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Vulnerabilities and vulnerable populations: The case of women and obstetric fistulas

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Vulnerabilities and Vulnerable Populations

Ethics and Women with Obstetric Fistula

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Disclosures

- I am affiliated with two not-for-profit public charities active in fistula-related matters:
  - Founder of, and consultant to, The Worldwide Fistula Fund.
  - President of Hamlin Fistula USA, supporting the work of Dr. Catherine Hamlin and the Addis Ababa Fistula Hospital in Ethiopia

This talk is about justice.

Specifically, it is about justice and women's reproductive health in resource-poor countries.

"It's damned difficult to be a woman in a poor country: physically, economically, socially, and reproductively."

World Medical Association Declaration of Helsinki (2008)

- “Medical research is subject to ethical standards that promote respect for all human subjects and protect their health and rights. Some research populations are particularly vulnerable and need special protection.

Which Populations are 'Vulnerable?'

(World Medical Association Declaration of Helsinki – 2008)

- "These include those who cannot give or refuse consent for themselves and those who may be vulnerable to coercion or undue influence."

Vulnerable Populations

Council for International Organizations of Medical Sciences 2002

- "Special justification is required for inviting vulnerable individuals to serve as research subjects and, if they are selected, the means of protecting their rights and welfare must be strictly applied."

Vulnerable Populations

Council for International Organizations of Medical Sciences 2002

- Vulnerable persons defined:
  - “those who are relatively (or absolutely) incapable of protecting their own interests.

Basic Questions

- What is an “obstetric fistula?”
- Why are women with this condition “vulnerable?”

What is an “Obstetric Fistula?”

- An obstetric fistula is a traumatic birth injury sustained during prolonged obstructed labor in which the tissues that normally separate the vagina from the bladder and/or rectum are destroyed.

- An obstetric fistula results in continuous incontinence of urine and/or feces.

Types of Obstetric Fistulas

- Genito-urinary fistulas
  - Vesico-vaginal – most common
  - Urethro-vaginal
  - Uretero-vaginal
  - Vesico-uterine or vesico-cervical
- Recto-vaginal fistulas

Vesico-Vaginal Fistula

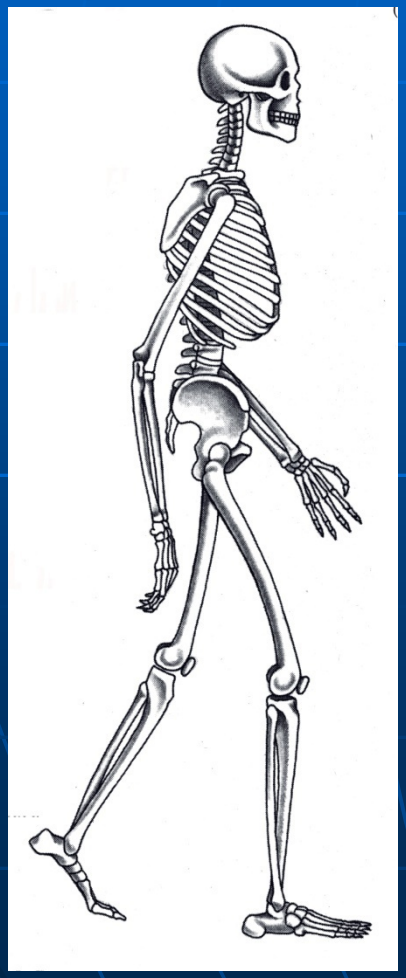
- Abnormal communication between the bladder and the vagina
- Results in continuous urinary leakage
- In developed countries:
  - Malignancy
  - Radiation therapy
  - Surgical misadventure
- Worldwide:
  - Pressure necrosis of the vesicovaginal septum from prolonged obstructed labor

Why Do Obstetric Fistulas Occur?

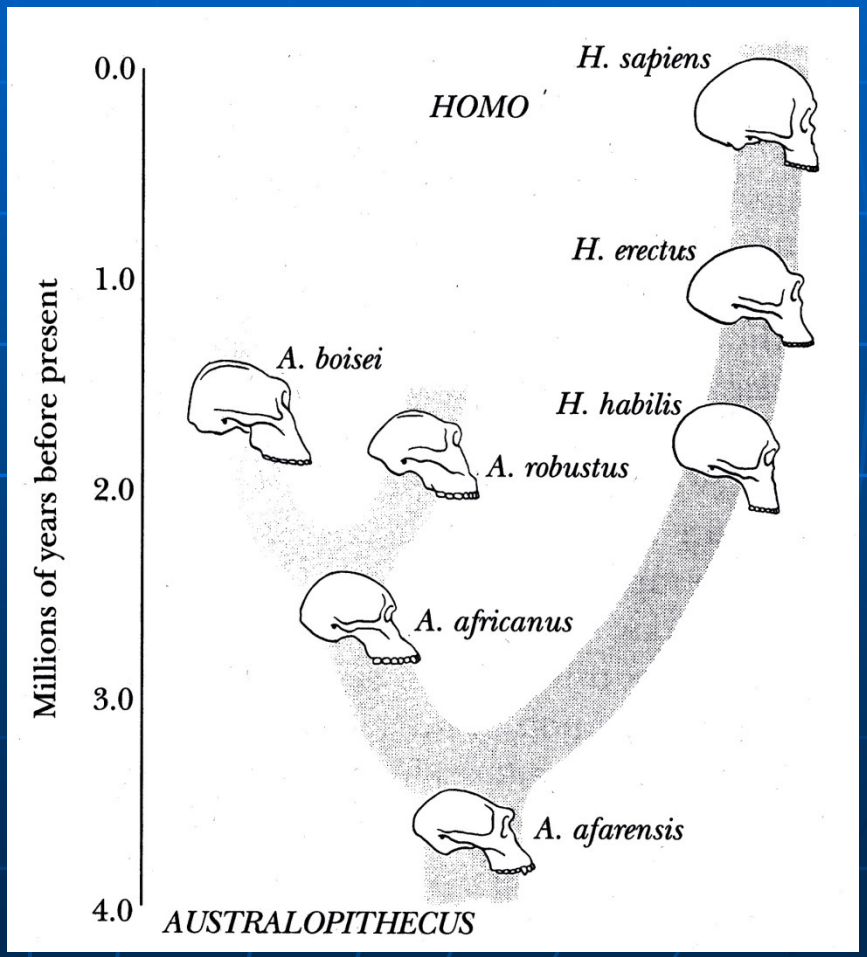
The Biological Background of Obstructed Labor

Competing Evolutionary Pressures in Human Birth

- Bipedalism



- Encephalization



Problem # 1:

Bipedalism alters pelvic anatomy in ways that are obstetrically disadvantageous.

Consequences of Bipedalism

- Changes in center of gravity
- Altered muscle function for lateral stability in walking
- Lengthening the femoral neck
- Shortening the distance between the hip joints
- Diminished capacity of the birth canal

Problem #2:

Increasing Brain Size in Hominid Evolution

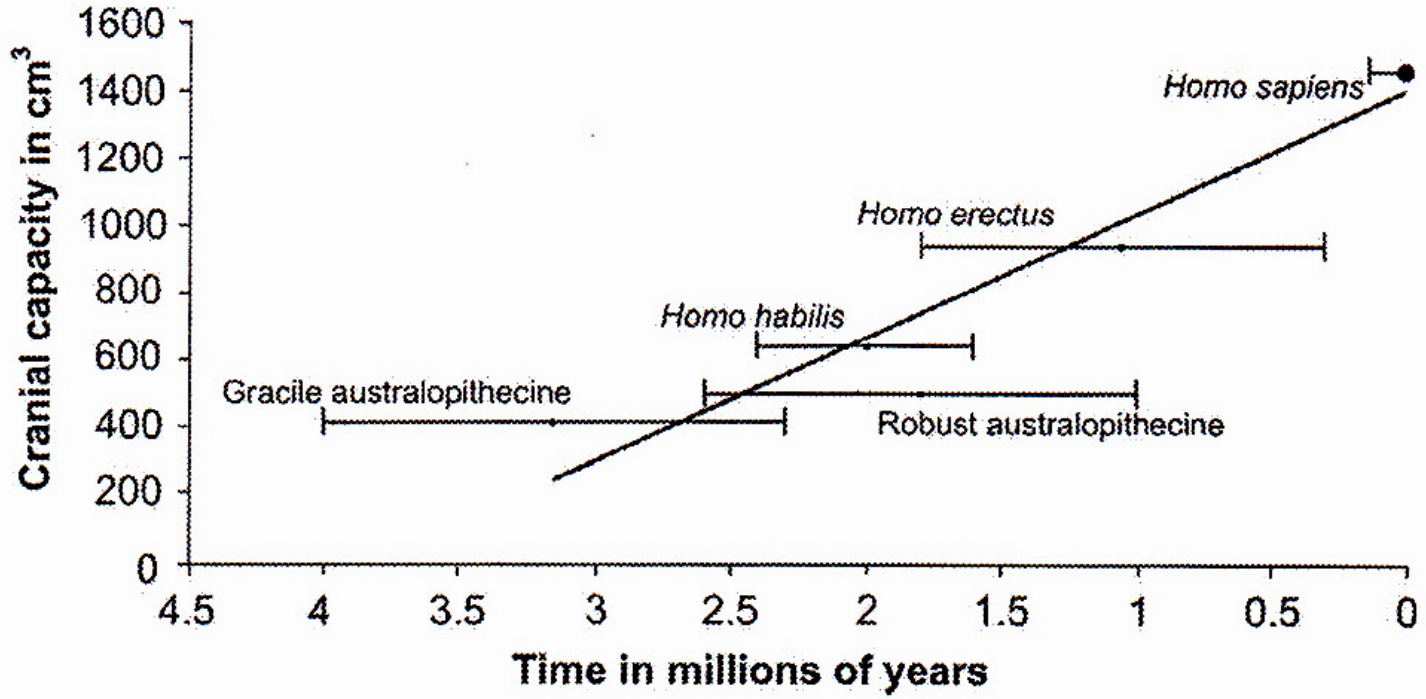


Fig. 4. Progressive encephalization (increasing cranial capacity) in hominin evolution. Copyright Worldwide Fistula Fund, used by permission.

