

# Anencephalic Babies and Organ Donation

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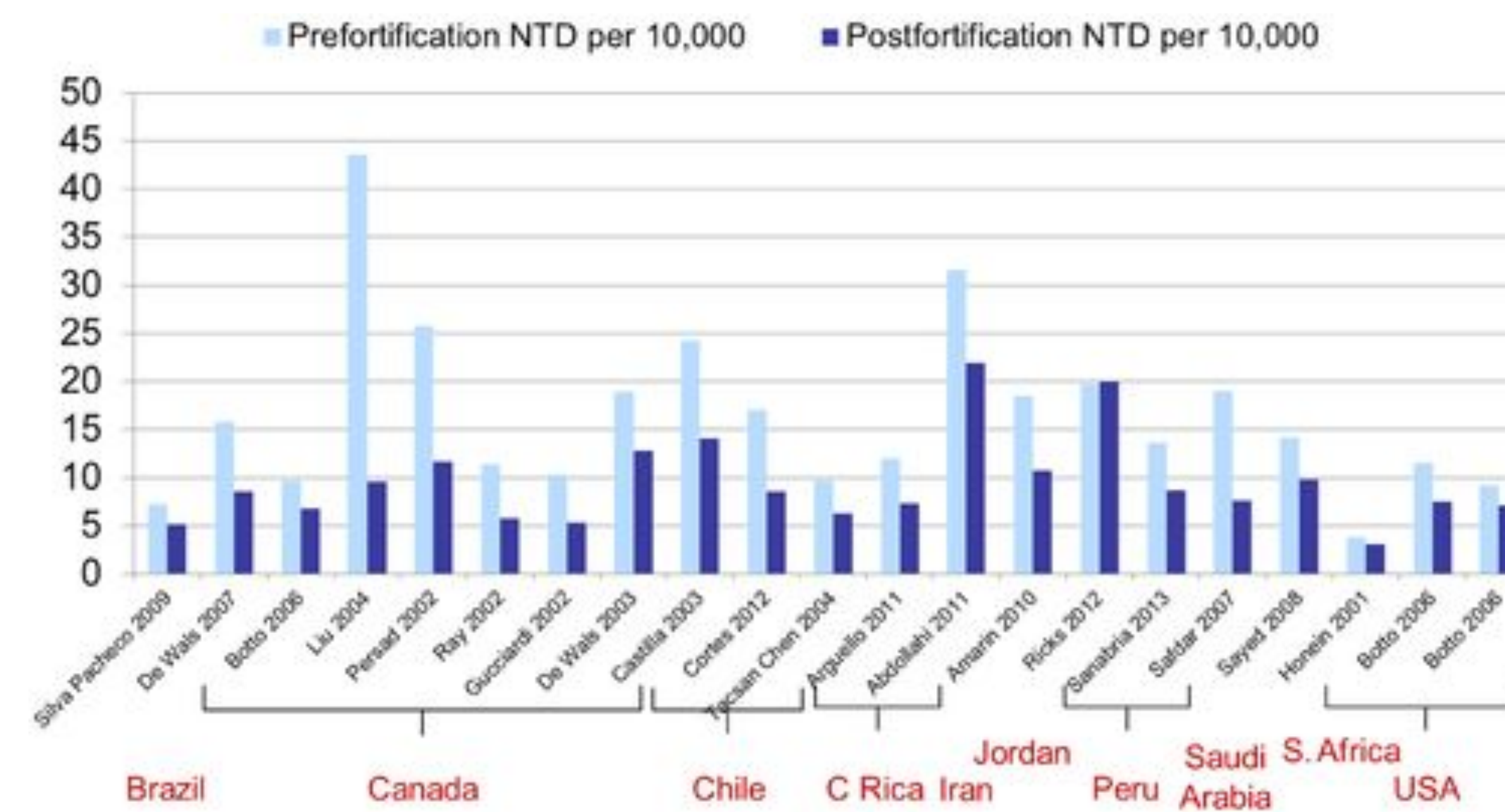
## Introduction

- Anencephaly is a fatal, incurable neural tube defect caused by the cranial neuropore failing to close between the third and fourth weeks of development
  - Lack a forebrain, skull and scalp, but have a functioning brainstem
- Babies with anencephaly are often candidates for organ donation although the ethics of this are debated in regards to the following issues:
  - Personhood of anencephalic babies
  - Whether or not anencephalic children should be used to harvest organs when they are alive and the organs are still viable
  - Religious views regarding the value of both the mother and an anencephalic child
- Should these children be delivered to make the ultimate sacrifice in order to save another child, or should they be given humane comfort and palliative care to ease them into a peaceful death?



