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Beyond newborn survival: the world you are born into determines your risk of disability-free survival

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Every year, 135 million newborns enter the world, each arriving naked and apparently equal. Yet, their chances of surviving and thriving vary dramatically depending on which world these babies are born into—ranging from high-income countries with universal neonatal intensive care to the world of home births without midwives, medical supplies, or health system support (**Figure 1**).

This supplement includes six research articles presenting the first systematic estimates of impairment after neonatal morbidity, bringing together the work of almost 50 authors representing 35 institutions from 12 countries, from more than a thousand different data inputs. We summarize global estimates of the incidence of impairments in the year 2010 as a result of four major neonatal conditions: preterm birth (including separate estimates of visual impairment due to retinopathy of prematurity), intrapartum-associated neonatal encephalopathy (sometimes referred to as “birth asphyxia”), severe neonatal infections, and hyperbilirubinemia (seen clinically as jaundice) (1–5).

Where you are born strongly affects your outcome, and you may be born into four very different worlds. First, 11 million neonates are born in high-income countries where intensive care is universally available, and stillbirth and neonatal mortality rates are very low (less than 5 per 1,000 births), despite attempts to rescue even extremely low-gestational-age newborns. Survival is now at 80% for those born at 25 wk gestational age, with disability risk very low for infants born beyond this threshold (3). Yet, even between and within high-income countries, the risk of death and disability varies.

Second, for 34 million births in middle-income countries, the majority of births are in hospitals, but access to intensive care is not universal, and there is less assurance for quality of care through detailed protocols, e.g., for safe oxygen use. Although neonatal mortality rates have been dramatically reduced in many middle-income countries, with more than 50 countries halving their neonatal mortality rates in the past 2 decades (6), the disability rates have increased during this same time period, including in moderately preterm babies with preventable disabilities (3,4). Of 32,000 estimated cases of visual impairment due to retinopathy of prematurity worldwide each year, 65% are in middle-income regions, with almost none identified in Africa outside South Africa, given few survivors at lower gestational age in these regions, and few being identified in high-income regions, given more investment in prevention and eye health management for preterm survivors (2).

In low-income countries, for 40 million births in facilities, let alone the 50 million home births (the fourth and most invisible world), the vast majority of the burden of disease is attributable to deaths rather than to disability; yet here too, these are mainly preventable. More than three quarters of the world's 2.9 million neonatal deaths occur in sub-Saharan Africa and South Asia, mainly among babies born beyond 32 wk gestational age, who are dying needlessly, e.g., due to infections and yet are not receiving antibiotics (7). These global numbers do not include 2.6 million third-trimester stillbirths (8), an estimated 1.2 million of who die during labor (9). Progress in reducing neonatal mortality (1.8% per year) is lagging behind that for maternal deaths (4.2% per year) and postneonatal deaths (2.3% per year) (6). Reducing

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Figure 1. The four worlds into which 135 million newborns are born each year. Republished with permission from ref. 17.

neonatal deaths is increasingly recognized as a public health priority in countries largely because of the impact that these deaths have on our potential to achieve the Millennium Development Goal 4 (10,11). Now, with 44% of all under-five deaths occurring in the first month of life (the neonatal period), reducing neonatal deaths is rising to the top of the child survival agenda (7,12).

The Global Burden of Disease estimates that of all global disability-adjusted life years in 2010, almost 1 in 10 was due to neonatal conditions, and of this, 95% were estimated to be due to neonatal deaths rather than subsequent disability (13,14). This burden is more than three times that of HIV, more than all cancers, similar to all cardiovascular conditions, and still remains barely mentioned in global health agendas.

As the focus shifts beyond 2015 to the post-Millennium Development Goal era, more recognition is being given to disability-free survival, human capital, and sustainable development (15). Although neonatal deaths are just beginning to receive attention (16), neonatal morbidity and its long-term impact on health, disability, and human capital have, to date, received almost no attention in many settings and are increasingly important issues for individuals, families, and nations.

This supplement removes the myth that saving newborn lives comes at the expense of an inevitable generation of disabled survivors. With basic newborn care, those now surviving are not severely disabled—surviving with severe disability is seen primarily among those who received neonatal intensive care, especially sustained ventilation. Yet, even this disability after intensive care is not inevitable, as seen by the doubling of impairment risk for preterm babies of 28- to 32-wk gestation in middle-income countries compared with the risk for babies in high-income countries. Higher disability risk is more likely with lower-quality intensive care or in the national start-up phase for provision of intensive care; this can and must be reduced over time.

This series of articles also features new analyses shedding new light on the observation that boys are at increased mortality risk in the neonatal period. We show that this risk for boys is driven by an increased risk for preterm birth and, given preterm birth, an excessive risk of death and disability in boys. In addition, boys have a higher incidence of neonatal sepsis and neonatal encephalopathy (4,5). These findings point out the need for more sex-specific global data to inform research and policy agendas, in addition to the need for more attention toward excess termination *in utero* for girls.

Our estimates are constrained by the data available, but this is the best attempt yet to combine all the available data and to map the size of the problem of neonatal morbidity. Current estimates are likely to underestimate the true global burden of the range of impairments and disabilities attributable to neonatal conditions because we did not cover all outcomes, e.g., behavioral conditions. Data gaps were greatest for the poorest countries, but worse for conditions that are now rare in rich countries, such as intrapartum complications and neonatal infections, in contrast with preterm birth, which is common, notably in the United States. Shockingly, there are almost no national data on neonatal hyperbilirubinemia, apart from Denmark and Canada, forcing the use of historical data from more than half a century ago (1). We observed a waterfall effect with usable data being fewer and fewer at each step from incidence and case fatality rate to impairment rates, and finally, very few cohort studies report on long-term survival of children with disabilities, even in high-income countries. The lack of usage of consistent definitions meant that valuable studies could not be used. Child development outcomes and disability are especially variable in measurement and also in timing of assessments. Improved estimates will require better data, from the poorest countries, counting birth and development outcomes and using consistent definitions.

We hope that this supplement will engage the pediatric, obstetric, and public health communities, partnering with parents, to strengthen policies and programs to prevent and manage these key causes of neonatal mortality and subsequent disability. Better data and better use of existing data are foundational. Countries, especially middle-income countries with increasing intensive care services, urgently need to improve quality of care, and the quality of follow-up data on child development, developing services for those with impairment (18). Neonatal conditions result in social and economic loss to families and nations. Investing in care of every woman and every newborn will reduce both deaths and disabilities.

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