Problem 1 + Problem 2 = The Human "Obstetrical Dilemma"

- Obligatory bipedal locomotion changed human pelvic anatomy in obstetrically disadvantageous ways
- Increasing encephalization created large babies with large heads
- As a result, cephalo-pelvic disproportion became a major problem during birth.

Fetal and Neonatal Adaptations to the "Obstetrical Dilemma" of Human Labor

- Molding of the fetal head
- "Secondary altriciality"
  - (Delay in brain growth until AFTER birth)

“Secondary Altriciality”

“Considered in terms of brain development, human gestation is really 21 months long, with 9 months in the uterus followed by 12 months in the mother’s care.”

--- Robert Martin, “Primate reproduction,” *Cambridge Encyclopedia of Human Evolution*, 1992

Change in Brain Capacity with Age in Modern *Homo sapiens* and in *Pan troglodytes* (ES Vrba 1994)

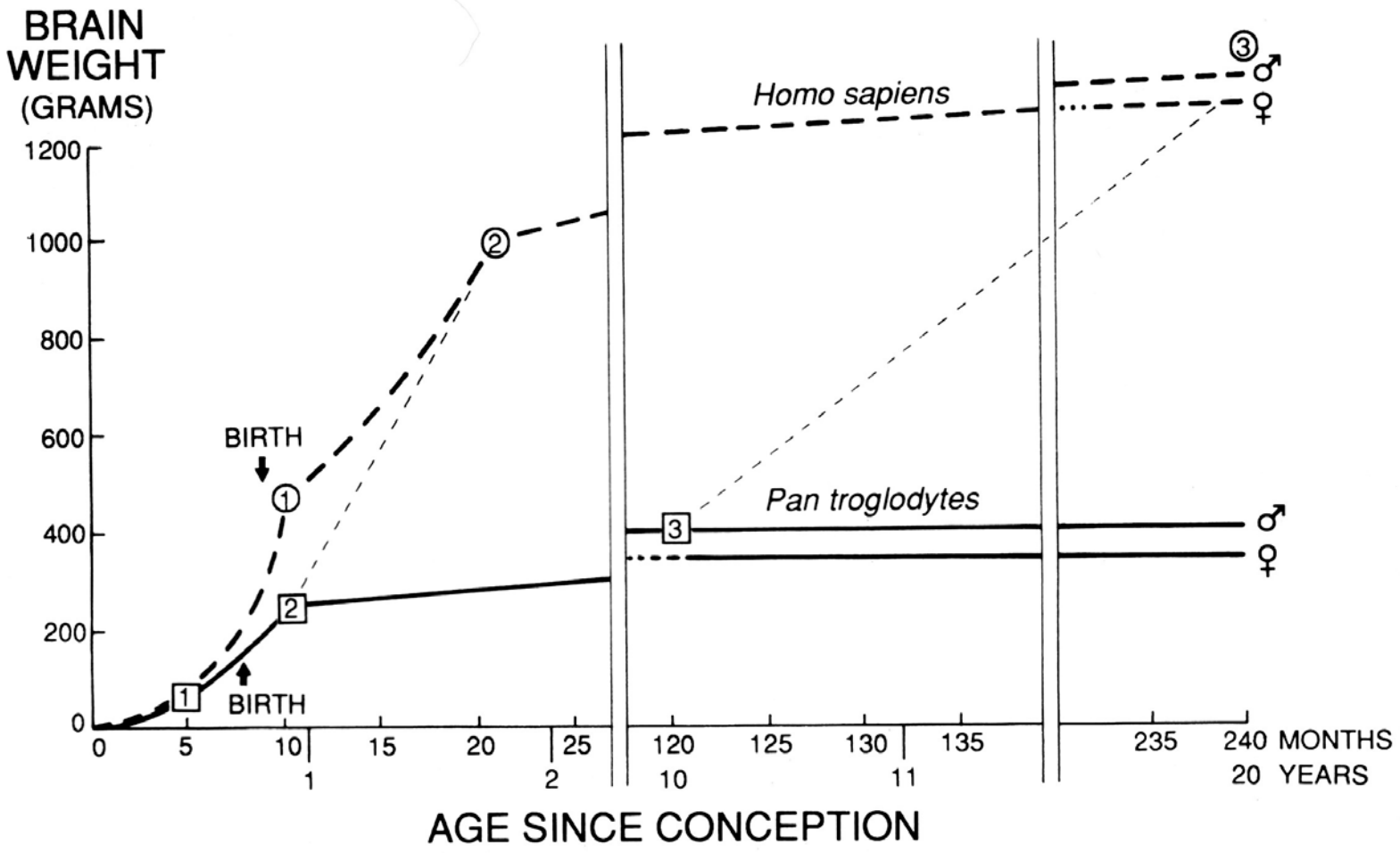
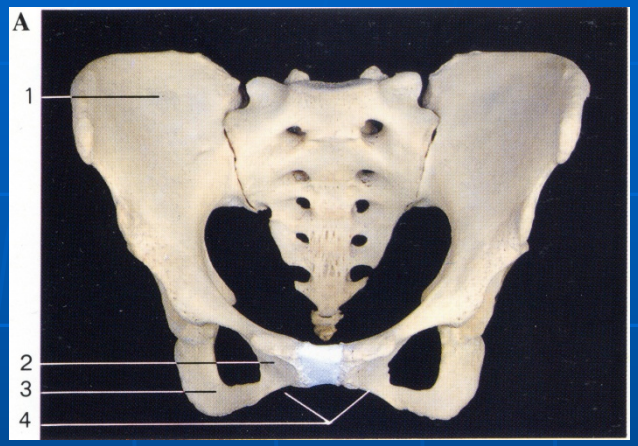
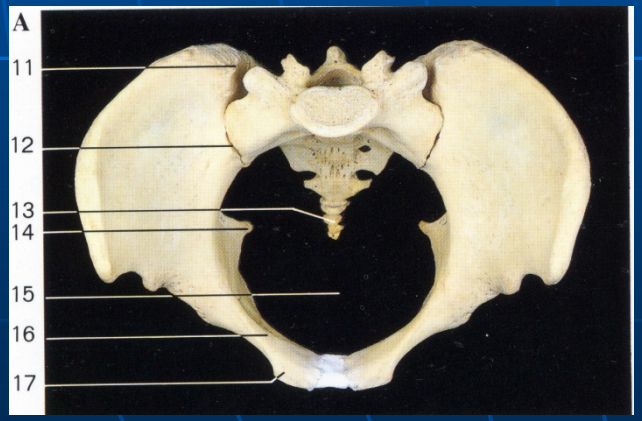


FIGURE 18-10 Change in brain capacity with age in modern *Homo sapiens* and in *Pan troglodytes*. (Compiled from numerous sources cited in the text.)

The Human Obstetrical Dilemma

The Anatomic Situation:





- Human pelvis is narrow
- Planes of the pelvic inlet, mid-pelvis, and pelvic outlet are *misaligned*
- Mid-pelvis is the plane of least dimensions
- Necessitates *rotational* birth mechanics

Obstetrical Mechanics

- "The movements made by the fetus as it passes through the maternal birth canal during parturition."

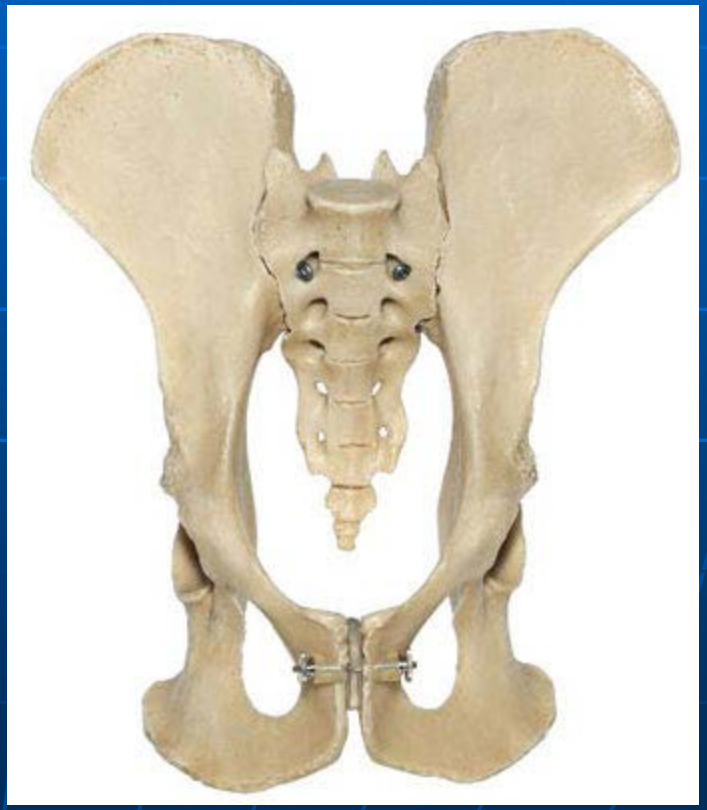
--- MM Abitbol, *Birth and Human Evolution*, 1996.

