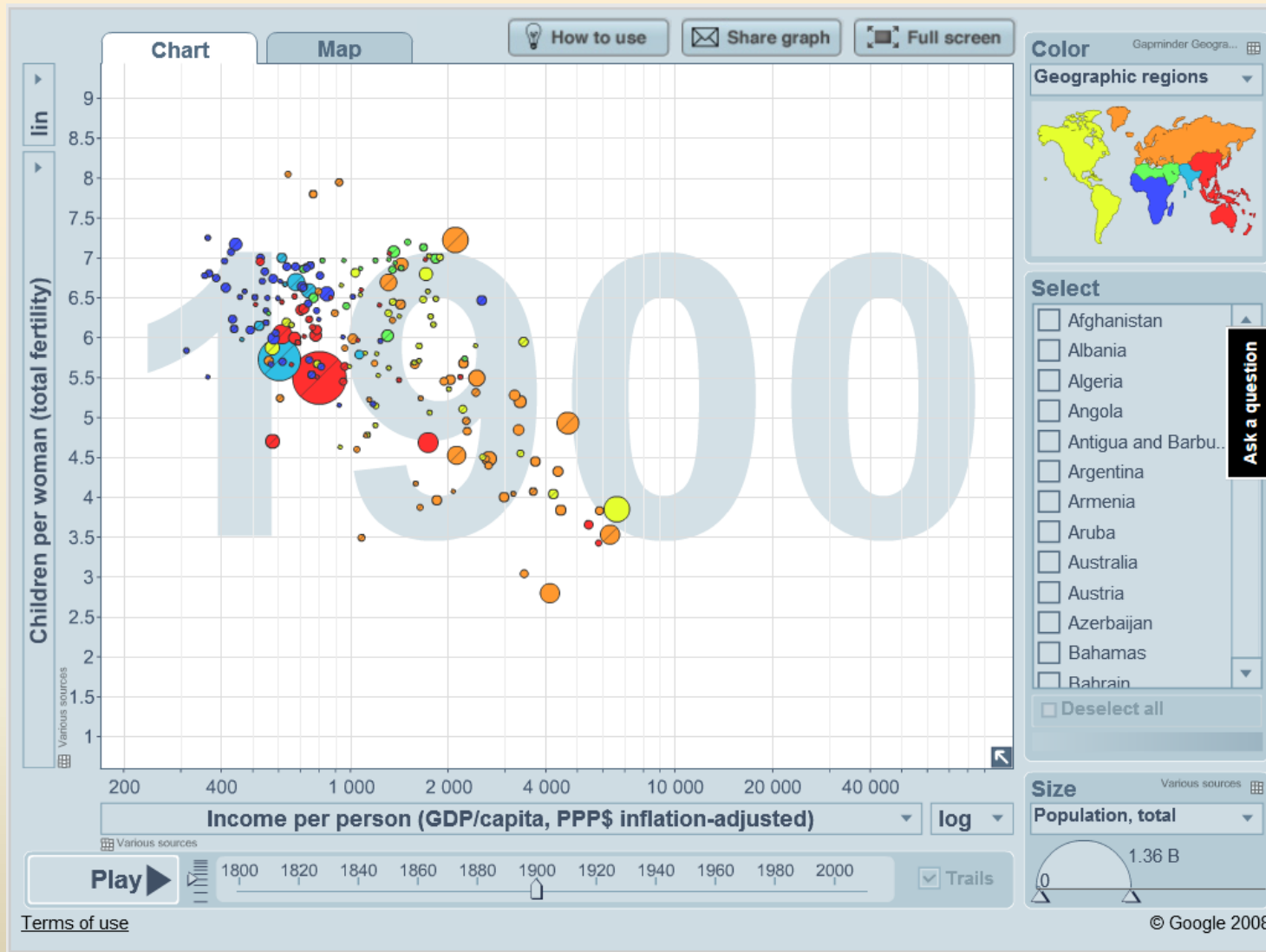
Source: Chapter 16, "Population and Human Development," Tables 16.3 and 16.6.

