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The fate of an infant with congenital hydrocephalus in a resource-limited country in sub-Saharan Africa



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Title figure:

At the Centre Hospitalier de Yopougon (CHUY), the signs of the last civil war of 2011 have not yet disappeared.

In September 2000, world leaders came together at the United Nations Headquarters in New York to adopt the United Nations Millennium Declaration, committing their nations to a new global partnership to reduce extreme poverty and setting out a series of timebound targets – with a deadline of 2015 – that have become known as the Millennium Development Goals (MDGs). The MDG-4 aims to reduce by two-thirds, between 1990 and 2015, the mortality rate of children under five. Increasingly, child deaths are concentrated in the poorest regions (Fig. 1) (1). In 2012, sub-Saharan Africa and Southern Asia accounted for 5.3 million (81%) of the 6.6 million deaths in children under five worldwide. The first month, and particularly the first 24 hours, is the most dangerous in a child's life. Newborns now account for almost half of under-five deaths. Finally, 99% of all neonatal deaths occur in low- and middle-income countries.

In 2013, the under-five mortality rate was 100 per 1000 live births in die Ivory Coast (for comparison the under-five mortality rate in Switzerland was 4 per 1000 live births in the same year, i.e., 27-times lower). Clearly, the country will not be able to achieve its MDG-4 (51 per 1000 live births by 2015). While these statistics are sobering, they fail to tell the full story. This case report is presented to illustrate the fate of an individual human being born in one of the poorest countries of the world.

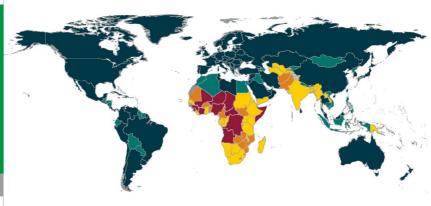


Fig. 1

Under-five mortality rate, 2013 (deaths per 1000 live births)

- Less than 20
- **20** 39
- **4**0 79
- 80 99
- 100 and above
- Date not available

Children in sub-Saharan Africa and Southern Asia face the highest risk of dying before their fifth birthday (1). The mother was a 28-year-old referred to the Centre Hospitalier Universitaire (CHU) de Yopougon for delivery. There had been five prenatal consultations, and pregnancy had been uneventful until 35 weeks, when a prenatal ultrasound examination revealed congenital hydrocephalus; at the time of writing of this report, no further details of this examination were available. This male infant was born by elective Caesarean section. After birth, the infant required vigorous stimulation and received intramuscular vitamin K and ACTH (Synacthène®). Apgar scores were 5 and 6 at 1 and 5 minutes, respectively.

The infant's birth weight was 4400 g (P95), his birth length was 54 cm (P75) and his head circumference was 54 cm (16 cm above P97). On physical examination, gross macrocephaly was apparent with bulging anterior and posterior fontanels. The infant was noted to have a weak cry and sucking reflex, as well as an incomplete Moro reflex. Muscular tone seemed normal and grasping reflexes were present. Apart from mild respiratory distress, physical examination was normal.

Once admitted to the neonatology unit, peripheral intravenous access was obtained and antibiotics were started. Intravenous glucose was administered (35 ml/kg/day) and gavage feedings (20 ml/kg/day) were initiated. The infant was also treated with 100% oxygen at 3 l/minute. Over the course of the first week of life, the infant's condition stabilized, anti-

biotics were discontinued and gavage feedings were increased without difficulties. An ultrasound examination and a CT scan confirmed massive hydrocephalus but failed to identify its etiology. The infant was not operated because, at the CHU Yopougon, neurosurgery is not performed in infants weighing less than 5 kg and because the parents were unable to cover the costs of ventriculo-peritoneal (VP) shunt surgery. In fact, the parents abandoned the baby during the first week of life.

When a Swiss medical team (WH, BS, BTM) visited the CHU de Yopougon, the boy was 2½ months old. His head was grossly deformed with bulging of the frontal and occipital regions (Fig. 2). The sagittal suture appeared to be closed. His head circumference was 74 cm (32 cm above P97) (Fig. 3). Pressure sores were noted on both ears and the infant appeared to be in pain when the head was repositioned. He had never received any pain medication. The infant exhibited a marked downward gaze (setting-sun sign) (Fig. 4). He was able to move all extremities and muscular tone appeared normal (Fig. 5, movie). He was still gavagefed with a cow's milk based formula but was emaciated (Fig. 6). A peripheral venous cannula was in place to provide intravenous access in case of a life-threatening emergency (Fig. 7). After 3 months in hospital, the baby died.



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Patient at 2½ months: extreme frontal and posterior bossing; manipulations were obviously associated with significant pain.



rig. 3

Patient at 2 ½ months: the infant's head circumference was 74 cm (32 cm above the 97th percentile).



Patient at 2½ months: massive hydrocephalus with frontal bossing and persistent downward gaze (setting-sun sign).

Fig. 4



Patient at 2 ½ months: the infant was able to move all extremities and exhibit signs of discomfort.