Consequences for Parturition

Human pelvis is an "hourglass"

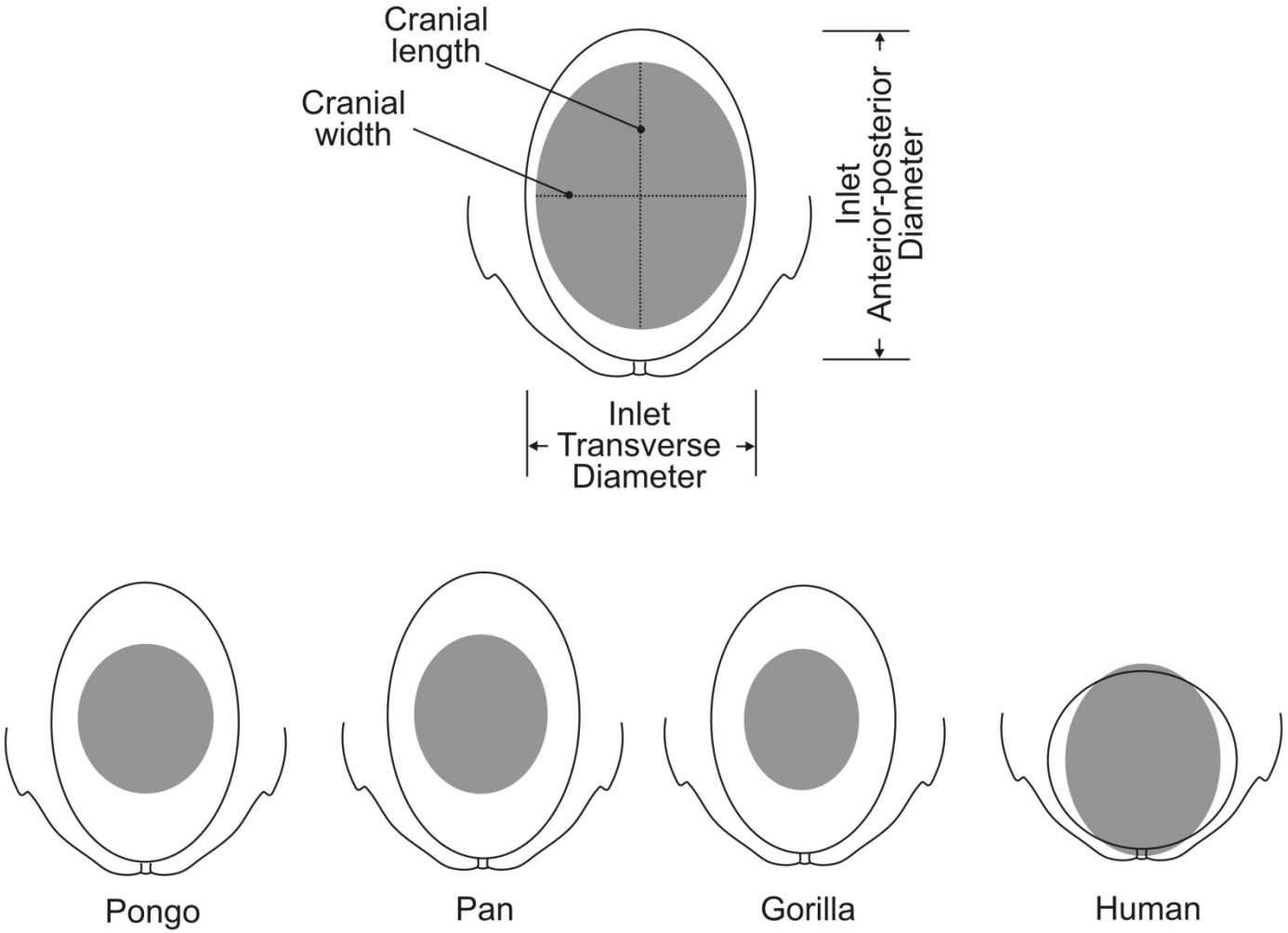
Planes of the inlet, mid-pelvis, and outlet are mis-aligned.

Chimpanzee pelvis is a "cylinder"

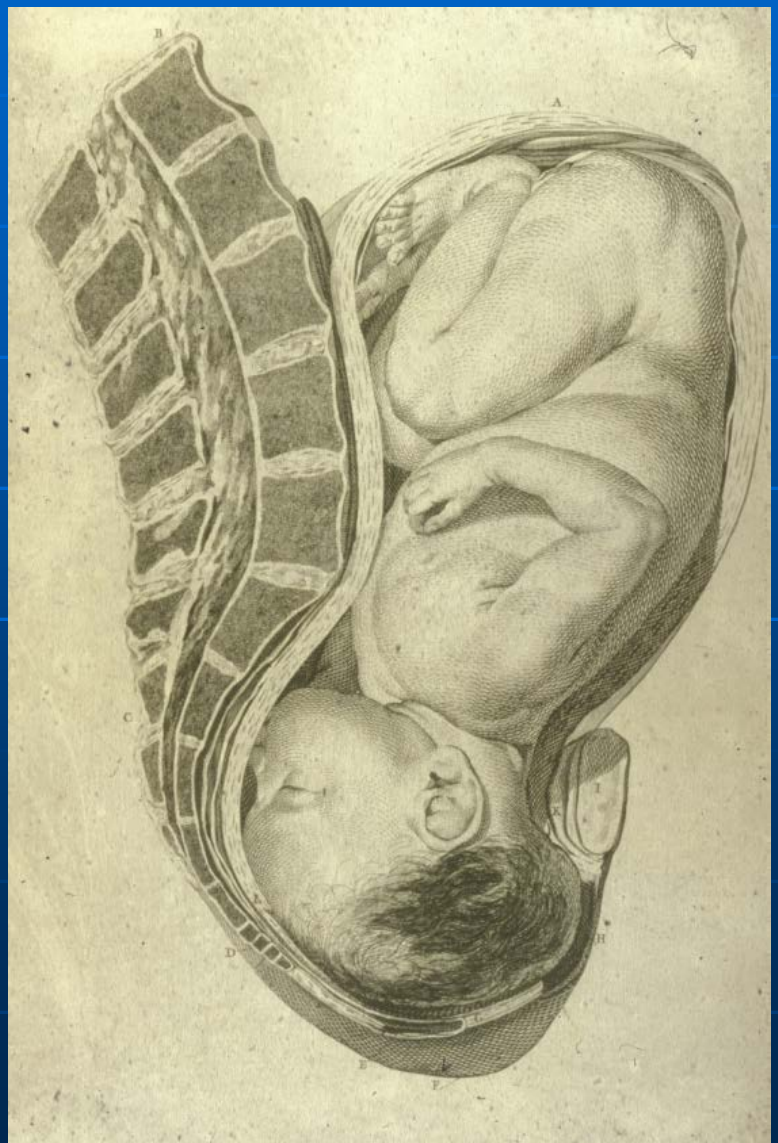


The planes are all aligned.

Obstetrical “Fit” In Higher Primates



“The Mechanism of Labor”