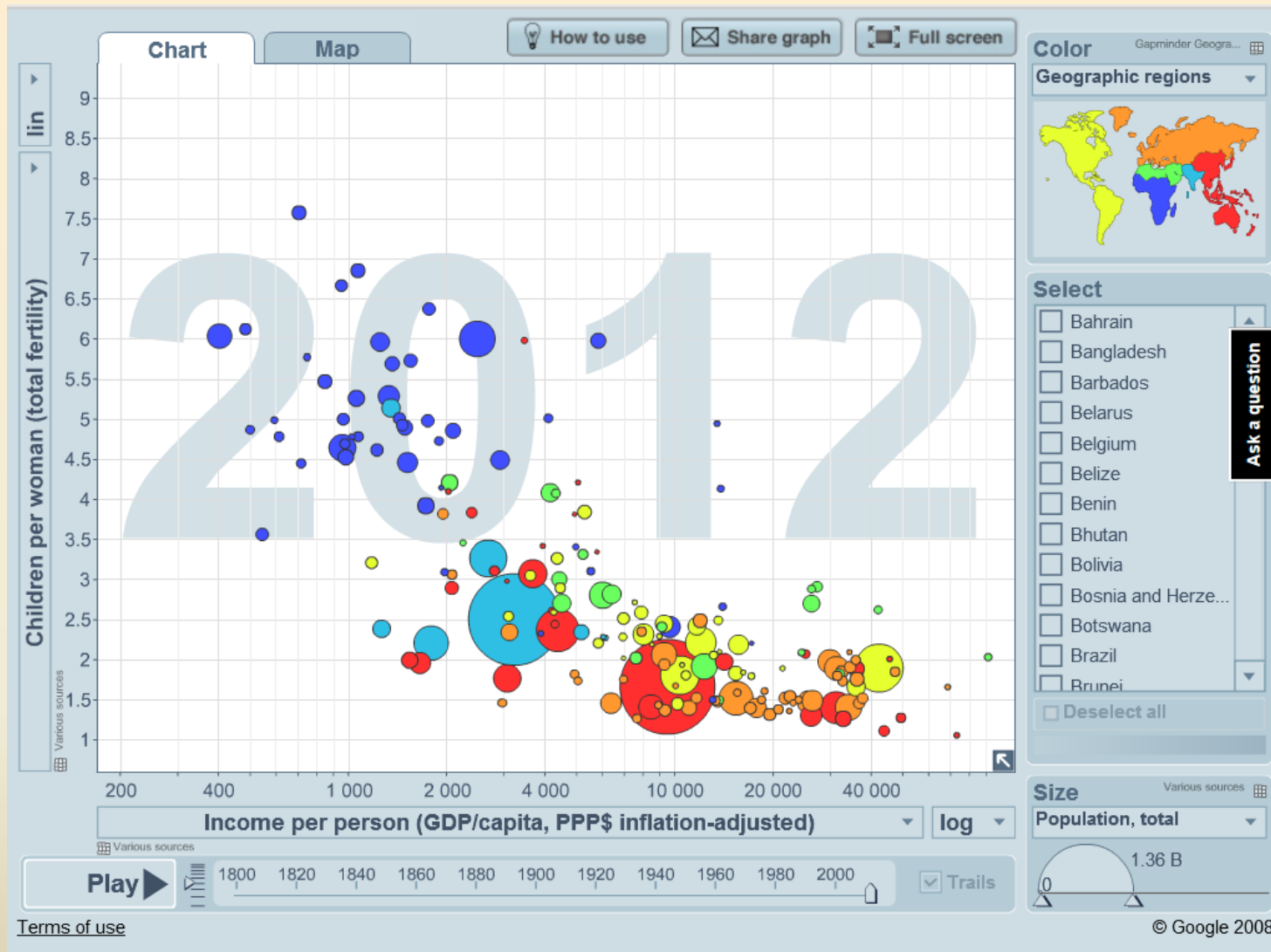
Family Planning in Bangladesh

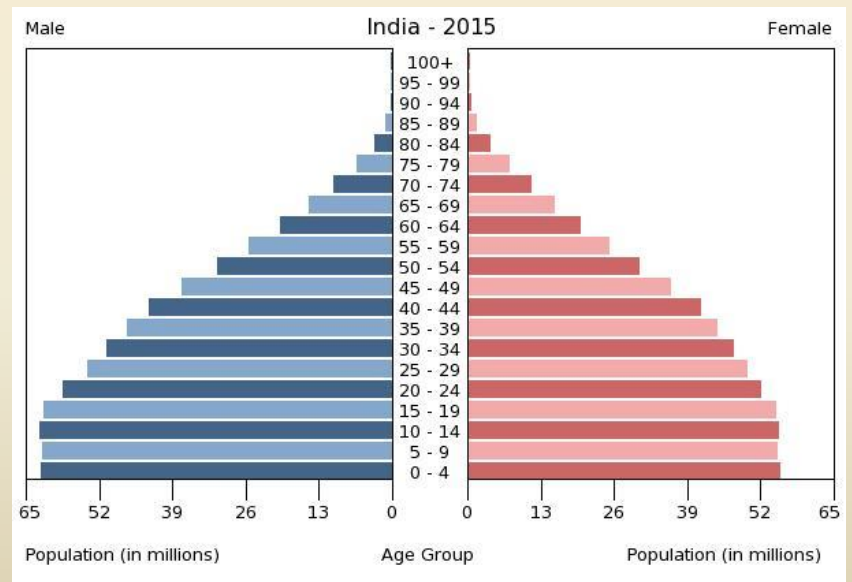