A peripheral venous catheter was kept in place to provide emergency access in case of life-threatening events.



Fig. 6

Patient at 2 ½ months: despite apparent full enteral nutrition with a cow's milk based formula, the infant appeared significantly emaciated.



Fig. 7

At the CHU de Yopougon, rates of nosocomial infections are high despite the fact that central venous access and mechanical ventilation (known risk factors in high-income countries) are not available; nursing staff appears to be poorly educated and simple rules of hygiene are not followed.

DISCUSSION

This case report illustrates the great difficulties that health care professionals face in low-income countries. While some of these difficulties are related to extreme limitations in resources and poor education, others are based on cultural beliefs. As a result, suffering of individual babies is immense.

The CHU de Yopougon is a tertiary referral center in Abidjan; however, because the availability of technical equipment is severely limited, delivery of care is well below the standards described for such an institution. Despite these difficulties, the mortality rate of neonates admitted to the neonatology unit at the CHU de Yopougon has slowly decreased from 28% in 2006 (2) to 20% in 2014. The majority of deaths are due to respiratory distress and hypoxic-ischemic encephalopathy.

The Dominique Ouattara Neonatology Unit at the CHU de Yopougon was reopened in September 2014 after extensive renovations. Unfortunately, the unit is severely understaffed (approximately one nurse for 10 patients). It is equipped with modern incubators (a donation from Russia and UNFPA); however, the nurses do not know how to operate them. The same holds true for an SLE5000 ventilator that was donated in September 2014: it has never been used. In fact, the only treatment option for neonates with respiratory distress is free flow oxygen; unfortunately, oxygen blenders are not available. The 27-bed-unit has

only two oxygen saturation monitors. Parenteral fluid therapy is limited to the administration of 5% or 10% dextrose solutions with added sodium, potassium and calcium through peripheral venous catheters. Peripherally inserted central catheters (PICCs) and parenteral nutrition solutions are not available. Rates of nosocomial infections are high despite the fact that central venous access and mechanical ventilation (known risk factors in high-income countries) are not available. Nursing staff appears to be poorly educated and simple rules of hygiene are not followed. According to one study, a staggering 80% of health care professionals did not wash their hands prior to invasive procedures (3). Not infrequently, the supplies needed for proper hand hygiene are lacking, which makes it even more difficult to establish a routine. Both early-onset sepsis and nosocomial infections are common. To improve the rational use of antibiotics, Amon-Tanoh-Dick F et al. have proposed a clinical score adapted to the local circumstances (4).

Non-pharmacological or pharmacological interventions for neonatal pain are not used. The therapeutic actions to reduce mortality in low-income countries are priorities and topics such as developmentally appropriate care including the management of pain are not addressed.

The concept of palliative care is largely unknown. According to Lasme-Guillao, the absence of a legal

framework and the unavailability of more sophisticated diagnostic tests (to improve prognostication) severely compromise the development of palliative care (5). The practice of withholding or withdrawing potentially life-prolonging therapies is unthinkable because it would be considered to be equivalent to killing (5). Apparently, the only active decisions that doctors take in hopeless situations is to return the child to the family. When a child with severe congenital malformations is brought back to the family's village, the parent's family alone will decide what to do with the child. At least in the past, birth defects were barely accepted in the Ivorian traditional societies, and infanticide was an accepted ritual (6). Newborns carrying severe malformations were not shown to their mothers for fear that this could negatively influence future pregnancies. According to Lasme-Guillao infanticide by drowning is still practiced in the Ivory Coast (personal communication); it is, however, kept secret and its prevalence is unknown. In the presented case, the parents had abandoned their child after the first week of life because of financial difficulties and feelings of helplessness and futility.

Acknowledgement

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by the Lottis Latrous Foundation (www.lottilatrous. ch). The president of ARMMAICI, Hans Werder (the former head of the Department of Obstetrics and Gynecology at the Cantonal Hospital Uri in Altdorf, Switzerland) wanted us to get to know the CHU de Yopougon, which serves as a referral center for the Hôpital Général de Dabou, and to make suggestions for affordable improvements of their neonatology unit. The Hôpital Général de Dabou has recently been equipped with several container buildings, including an operating room to allow for Caesarian sections and a level II neonatology unit. Combined with the project «Clinique Mobile», which uses portable ultrasound units to screen for high-risk pregnancies (i.e., placenta previa, multiple gestation, breech presentation, etc.) in the villages of the region, it is hoped that the improvements at the level of the Hôpital Général de Dabou will help to reduce the staggering toll of preventable maternal and neonatal deaths. Collaboration with the CHU de Yopougon will complete the regional network and enhance its capability to take care of sick neonates. It is very encouraging that Prof. Daniel Sess, director of the «Institut National de Formation des Agents de Santé» (INFAS) has pledged to support these efforts. Prof. Berger and his wife Sabine Berger wish to thank the NGO ARMMAICI, Hans and Therese Werder, as well as the friendly staff of the Department of Pediatrics at the CHU de Yopougon for their hospitality.

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