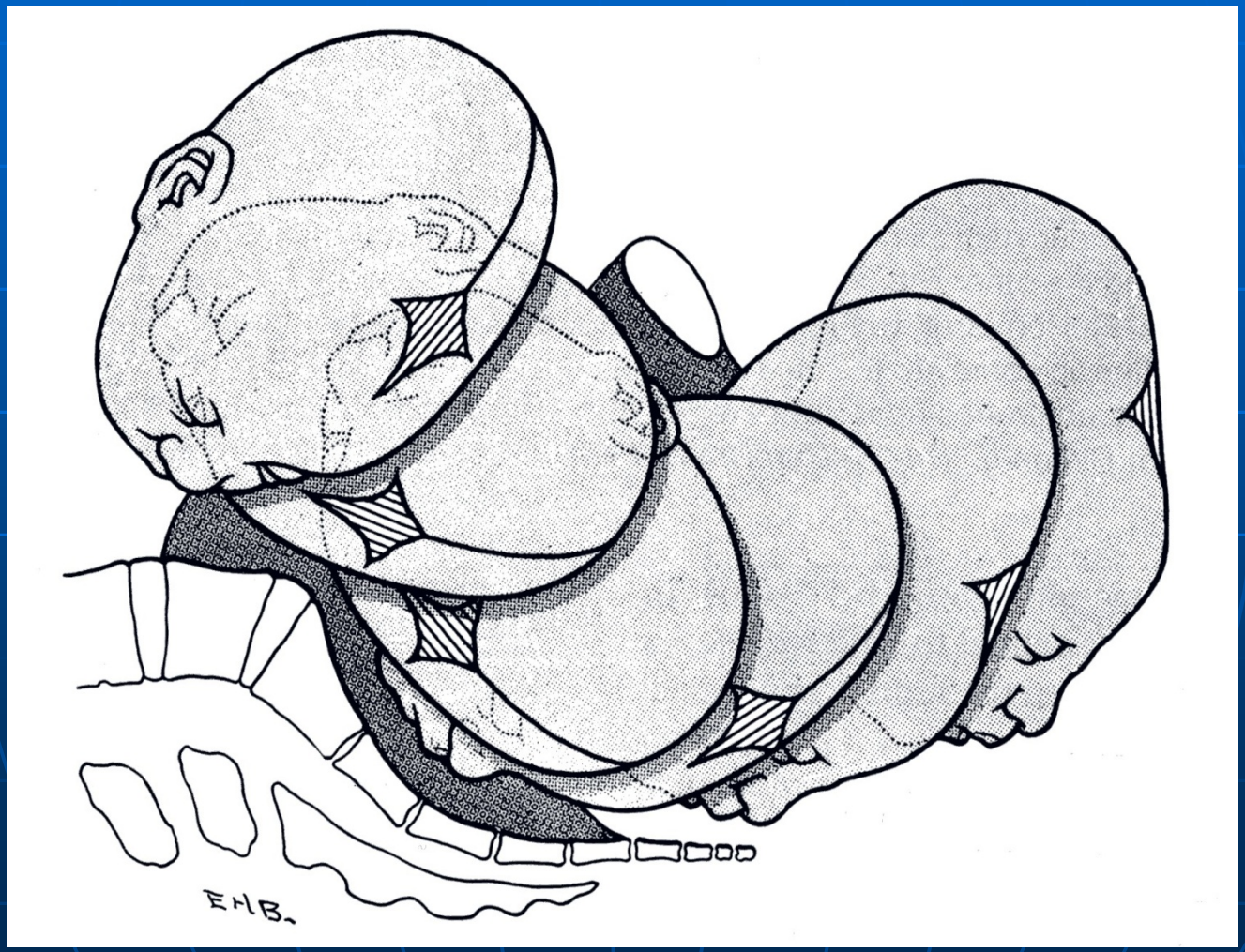


- Engagement
- Descent
- Flexion
- Internal rotation
- Extension
- External rotation
- Expulsion

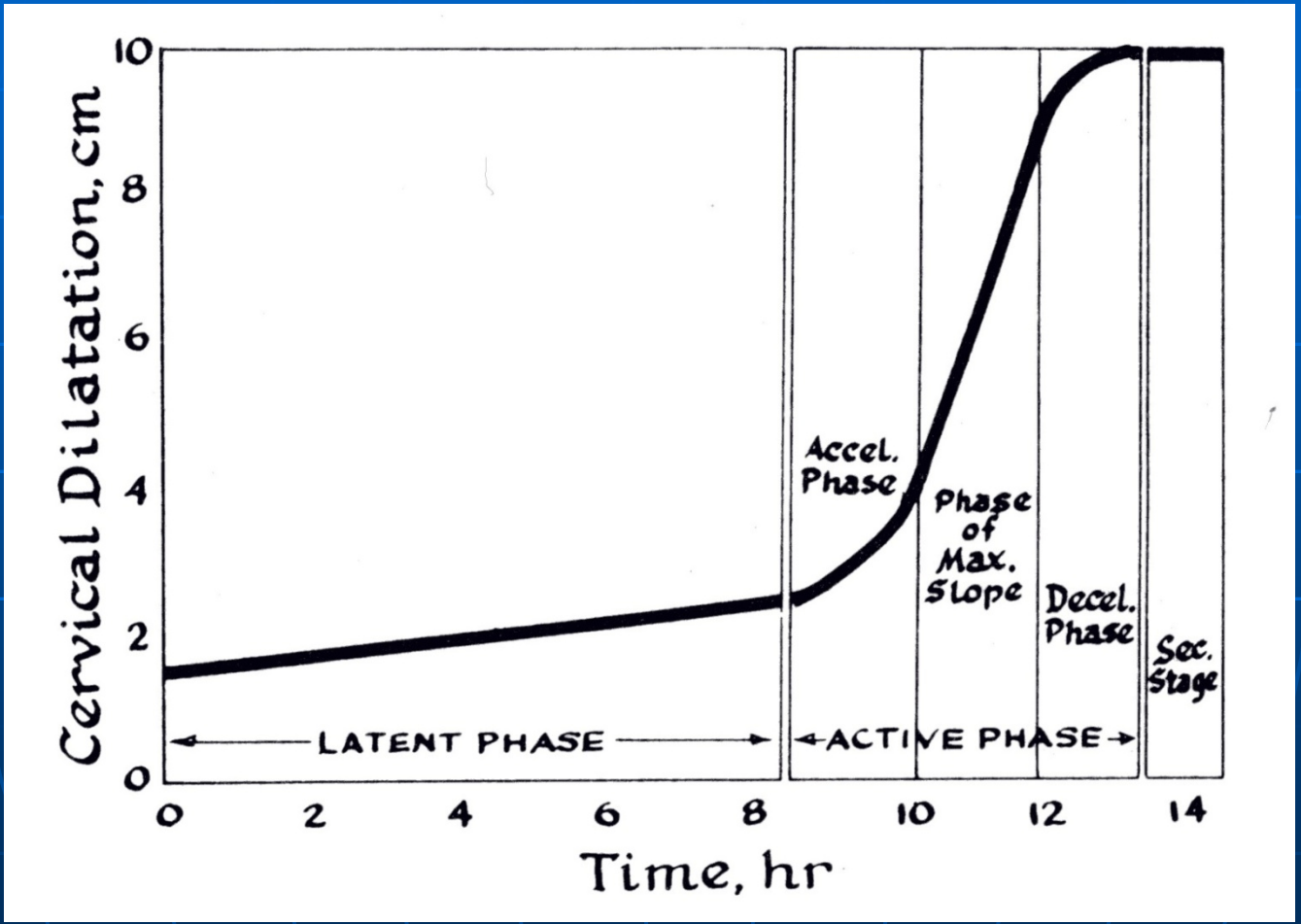
Overview of the Mechanism of Labor

From the Left Occiput Anterior Position

Williams' Obstetrics, 16th Edition



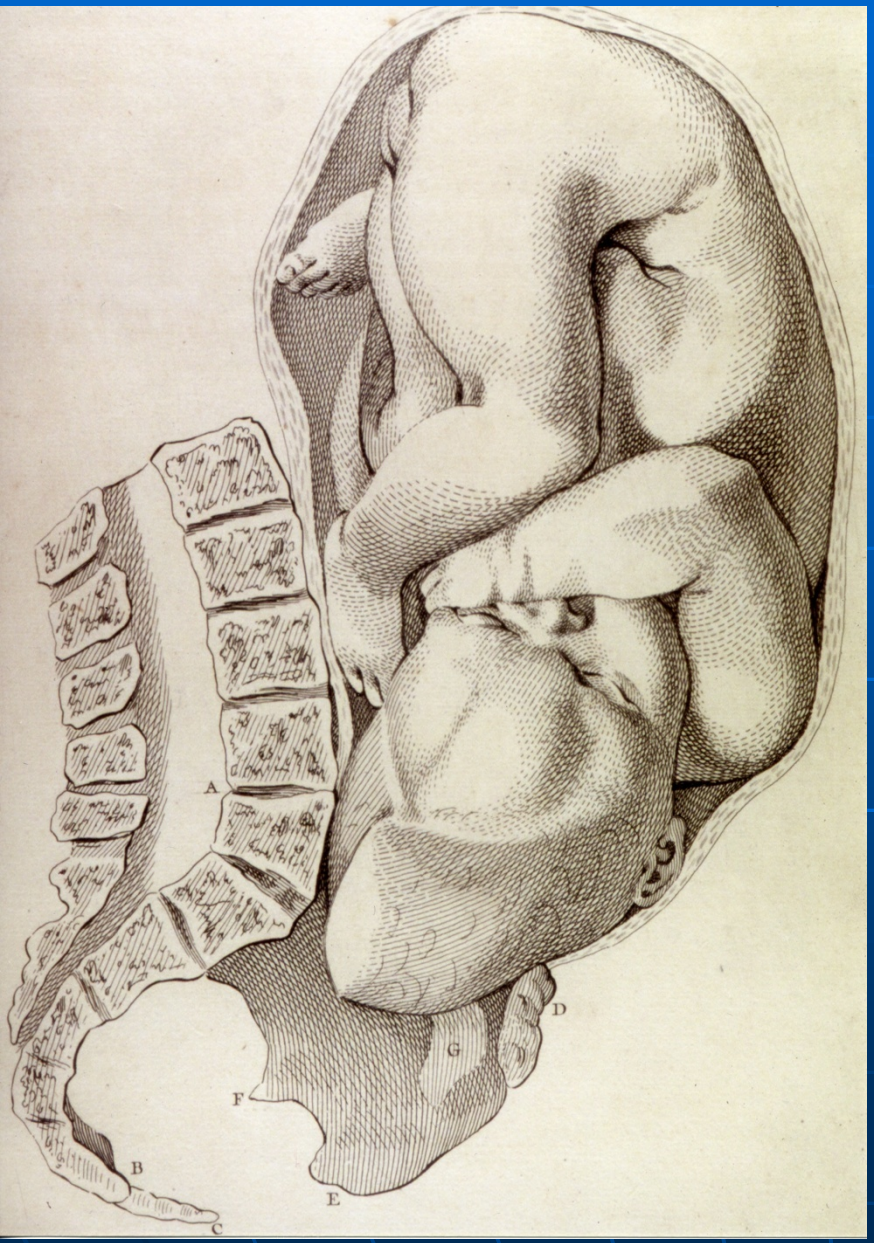
Human Labor is Prolonged
(Compared to Other Primate Species)



Duration of labor in normal nulliparas ("Friedman's Curve"), *Williams Obstetrics,* 16th edition.