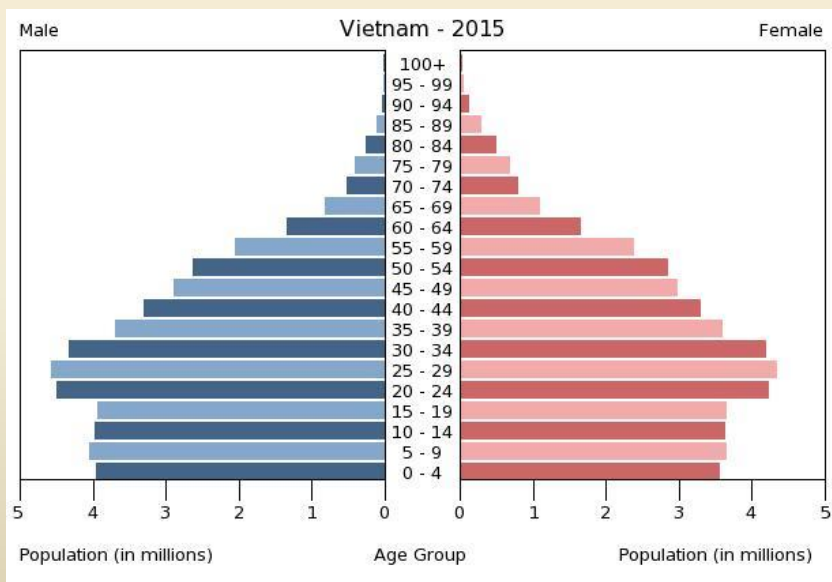
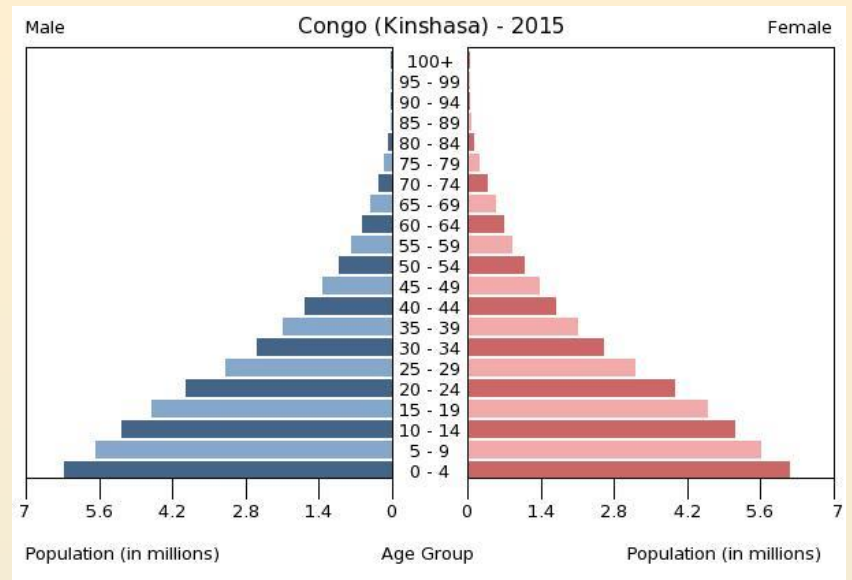
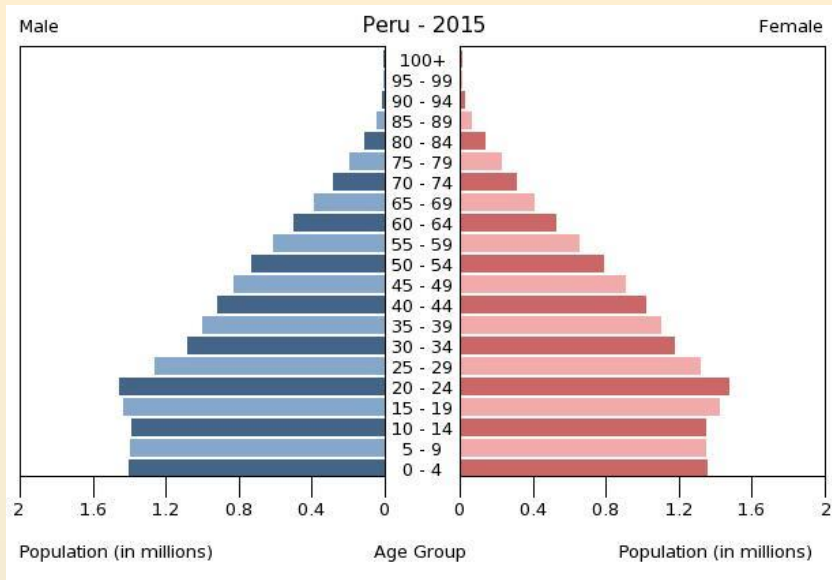