## What Causes Anencephaly?

- Unknown cause but theories are evolving around the mother diet and vitamin intake
- Recent studies show that folic acid intake (Vitamin B9) helps in decreasing neural tube defects



## Religious Concerns:

- According to the United States Conference of Catholic Bishops, “Abortion (that is, the directly intended termination of pregnancy before viability or the directly intended destruction of a viable fetus) is never permitted. Every procedure whose sole immediate effect is the termination of pregnancy before viability is an abortion” (USCCB, 1)
- Through this perspective, the argument remains that children of any age are considered persons and deserve the same rights as any other person
- The death of one should never be a means to treat or save another
- Child should be given comfort and palliative care before dying
- Regarding the criteria to be an organ donor, it appears that the perspectives are in agreement: “It is most commendable for parents to wish to donate the organs of an anencephalic child for transplants that may assist other children, but this may never be permitted before the donor child is certainly dead” (USCCB, 1)

## Anencephalic Babies as Organ Donors?

- The ‘dead donor rule’ states that an organ donor must be brain dead or somatically dead
- Anencephalic babies are not considered brain dead because they have brainstem functions
- By the time the baby meets the ‘dead donor rule’ requirements, their organs will go through ischemic damage because of the gradual decrease in respiratory and cardiovascular functions
- Organ functions may be preserved with life support but multisystem organ failure will develop before death due to the deterioration of the brainstem

## Ethical Concerns:

- Should anencephalic babies be delivered only to die and be harvested of their organs to save another life, or should they be aborted to prevent their own pain and suffering?
- “Organ donation may only be considered if the anencephalic infant has satisfied the criteria for brain death or somatic death as applied to other human beings” (Byrne, 1)
- Because of this criteria, the child would essentially be a predetermined organ donor and delivered only to die
- If we are to treat anencephalic babies as actual persons, it is arguably immoral for anyone else to authorize the child’s organ donation on their behalf
- Anencephalic children would be born only to suffer for the few moments that they are alive, but does this justify saving the life of an organ recipient?

## Personhood and Beneficence

- Do anencephalic babies meet the qualifications that constitute personhood?
- Some argue that anencephalic babies do not meet the criteria to have personhood as it does not fall on the scope of intrinsic morality.
- In opposition, “children are not just biologically human entities but persons who could have been, in more fortunate circumstances, healthy human beings” (Kittay, 2005 as cited in Häyry, 2016). Anencephalic babies have moral worth.



### Case Study 1:

A 26-year-old mother carried a fetus to full-term after it presented anencephaly with no other abnormalities during 28 weeks of gestation. Routine prenatal care continued until full-term. After birth, the mother signed a do-not-resuscitate form and considered organ donation. Three days post-discharge, the infant was admitted into a hospice as this is what the family desired. The infant survived several weeks of continued palliative care at home.

### Case Study 2:

A 35-year old pregnant woman received a routine ultrasound at 12-weeks, and the fetus was diagnosed with anencephaly. The obstetrician and midwife provided counseling to the parents, and the parents decided to carry the fetus to full-term for organ donation. The pediatric donation plan was to retrieve the organs within 24 hours of the infant’s birth. Three hours after delivery and the infant’s passing, the organ donation retrieved the infant’s heart valves.