Obstructed Labor

- Failure of labor to progress despite adequate uterine contractions because of mechanical obstruction in the birth canal.



Obstructed Labor

Irresistible Force

vs.

Immovable Object

Treatment of Obstructed Labor

- "Vaginal By-Pass Surgery" (Cesarean Section)
- C-section rate in the US: >30%
- In industrialized countries the capacity for cesarean delivery is taken for granted
- The problem:
  - Lack of access to emergency obstetric services in resource-poor countries

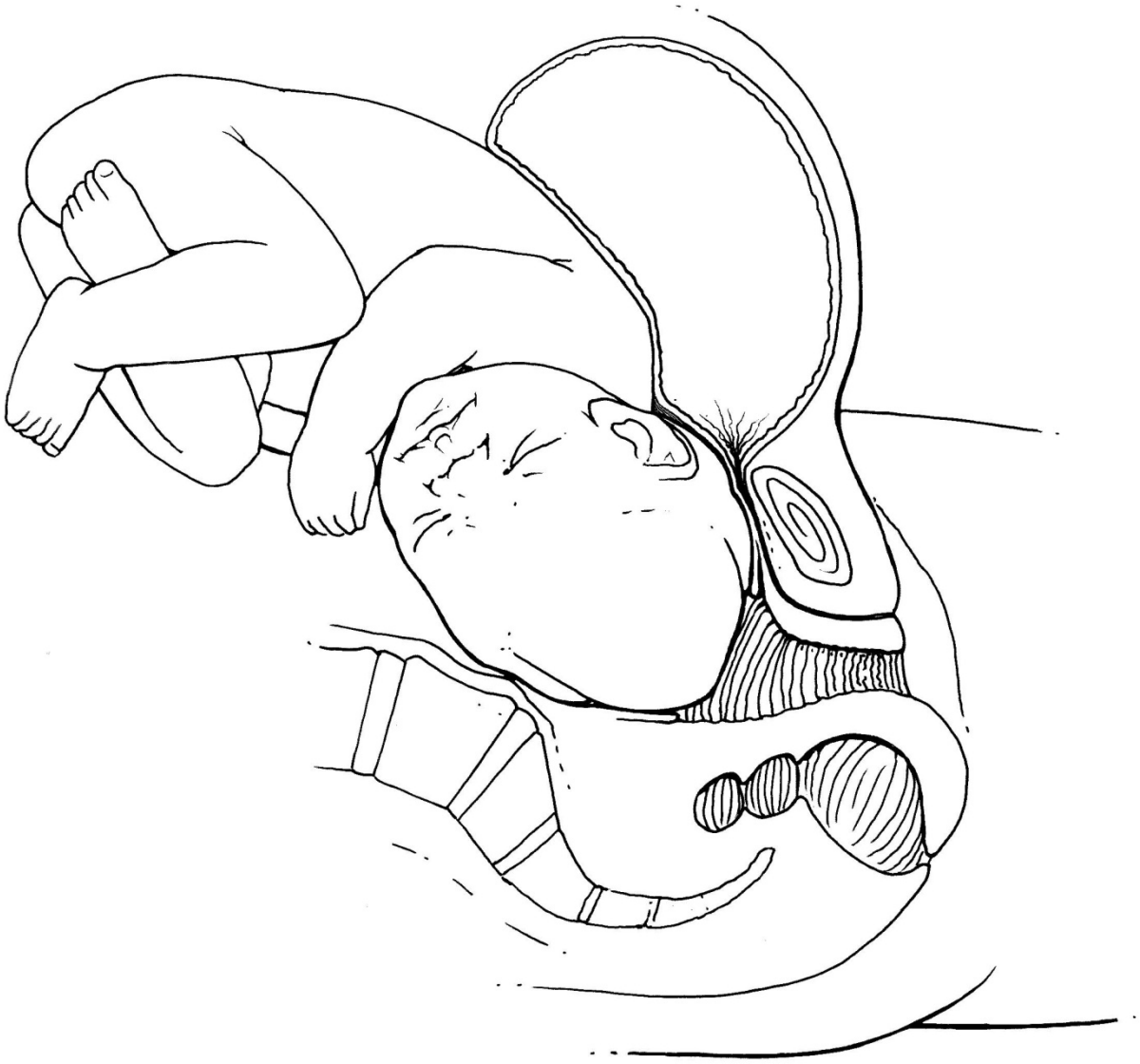
Cesarean Section in Poor Countries

- What happens when the medical infrastructure cannot provide emergency cesarean delivery?
- Cesarean section rate in West Africa 1.2%
- Grossly inadequate to meet maternal healthcare needs

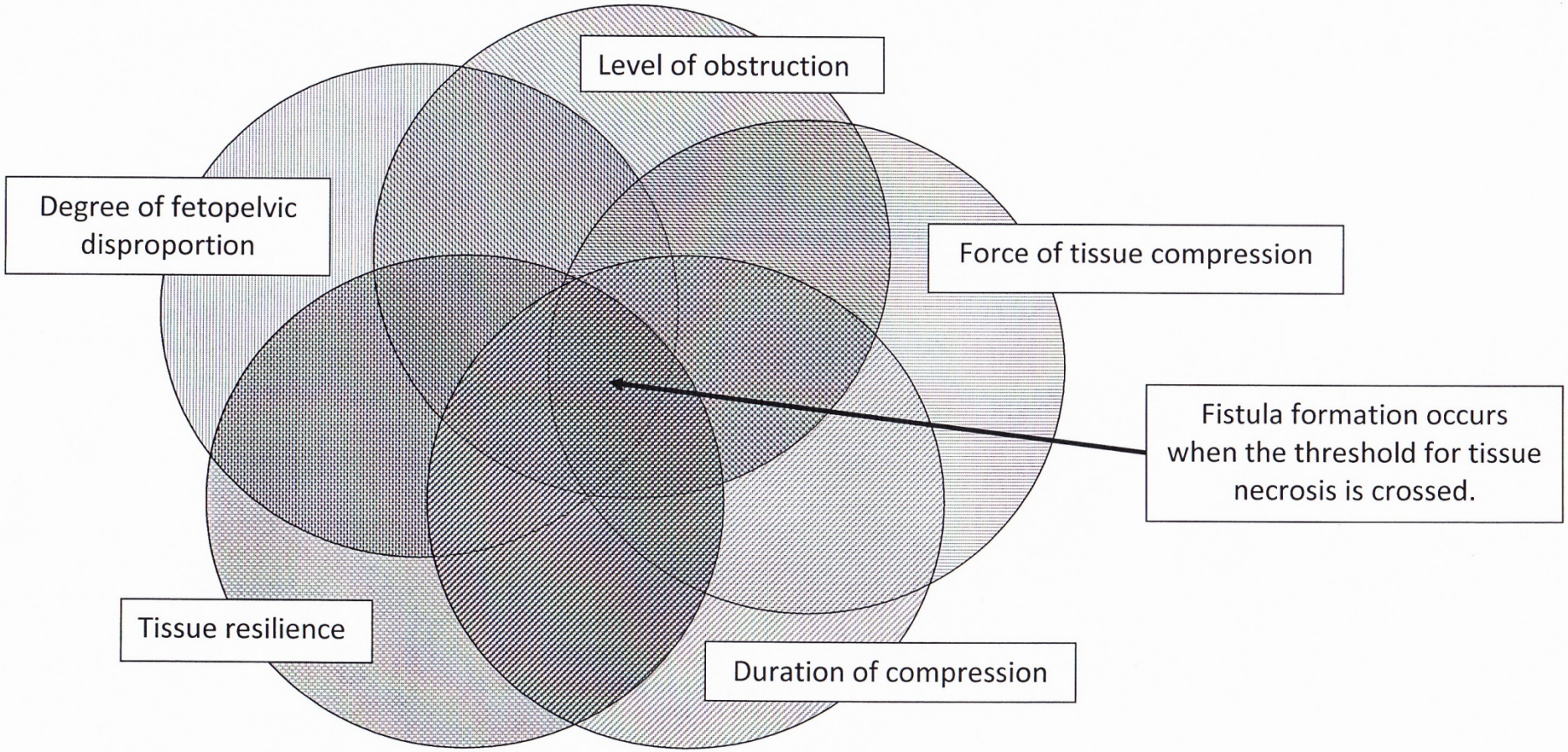
Natural History of Unrelieved Obstructed Labor

Cascade of Injuries in Obstructed Labor

1. Labor becomes obstructed
2. Fetal head becomes impacted against soft tissues in the maternal pelvis
3. Blood flow is compromised, then occluded
4. Urinary outflow may also be obstructed
5. Tissue necrosis leads to fistula formation and other injuries
6. Extremely high rates of fetal death (>90%)