1972: 7 to 8 children with a life expectancy of 50 years
2015: 2,2 children with a life expectancy of 70 years





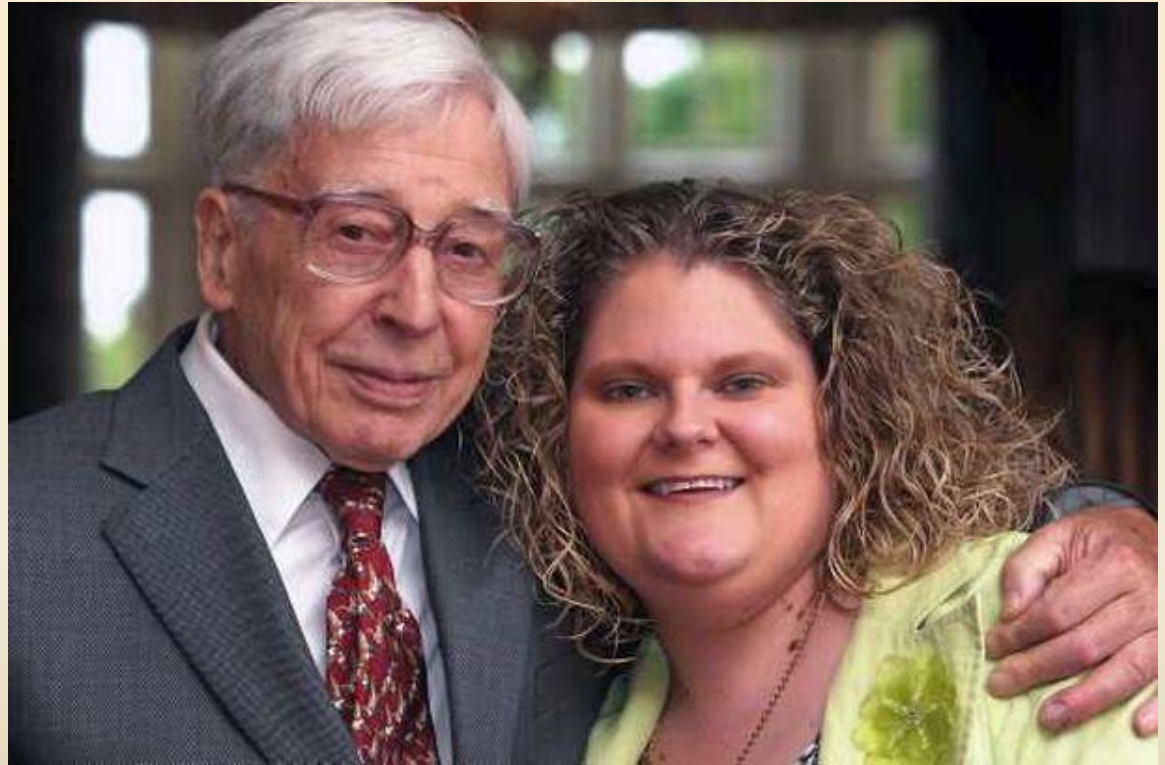




Assisted Reproductive Technologies



1978: Louise Brown – Bob Edwards



The real numbers:

1978 – 2012: 5million children via IVF
= 147.059 per year

130.000.000 millions yearly newborns,
worldwide

= 0,1% of births via IVF

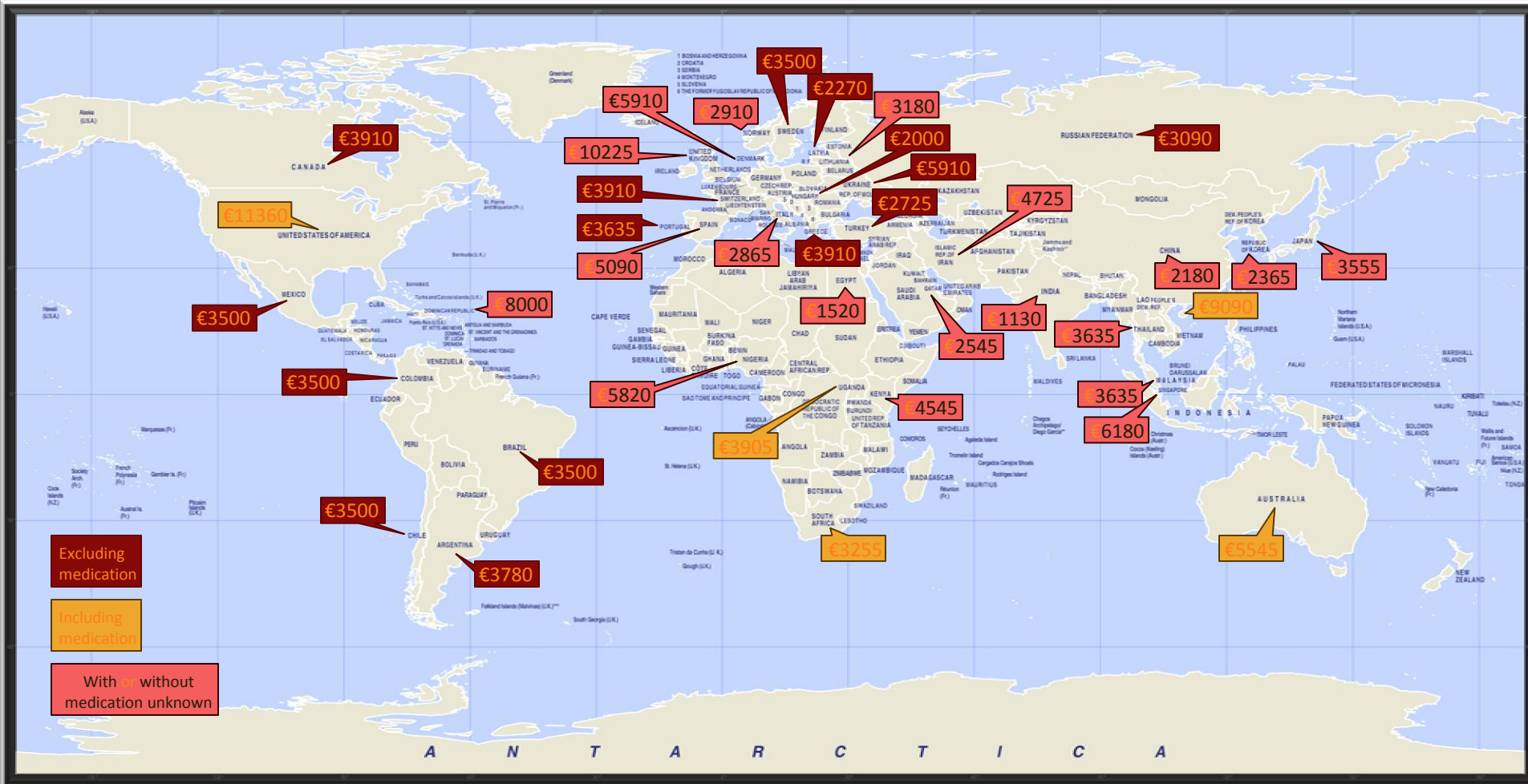
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Why should we care?