## How Common is Anencephaly?

- This is estimated to occur in 1/1000 pregnancies, but the rate is not exact due to the high rate of termination, shown in figure 1 to be ~43-59%
- Anencephaly has an almost 100% rate of detection in a prenatal ultrasound
- Many fetuses do not survive to birth. If they do survive until birth, they live on average 51 minutes due to lack of brain function, although some rudimentary function such as reflexes and breathing can be observed since the brain stem may be intact
- Newborns are not capable of experiencing consciousness or pain and are born blind and deaf

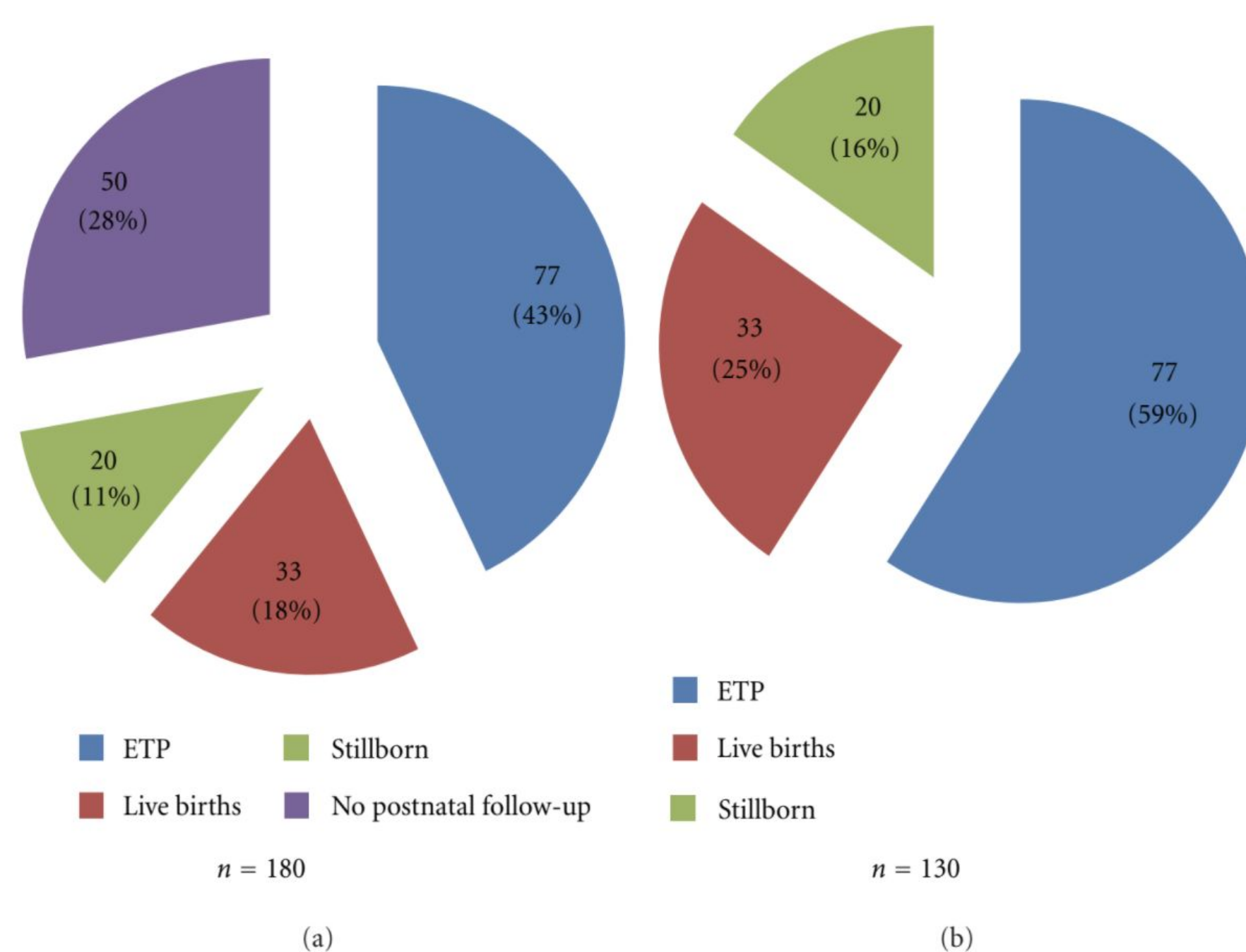


FIGURE 1: Frequency distribution of the anencephalic fetuses according to the outcome. ETP: elective terminated pregnancies. n = 180 (all included), n = 130 (excluding the cases without postnatal follow-up).

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