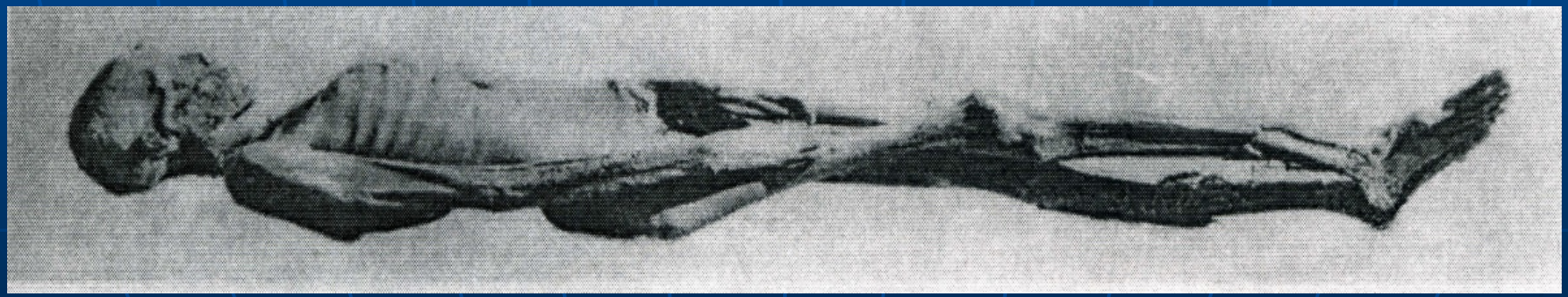
Interplay of Factors in Fistula Formation

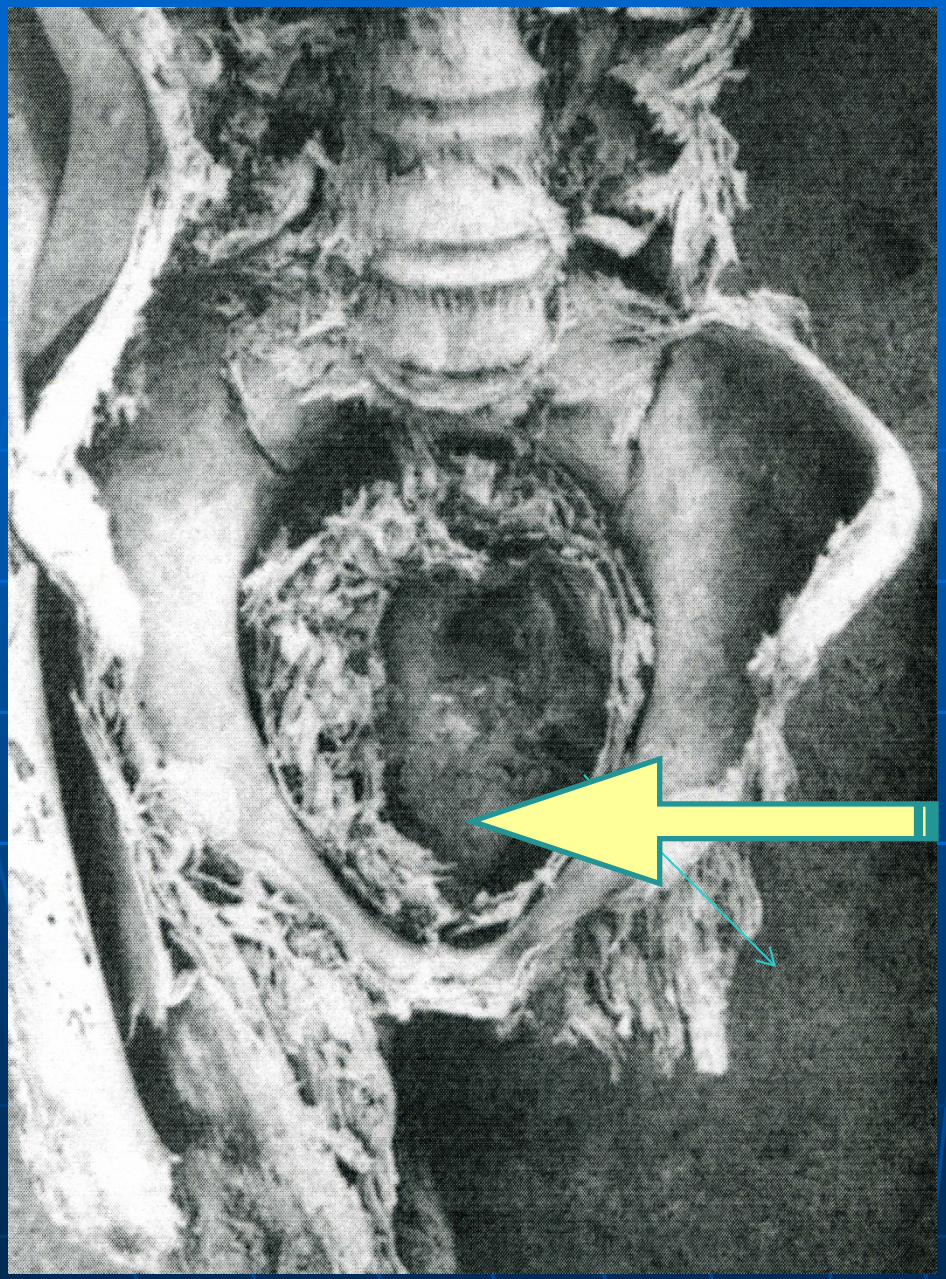


Note on Five Pelves of Women of the Eleventh Dynasty in Egypt

BY

D. E. DERRY,
Egyptian University, Cairo.





The Mummy of Queen Henhenit (Dynasty XI)

A huge hole (“fistula”) between her bladder and her vagina – the earliest known example of this injury.

“Obstructed Labor Injury Complex”

- Urologic Injury
- Gynecologic Injury
- Neurologic Injury
- Musculoskeletal Injury
- Gastrointestinal Injury
- Dermatological Injury
- Fetal Death
- Social Ostracism

Combined Vesicovaginal and Rectovaginal Fistula

Dermatologic Injury

The Social Context of Obstetric Fistula

Women with Obstetric Fistula

- Who gets a fistula?
- Why does it happen?
- What happens to a woman aftger she gets a fistula?

Physical Size

Wall et. al. "Characteristics of 899 Fistula Patients from Jos, Nigeria," American Journal of Obstetrics and Gynecology 2004;190:1011-1119

- Small and short
- Mean weight – 43.6 kg
  - (Range 31 – 84 kg)
- 55% weighed less than 50 kg
- 79% less than 150 cm tall
  - (Range 121 – 180 cm)

Fistula Patient Demographics

- BUT…
- 352 (39.1%) married *prior to* menarche
- 302 (33.6%) married *before age 14*

Fistula Patient Demographics

- Median age at presentation 27 years
  - (Range 13 – 70 years)
- Mean age of menarche 14.5
- Mean age at marriage 15.5 years

Education

- Poorly educated
- 700 women – no formal education (78%)
- 126 - some primary education (14%)
- Only 13 women had any secondary education (1%)
- 60 women had Koranic education (7%)

Occupations of Patients, Husbands, and Patients' Fathers

Occupation	Patient	Husband	Father
Agriculture	394	431	646
Housewife	259	---	---
Menial labor	127	88	51
Petty trading	109	121	63
"White collar"	10	43	25

Duration of Labor in 899 Women with Obstetric Fistulas from Jos, Nigeria

Duration of Labor	Number of Women
One day or less	190 (21.1%)
2 days	272 (30.2%)
3 days	244 (27.1%)
4 days or more	193 (21.4%)

Attributes of Fistula Patients

- Tend to be small and short
- Little education
- Impoverished
- Often married young

- Lack of timely access to emergency obstetrical services

Structural Violence

Violence

(WHO, World Report on Violence and Health,)

- “The intentional use of physical force or power, threatened or actual, against oneself, another person, or against a group or community, that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment, or deprivation."

Structural Violence

James Gilligan; *Violence: Reflections on a National Epidemic*; New York: Vintage Books edition, 1997, p. 192.

"...the increased rates of death and disability suffered by those who occupy the bottom rungs of society, as contrasted with the relatively lower death rates experienced by those who are above them."

Structural Violence

Johan Galtung; “Violence, peace, and peace research;” Journal of Peace Research 1969;6(30):167-191.

“Those excess deaths (or at least a demonstrably large proportion of them) are a function of class structure; and that structure itself is a product of society’s collective human choices, concerning how to distribute the collective wealth of society.”

Types of Violence

Johan Galtung; "Violence, peace, and peace research;" *Journal of Peace Research 1969;6(3):167-191.*

- Direct violence
  - Personal violence – as per WHO definition
- Indirect violence
  - Structural violence

Structural Violence and Women's Reproductive Health

- Females are humanity's child-bearers
- As a result, they bear the health consequences of reproduction
- Social factors have a huge impact on reproductive health and pregnancy outcomes
- Many differentials in health status between males and females are a direct reflection of gendered structural violence

Women develop fistulas when they experience prolonged obstructed labor without timely and effective obstetric intervention.