1. Overpopulation is a real problem
2. The problem of infertility can only be solved when using very expensive treatments

Approximatif cost of ART services



A private centre in Kampala, Uganda

The screenshot displays the website of the Women's Hospital International and Fertility Centre in Kampala, Uganda. The browser address bar shows the URL: <http://www.whatclinic.com/fertility/uganda/kampala/womens-hospital-international>. The website features a navigation menu with links to Profile, Treatments & Prices, Staff, Reviews, and Map. A sidebar on the left lists fertility specialists and popular locations. The main content area includes a 'Show Phone Number' section with the contact number #16233 Wandegeya, Kampala, 256, and a 'Contact Clinic' button highlighted by a red arrow. Below this is an advertisement for 'Advies over Fibromyalgie' from www.andulatie.be. The website also displays a 'Customer Service Award' image, 'Opening Hours' information, and a map of the location. The footer section lists services provided, including IVF - In Vitro Fertilisation, and insurance options for private patients. The desktop taskbar at the bottom shows various application icons and the system clock indicating 9:17 on 25/02/2013.

Filter 1 Fertility Specialists in Uganda

- All Fertility Clinics (1)
- IVF - In Vitro Fertilisation (1)
- Egg Donor (1)
- ICSI - Intracytoplasmic Sperm Injection (1)
- IUI - Intrauterine Insemination (1)

Popular Locations

- All of Uganda

Women's Hospital International and Fertility Centre Fertility Clinic

Uganda

Profile Treatments & Prices Staff Reviews Map

Show Phone Number -
WHIFC Bukoto. #16233 Wandegeya, Kampala, 256

Customer Service

Contact Clinic

Advies over Fibromyalgie
www.andulatie.be
Doe de pijntest en ontvang advies van specialist Guy Declercq

IVF - In Vitro Fertilisation Price On Request

Reviews & Feedback

They provided required info. Postponed the IVF until I get enough funds
Ashura, Tanzania, 17 Feb 12

Good
Alfred, Uganda, 15 Feb 12

3 Comments 1 Recommend

About Women's Hospital International and Fertility Centre

We understand the delicate needs of our prestigious patients. So Through state-of-the-art technology, innovative research, highly trained medical personnel, and specialized psychological support, WHI can assist you in building a family

Get Quote

Provides
Fertility Treatments &

Insurance
Private Patients

Opening Hours
Please contact clinic for their opening hours

Customer Service Award

Map

Mulago
Bombo Rd
Kira Rd
Uganda

NL 9:17 25/02/2013

The joy for a child is not the privilege of the western world and the rich



Magic solution?



Recommendations

(Gerrits et al 1999, based on studies in Mozambique, Bangladesh, Thailand , Mexico)

- Improve coping and destigmatization
 - Training of health workers to better support and counsel patients
 - De-stigmatize infertile women and men
 - Enable adoption and fostering
 - Strengthen existing support mechanism and creating new ones
 - Empowerment / enhancing gender roles
- Prevention
 - Increasing services to prevent and treat STDs, obstetric care and safe abortions
 - Sensitizing the public about factors that affect fertility
- Diagnosis and treatment
 - Improving diagnosis and – low tech - treatment of infertility
 - Introducing high tech diagnosis and treatment where feasible and affordable (providing realistic information)

The Walking Egg lab: Simplified method, but efficient and of high quality



Start-up Ghana



HOPE for the STIGMATIZED!





"Change will not come if we wait for some other person or some other time.

We are the ones we've been waiting for.

We are the change that we seek."

Thank you for your attention



Jan Goossens

Brussels

November 10th 2016