Prevention of Obstetric Fistulas

1. Early detection of obstructed labor

2. Prompt intervention before the threshold for tissue necrosis is reached

3. Time threshold before injury occurs varies considerably in individual circumstances. There is no minimum “cut-off”

Delay in Receiving Emergency Obstetric Care:

"The Three Phases of Delay"*

1. Delay in deciding to seek care
2. Delay in arriving at a suitable healthcare facility
3. Delay in receiving appropriate care at that facility

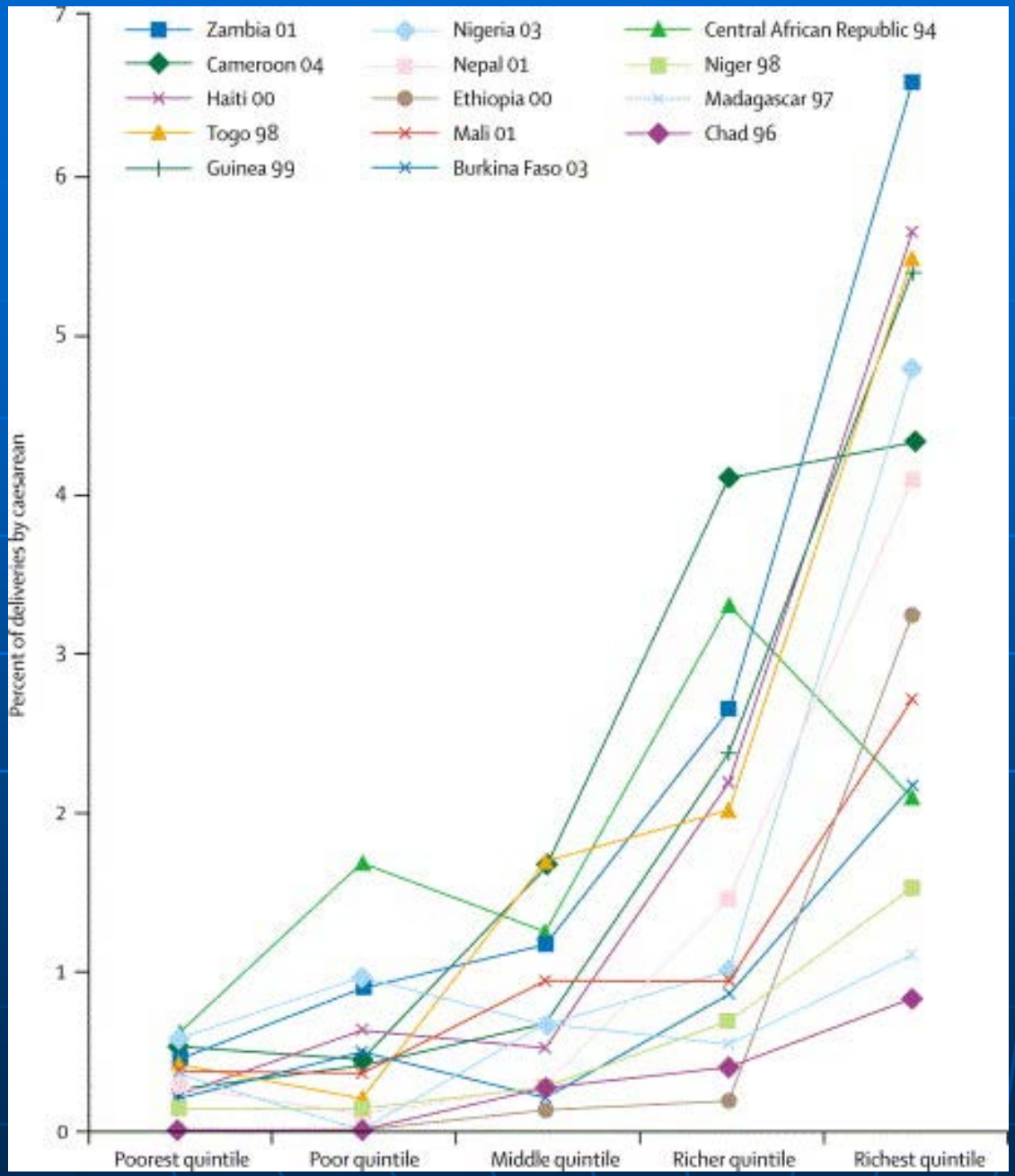
- *S. Thaddeus, D. Maine; "Too far to walk: Maternal mortality in context;" *Social Science and Medicine* 1994;38:1091-1110

Causes of Delay in Seeking Care in Obstructed Labor (Jos, Nigeria)

Cause of Delay	No. Patients
No permission from family	258 (28.7%)
Lack of transportation	225 (25.0%)
Tried traditional medicine first	67 (7.4%)
Unaware of hospital care	58 (6.5%)
No health facility nearby	50 (5.6%)
Unknown	241 (26.8%)

Women develop fistulas when they experience prolonged obstructed labor without timely and effective obstetric intervention.

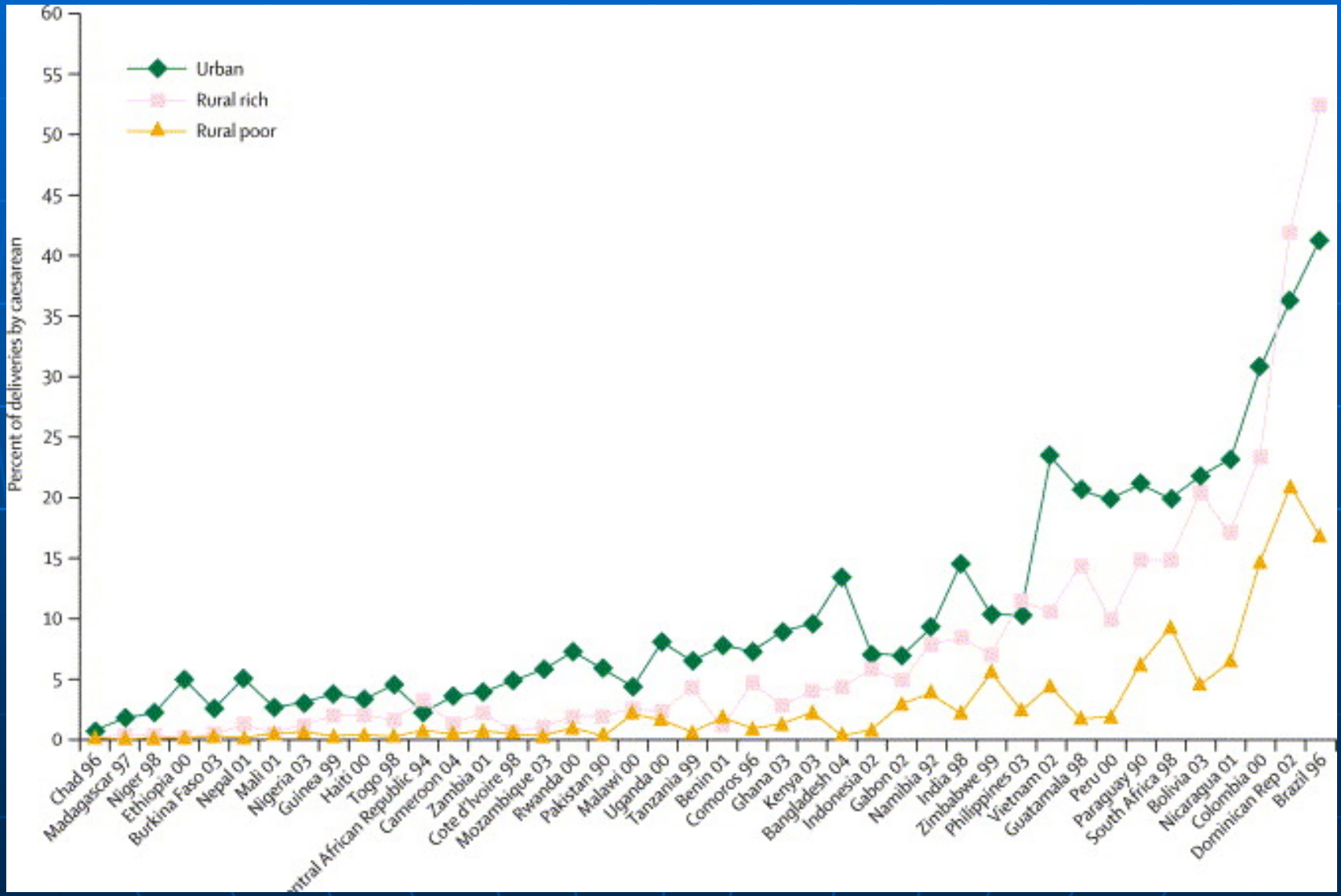
Usually this means they need emergency cesarean delivery.



Rates of Cesarean Delivery by Wealth Quintile in Countries with Cesarean Section Rates of <2%

C. Ronsmans, S. Holtz, C. Stanton; "Socioeconomic differentials in caesarean rates in developing countries: a retrospective analysis; *Lancet* 2006;368:1516-1523.

Cesarean Rates Among Urban, Rural Rich and Rural Poor Women from 42 Countries



Why Obstetric Fistula is Important

- Disorder affects women exclusively
- Fistula prevalence is a direct marker for the social status of women
- Important human rights issue:
  - Women are the exclusive bearers of reproductive morbidity
  - As a matter of basic social justice, all women have a right to safe delivery and effective emergency obstetric care.

Why Obstetric Fistula Is Important

- The biology of human reproduction dictates that women are the exclusive bearers of reproductive morbidity and mortality.
- Women often have limited reproductive autonomy.
- Fistula prevalence is a direct marker of the social status of women.
- For all these reasons, obstetric fistula is an important human rights issue.

Social Consequences of Fistula

- Devastating
- Only 238 still married 26.4%
- 440 divorced by husband 48.9%
- 199 separated from husband 22.1%
- 22 widows 2.4%

Why Women with Fistulas Are a "Vulnerable Population"

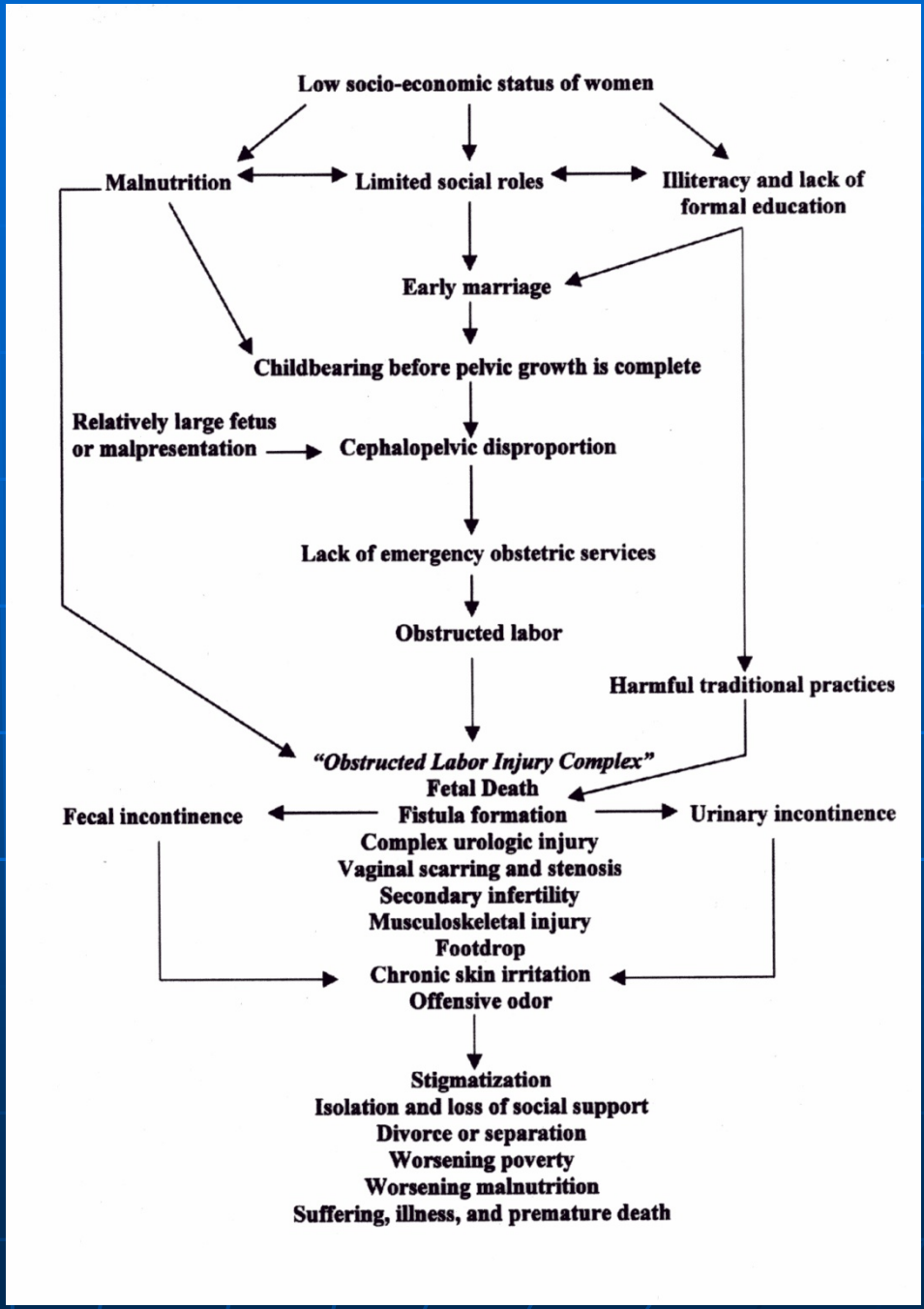
- They are women who live in societies where their social status is low.
- Their social status is defined largely by their reproductive functions and capacity, which has become markedly diminished.
- They have limited social, economic, and political autonomy.
- They have a stigmatizing disability that can only be corrected by surgical repair.

Why Women with Fistulas Are a "Vulnerable Population"

- The surgery they need is often difficult.
- Surgical resources are scarce and difficult to come by.
- They cannot pay "out of pocket" for surgical services.

The Obstetric Fistula Pathway

- Low status of women
- Poor nutrition
- Poor education
- Harmful practices
- Lack of emergency obstetric services
- Poverty



Obstetric Fistula is a "Neglected Tropical Disease"

Obstetric Fistula: What's "The Deal?"

(CH Coleman, J Low, Medicine, and Ethics 2009;37(1):12-18.)

- To what is a "vulnerable" population vulnerable?
  - Consent-based vulnerability
    - Is it truly voluntary?
  - Risk-based vulnerability
    - Is the risk/benefit ratio unfair for the subject?
  - Justice-based vulnerability
    - How are risks and benefits distributed?

Obstetric Fistula: What's "The Deal?"

(CH Coleman, J Low, Medicine, and Ethics 2009;37(1):12-18.)

- "Within this framework, a vulnerable person can be seen as someone who is at risk of being enrolled in research in violation of one or more of the deal's basic premises."
- In resource-poor settings (obstetric fistula) this applies to clinical care as well as research.

Health Care Delivery as an "Experiment"

- The provision of medical services which are not normally available to patients in resource-poor countries (such as obstetric fistula care) is an experiment in health care delivery.

Seven Forms of Vulnerability

K. Kipnis; "Vulnerability in research subjects: An analytical approach;" in Thomasma and Weisstub (Eds), *The Variables of Moral Capacity;* Boston: Kluwer, 2004: 217-231.

1. Cognitive vulnerability.
   - Does the patient have the capacity to deliberate about and decide whether or not to receive the proposed care?
2. Juridical vulnerability.
   - Is the patient liable to the authority of others who may have an independent interest in their care?
3. Deferential vulnerability.
   - Is the patient given to patterns of deferential behavior that may mask an underlying unwillingness to participate?

Seven Forms of Vulnerability

K. Kipnis; "Vulnerability in research subjects: An analytical approach;" in Thomasma and Weisstub (Eds), *The Variables of Moral Capacity;* Boston: Kluwer, 2004: 217-231.

4) Medical vulnerability.
   - Has the patient been selected, in part, because she has a serious health-related condition for which there are no satisfactory remedies?

5) Allocational vulnerability.
   - Is the patient seriously lacking in important social goods that will be provided as a consequence of her participation?

6) Social vulnerability.
   - Does the patient belong to a socially undervalued group?

Seven Forms of Vulnerability

K. Kipnis; "Vulnerability in research subjects: An analytical approach;" in Thomasma and Weisstub (Eds), *The Variables of Moral Capacity;* Boston: Kluwer, 2004: 217-231.

- Infrastructural vulnerability.
  - Does the political, organizational, economic, and social context of the clinical setting possess the integrity and resources to manage care?

Vulnerabilities of Fistula Patients

- "Fistula Tourism"
  - The poorly skilled short-term volunteer
- Unexpected consequences of foreign aid
  - Paying surgeons for fistula operations
- Arbitrary odious behavior
  - Dr. Kees Waaldijk and anesthesia

Arbitrary Odious Behavior

- K. Waaldijk; “The immediate surgical management of fresh obstetric fistulas with catheter and/or early closure;” *International Journal of Gynecology and Obstetrics* 1994;45:11-16.

Dr. Kees Waaldijk, Katsina, Nigeria

Arbitrary Odious Behavior

K. Waaldijk; "The immediate surgical management of fresh obstetric fistulas with catheter and/or early closure;" *International Journal of Gynecology and Obstetrics* 1994;45:11-16.

- Advocates surgical repair of obstetric fistulas without the use of anesthesia because "not everybody is so lucky to have an anesthetist."

Arbitrary Odious Behavior

K. Waaldijk; "The immediate surgical management of fresh obstetric fistulas with catheter and/or early closure;" *International Journal of Gynecology and Obstetrics* 1994;45:11-16.

- Examination of fresh fistulas in operating theatre
- Lithotomy position with placement of weighted vaginal speculum followed by surgical repair in two layers *without anesthesia.*

Arbitrary Odious Behavior

K. Waaldijk; "The immediate surgical management of fresh obstetric fistulas with catheter and/or early closure;" *International Journal of Gynecology and Obstetrics* 1994;45:11-16

"If it was too complicated or if the patient could not stand the insertion of the Auvard speculum, she was prepared for a VVF repair under spinal anesthesia the following day, i.e. if her general condition was alright; Otherwise she had to wait until her general condition had improved."

Arbitrary Odious Behavior

K. Waaldijk; "The immediate surgical management of fresh obstetric fistulas with catheter and/or early closure;" *International Journal of Gynecology and Obstetrics* 1994;45:11-16

"It could be done without anesthesia as most of the patients did not feel very much and had been instructed that it might be uncomfortable. To give spinal anesthesia was considered to make the procedure unnecessarily complicated; as well it might have been a risk as the general condition of many patients was not optimal."

Arbitrary Odious Behavior

K. Waaldijk; "The immediate surgical management of fresh obstetric fistulas with catheter and/or early closure;" *International Journal of Gynecology and Obstetrics* 1994;45:11-16

"Only some 30% of the world population have access to sophisticated medical facilities; this does not mean that the other 70% do not have the right to medical-surgical care, within their own limited facilities. Not everybody is so lucky to have an anesthetist. In the whole of Katsina State, 24 000 sq km with 4 million people, there is not a single consultant anesthetist present."

Discussion